

CHAPTER 6

Participation of people with dementia in developing an interactive web tool

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Submitted

ABSTRACT

Purpose

The aim of this study was to gain insight into the ways in which people with dementia participated in developing the DecideGuide, an interactive web tool facilitating shared decision-making in their care networks.

Methods

An explanatory case study design was used when developing the DecideGuide. A secondary analysis focused on the data gathered from the participating people with dementia during the development stages: semi-structured interviews (n=23), four focus groups with a total of 18 participants, three usability tests, and a pilot study with 4 participants. Framework analysis was applied to the data.

Results

People with dementia participated especially as informants and advisors in most phases of the development. Four themes proved to be important regarding the impact of the participation by people with dementia: influence on content and design of the DecideGuide, motivation to participate, time investment, and the balance between challenge and concern.

Conclusions

People with dementia can give essential feedback and, therefore, their contribution is valuable. Other roles than informant and advisor need to be explored. Significant participation of people with dementia takes time that should be taken into account. It is important for people with dementia to be able to reciprocate the efforts others make and to feel of significance to others.

1. INTRODUCTION

It is uncommon for people with dementia to participate, whether in society (Van Gorp & Vercruysse, 2012), in research (Murphy, Jordan, Hunter, Cooney, & Casey, 2014), or in the development of IT applications (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). Often, informal caregivers and professionals tend to shield them and decide for them rather than with them, even though many caregivers do not have a clear insight into their values and preferences (Reamy, Kim, Zarit, & Whitlatch, 2011). Reasons for exclusion are that participation is too difficult and/or too stressful for people with dementia. Although these reasons may apply to some people with dementia and in some situations, exclusion does no justice to the experiences and capabilities of many people with dementia. It may result in suboptimal research findings (Taylor, DeMers, Vig, & Borson, 2012) and subsequently in inadequate IT applications (Hanson et al., 2007).

Research shows that people with dementia, even people in advanced stages of dementia, can express their needs (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012) and preferences (Whitlatch, 2009). Their voice needs to be heard in order to better understand living with dementia (Pesonen, Remes, & Isola, 2011; Wilkinson, 2002). Therefore, it is important for people with dementia to participate in society, research, and development. Unfortunately, people with dementia, as a marginalized and vulnerable group, are met with negative and fixed perceptions of dementia. Negative perceptions about participation by people with dementia are visible in society (Van Gorp & Vercruysse, 2012), among care professionals (Brannelly, 2011), and general practitioners (Gove, 2012).

Currently, patient participation is part of sound research in social sciences (Abma, Pittens, Visse, Elberse, & Broerse, 2014; Smit, van der Valk, & Wever, 2011; Visse, Abma, & Widdershoven, 2012). For years, experimentation has been the exclusive domain of researchers and patients have been involved only as objects of study. Research and research activities have been considered too difficult and stressful for patients for a long time. This view is changing as a result of social debates and developments in society. Empowerment, self-management, and participation are important topics in health and governmental policies (RIVM, 2013; WHO, 2013, 2014). Patients, including people in the earlier stages of dementia, have become more assertive and are asking for more participation (Alzheimer Europe, 2012; ZonMw, 2012). Research topics do not always match their needs and wishes, and patients no longer accept being patronized. Participation in research may help patients influence what is important to them.

This shift from exclusion to inclusion also applies to consumer participation in developing IT applications. For a long time, designers have not included consumers in the process of development. At best, consumers have been involved towards

the end of the process to test new applications. As a consequence, IT applications have not fulfilled consumer needs (van Kuijk, Christiaans, Kanis, & van Eijk, 2006). A recent review shows that involving people with dementia in IT development is a new phenomenon (Span et al., 2013). They are primarily involved as objects of study and sometimes as informants in a number of development phases, rather than in all. Involvement of people with dementia in all of the development phases might lead to IT applications that are more user-friendly and better suited to their needs (Span et al., 2013).

People can participate in various ways. In 1969, Arnstein (1969) developed the participation ladder, a well-known model that describes the roles that consumers can play in society. The participation ladder is often used in domains such as national and local policy-making (Cromwijk, Lucassen, Winsemius, M., & Sok, 2010), in health care for patient participation in research (Abma & Broerse, 2007; Abma et al., 2014), and in child participation (Hart, 1992). Despite the various participation models, there is currently no valid participation measure (Tritter & McCallum, 2006; Visse et al., 2012). Researchers consider this an omission. As a result, discussions often focus on what is described as ‘the snakes and ladders’: the pros and cons of participation, with the vertical representation of the ladder suggesting that higher levels of consumer and patient participation are better (Tritter & McCallum, 2006; van Staa, 2009).

To facilitate shared decision-making in the care networks of people with dementia, an interactive web tool, the *DecideGuide*, was developed (Span et al., 2014a; 2014b). Shared decision-making is an approach that facilitates the involvement of patients in making medical decisions together with their clinicians (Elwyn, Edwards, & Kinnerley, 1999; Elwyn et al., 2010). Shared decision-making increases patient autonomy and satisfaction with the overall decisions (von Kutzleben et al., 2012). The *DecideGuide* supports the complex process of making shared decisions for crucial aspects of life with multiple people whose capacities and interests differ. This tool can be used by people with dementia, by their informal caregivers, and by case managers, and all of them were involved in developing it. As people with dementia are the most vulnerable target group, easily overruled by others and often neglected, this study focuses on the ways they co-operated. So far, research has not provided an insight into which elements of participation models are feasible for people with dementia in IT development. Therefore, the aim of this study was to critically describe the ways in which people with dementia participated in developing the *DecideGuide*. The main research questions of this study are: (1) in which ways did people with dementia participate in developing the *DecideGuide*, an interactive web tool to facilitate shared decision-making in dementia-care networks (phases and roles) and (2) what is the impact of their participation (on the tool and on themselves)?

2. MATERIALS AND METHODS

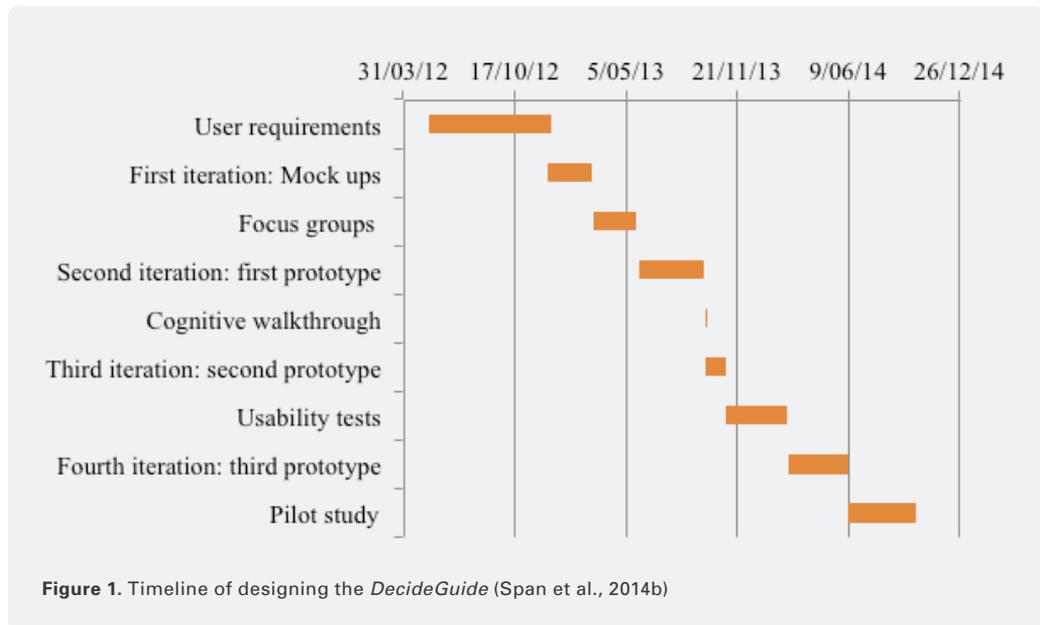
2.1 Study design: a case study

In order to capture all details of an individual or of a small group of individuals within a real-life context, an explanatory case study design was used (Kohlbacher, 2006; Yin, 2014). The process of developing the *DecideGuide* was studied while focusing on the participation of people with dementia. For this purpose, a secondary analysis of existing data of a rich and varied nature (i.e., transcripts of semi-structured interviews and focus groups, field notes, observational records, and a log book) was used (Heaton, 2004; Hinds, Vogel, & Clarke-Steffen, 1997). These data were collected by the principal researcher assisted by other researchers of the team developing the *DecideGuide*.

2.2 The case

The *DecideGuide*, a responsive web tool for supporting shared decision-making in a dementia context, was developed and refined in four iterations (Fig. 1) on the basis of feedback from intended users: people with dementia, informal caregivers, and case managers. The design principles of the *DecideGuide* are threefold. First, we aimed for transparency in order to reduce feelings of suspicion that people with dementia, due to the disease, often harbour (Murphy & Oliver, 2013). Second, we aimed for open communication and information to ensure that all network members share the same information. The third aim was to give a voice to people with dementia as their opinion is often neglected (Savitch & Zaphiris, 2006). The *DecideGuide* incorporates perspectives from three user groups: those of people with dementia, their informal caregivers, and their case managers. The *DecideGuide* has three functionalities. The first functionality, a *Chat*, supports transparency and enables users to communicate with each other online. The second functionality, *Deciding together*, guides decision-making step-by-step and supports information exchange within the network. The third functionality, *Individual opinion*, enables users to give their individual opinions about dementia-related topics and their own circumstances. It is specifically designed to give a voice to the person with dementia. The *DecideGuide* is a safe and shielded web tool, and it is available for tablets, laptops, and computers. The case manager, the person with dementia, and the informal caregivers discuss whether using the *DecideGuide* would suit the person. All participants (person with dementia, informal caregiver, and case manager) have an individual login and use the tool of their own accord or after an alert by the case manager (Span et al., 2014b).

Two instruction manuals were produced for the *DecideGuide*. The manual for case managers explains the buttons and describes shared decision-making principles and



steps, and how these principles and steps are incorporated into the *DecideGuide*. The manual for people with dementia and informal caregivers provides a short overview of shared decision-making principles and explains the buttons with screenshots of the *DecideGuide*. The wording in this manual was simplified, and the font size was enlarged.

2.3 Recruitment of participants

People with mild to moderate dementia were recruited in three different ways: by case managers, by contacts in nursing homes and day-care centers, and on the website of the Dutch Alzheimer's Association. Inclusion criteria were: a diagnosis of any form of dementia and the ability to participate in an interview, a focus group session, a usability test, or a field study. This ability corresponds with a score of 2 to 4 on Reisberg's Global Deterioration Scale, which excluded people with severe dementia (Reisberg, Ferris, de Leon, & Crook, 1982). The exclusion criteria were: no diagnosis of any form of dementia and the inability to participate in one of the activities just mentioned. We aimed for diversity of characteristics with regard to subtype diagnosis, gender, age, marital status, and socio-economic status. This was discussed with the referrers, case managers and other professionals, and they were instructed to

recruit a variety of participants so that the diversity characteristics were met. These characteristics were checked by researchers when they first met with the people with dementia recruited. If necessary informal caregivers gave additional information.

2.4 Data collection

For this case study, transcripts and memos of semi-structured interviews and focus groups, field notes of observations from usability tests, and logbooks kept during the development were used. Data triangulation was used to strengthen the validity of the findings. This rigor was enhanced by a step-by-step approach, in which participants checked findings from a prior step during the next (e.g., findings from interviews were confirmed in focus group interviews). Furthermore, the data were compared to other data available (e.g., video recordings of usability tests were screened to see whether they matched audio recordings and observations). All steps were discussed within the research group.

Prior to the actual designing a systematic literature search was conducted to gain an understanding of how people with dementia could be involved in the process of developing supportive IT applications. The search was executed up to July 2011 with no restriction of date and in all languages using Cochrane Library, PubMed, PsychInfo, EMBASE, and CINAHL. Inclusion criteria were: publications had to address a development process of an IT application and people with dementia had to be involved.

To determine the content of the interactive web tool, the needs and preferences of people with dementia were identified. To participate, people with dementia were required to be able to converse with a researcher. Consecutively, 23 semi-structured individual interviews and two separate focus group interviews with people with dementia were conducted. The semi-structured interviews aimed to identify some of the difficulties and decisions that people with dementia face. The interviews lasted 30 to 60 minutes; they were audiotaped and transcribed verbatim. The interview topics included decision-making elements such as values, problems experienced, decisions, personal considerations and preferences, involvement in decision-making, and the ways in which people with dementia were involved in decision-making.

Next, the interview results were checked in two focus groups. One group consisted of four persons with dementia, the other of five. Both groups attended a day-care center. Two researchers moderated the focus group interviews, which lasted 1 to 1.5 hours each. The principal researcher led the focus groups and used an interview protocol to direct the discussion. The second researcher assisted the principal researcher.

Based on the results of the semi-structured interviews and the focus group interviews, a mock-up (a paper-based prototype) of the *DecideGuide* was developed.

The mock-up was presented in two additional focus group sessions with people with dementia for feedback on content and design. One of these groups consisted of six participants, the other of four, all attending a day-care center. The mock-up of the *DecideGuide* included 11 sketches that were all presented in the focus group of six. Based on the feedback of this focus group session, 6 sketches were presented to the focus group of four. Both focus group sessions lasted 1 to 2 hours. The principal researcher and a designer moderated them. The second of these sessions was audio-taped and transcribed verbatim. The six people participating in the first focus group initially agreed to recording the session, but preferred not to be recorded when the session started. They felt they could speak more freely without being recorded. That is why only field notes were made at this session. With the feedback gathered in these focus group sessions, an interactive prototype of the *DecideGuide* was developed, tested by researchers in a cognitive walkthrough, and subsequently adapted for usage in usability tests.

Next, after older adults had tested the *DecideGuide* for the perspective of people with dementia, individual usability tests were conducted with people with dementia. Three community-dwelling people with dementia (Reisberg score: 2 – 4), recruited by participating case managers, tested the *DecideGuide* on a tablet at home. They did so individually without any coaching by informal caregivers. These sessions lasted between 30 and 60 minutes. The think-aloud method was used to identify thoughts and feelings of participants while using the prototype (Jaspers, Steen, Bos, & Geenen, 2004). During these individual usability tests, participants were asked to carry out tasks in the interactive prototype of the *DecideGuide*. They were encouraged to comment on the design, content, and user-friendliness of the *DecideGuide*. The principal researcher moderated the usability tests and asked the participants to complete some tasks. Another researcher assisted and made field notes. The usability tests were video- and audio-taped and field notes were taken. Utilizing the participants' feedback on the usability tests, a final prototype was developed and used in a field study.

Four people with dementia and their care networks (19 participants in total) took part in a 5-month field study to test the *DecideGuide* in their daily lives. This study started with a small sample of participants because researchers were looking for exploratory evaluations of the degree of its user-friendliness, of participants' contentment with the tool, and of how they valued the tool for decision-making. They worked with the *DecideGuide* on a daily basis on an iPad for 5 months. Participants were recruited via case managers. Several home visits preceded the actual participation. During the first visit, the principal researcher explained about the research and its aims, and then asked the person with dementia for consent. A case manager accompanied the principal researcher on the second visit. The people with dementia were asked for their written consent and then instructed about how to use the *DecideGuide* on an iPad. The researcher explained things and participants were given a hardcopy

instruction manual. These visits were also used to get acquainted, and small talk was an important icebreaker. After these two visits the case managers visited the person with dementia again to discuss the first times the tool was used, to see whether there were any problems, and to re-explain the tool.

Participants' networks consisted of 3 to 6 people. Structured interviews took place with network members at the beginning, in the middle, and at the end of the five-month period of participation. Moreover, the case managers' home visits were observed by the researchers.

2.5 Analysis

Content analysis was used for the primary analyses (Bryman, 2008). To determine the content of the *DecideGuide* the transcripts were coded focusing on problems encountered and decisions made. These codes were clustered using Affinity Diagramming (Beyer & Holzblatt, 2010). In designing the *DecideGuide*, framework analysis was used (Lacey & Luff, 2009; Ritchie & Spencer, 1994) to analyze the quality of the design in terms of system, content, and service. The data of the field study were analyzed using content analysis.

A secondary analysis of the data was conducted for this study (Heaton, 2004; Hinds et al., 1997). To address research question 1, about the ways in which people with dementia participated in the design process, the five stages of Ritchie and Spencer's framework analysis were used (Ritchie & Spencer, 1994). These stages are: reading and re-reading to familiarize ourselves with the data, identifying a thematic framework (identified themes showed similarities with existing frameworks), indexing (coding within the thematic framework), charting (rearranging the thematic framework if necessary), and mapping and interpretation (explanation of the findings) (Lacey & Luff, 2009). A framework was used to evaluate the phases of development and the roles connected. This framework was twofold, containing elements from both the Center for eHealth Research and Disease Management (CeHRes) roadmap for the phases of involvement of people with dementia (Van Gemert-Pijnen et al., 2011), and Abma's patient participation ladder (Abma et al., 2014) for the roles of people with dementia. This 'phase and role framework' was applied to the methods used and the data gathered were put in.

To address research question 2, the impact of dementia patients participating in the development of the interactive tool, the data were content-analyzed by reading and re-reading the transcripts while focusing on the impact of participation on the tool and on the people with dementia themselves (Kohlbacher, 2006). The codes that originated from the data were clustered using Affinity Diagramming (Beyer & Holzblatt, 2010).

2.5.1 CeHRes roadmap

The CeHRes roadmap is an approach that connects a human-centered design with eHealth business modeling and emphasizes the importance of involving all of those concerned to develop sustainable innovations (Van Gemert-Pijnen et al., 2011). The roadmap aids developers in structurally integrating IT applications and health care, and it involves participants in all phases of the development. The CeHRes roadmap has five phases:

1. The *contextual inquiry phase*, in which information is gathered from the environment where the technology will be implemented.
2. The *value specification phase*, which defines user requirements based on participants' values.
3. The *design phase*, which translates values and user requirements into technical specifications and requirements for communicative and lucid prototypes to facilitate participants' feedback.
4. The *operationalization phase*, which implements the technology in practice.
5. The *summative evaluation phase*, which determines the effects of the technology on behavior, health, and organization. Since the *DecideGuide* is still being developed, this phase does not apply to the case study explored in this paper.

2.5.2 Patient participation ladder

Abma's patient participation ladder (Abma et al., 2014) distinguishes six gradations of participation in research:

1. The *research subject*: the minimum form of participation, in which patients undergo an experiment or are represented by patient organizations.
2. The *informant*: the patient is seen as the primary object of study and provides information by answering researcher's questions.
3. The *advisor*: the patient gives advice on aspects of research and reflects on findings.
4. The *referent or reviewer*: the patient examines and assesses research proposals and publications.
5. The *co-researcher*: the patient for example interviews respondents.
6. The *driving force*: the highest degree of participation, which enables patient organizations to determine the research agenda.

2.6 Ethical considerations

The institutional review board of the regional ethics committee of Isala Clinics gave written approval for the study (number: 10.11113). Special attention was paid to the informed consent of people with dementia to be sure of their voluntarily participa-

tion. This included investing in their ongoing consent (Murphy et al., 2014). People with dementia received written and oral information about the research activity, and were asked for their initial consent. Their agreement was checked before the research activity started. Researchers took time for social conversations to get to know the person with dementia and ended them with positive affirmations about the value of their contribution. The researchers took care to pay attention to any signs, verbal or non-verbal, of restlessness and discomfort. Participants were given ample opportunity to quit in those cases.

3. RESULTS

This section starts with participant characteristics (Table 1). Next, this section for each development phase of the *DecideGuide* describes the role of the people with dementia, and the impact of their involvement in its development. Table 2 provides a brief overview of the roles the people with dementia played in each development phase.

3.1 Participants' characteristics

For the semi-structured interviews to identify user requirements, 30 people with dementia and their care networks were reached of whom 23 consented to participate. Stress experienced by people with dementia and the burden of informal caregivers were the main reasons to refuse participation in one of the research activities. There were no drop outs after people with dementia decided to take part in an activity.

For the two focus groups to determine and check user requirements, 15 people with dementia were reached in two day-care center groups in the same region. Nine of them consented to participate. The other six doubted to consent. Due to their doubts they were excluded. No participants withdrew from these focus groups.

For the two focus group sessions to determine the design, 20 people with dementia in two day-care centers were contacted, one in a rural and one in an urban environment. Twelve of them consented to participate, the prime reason for refusal being the hesitation to participate. Four people with dementia dropped out in the urban focus group session because they did not like the activity and quit.

For the usability tests three people with dementia were contacted, who all consented to participate. Nobody refused.

For the field study, six people with dementia and their care networks were ap-

proached. All of them consented to participate. Four people with dementia and their care networks completed their participation. Two people with dementia and their care networks dropped out. One of them stopped participating quite soon because a daughter decided that her parent was unable to continue as this would be too difficult. The second person dropped out owing to deterioration to such an extent that relocation was necessary, which increased the spouse's burden.

3.2 Research question 1: participation of people with dementia in developing the *DecideGuide*

Table 2 provides a brief overview of the ways in which people with dementia were involved in developing the *DecideGuide*.

Contextual inquiry phase - research subject

In this first phase of the CeHRes roadmap, information needed is gathered from the environment where the technology will be implemented. Information that is relevant for this phase bears on problems and needs in care and the identification of important stakeholders. Activities include a literature review and consulting stakeholders e.g. (Stirling et al., 2012).

Developing the *DecideGuide* project was the result of consultations with representatives of patient organizations (Dutch Alzheimer's Association) and professionals working with people with dementia. (Smits & Jukema, 2010). In these consultations representatives and professionals were questioned about what problems needed to be addressed in decision-making in the context of dementia. The most urgent needs expressed were to increase involvement of people with dementia in decision-making about their own situation in order to reach shared decisions and to facilitate and equip professionals with tools supporting shared decision-making in the dementia context.

The actual development of the *DecideGuide* started with the systematic literature review. This resulted in insight into how people with dementia were involved in the development of supportive IT applications (Span et al., 2013). From 893 potentially relevant publications 26 met the inclusion criteria. Exclusion mainly concerned the lack of actual involvement of people with dementia, and/or the absence of a development process, and/or the application not being an IT tool. The results of this review suggest that involving people with dementia in developing supportive IT applications is a fairly recent phenomenon. If people with dementia were involved it was mainly in the first phase and the testing phase rather than in the overall development. Furthermore, the results suggest that people with dementia can provide useful feedback and recommendations to researchers and that their involvement could lead to valuable and user-friendly IT applications.

During this first phase of the CeHRes roadmap, the actual participation of people with dementia was minimal as they were represented by patient organizations. People with dementia were indirectly involved in the process, rather than directly. This matches the role of research subject in Abma's patient participation ladder, as the role is characterized by minimum participation. Patients are especially represented by a patient organization, which e.g., gathers scientific knowledge and makes it accessible, and which mediates between researchers and patients about participation in research.

Value specification phase – informant

In the value specification phase the stakeholders' wishes for improvements in care and important values need to be identified and prioritized to define requirements. Stakeholders' needs can be identified using e.g., interviews and (multi-disciplinary) focus groups.

To identify user requirements for the *DecideGuide* researchers were looking for information from people with dementia (as intended final users) about their experiences with decision-making in their own situation. They started exploring this in semi-structured interviews. People with dementia were individually asked about the problems they experienced, decisions they made, their needs, and values. In focus group interviews people with dementia considered the findings of the interviews, gave additional information where appropriate, and were asked about what other needs and preferences an interactive web tool should address. Furthermore, they discussed the questions among themselves.

In summary, people with dementia participated actively in the value specification phase by answering researchers' questions and giving information doing so. This matches the role of informant on the patient participation ladder.

Interviewer: "Well, I think we should start. First of all, I am very curious how you are doing at this moment."

Respondent: "Yeah, well I can manage things, so to say. Yes, I sometimes forget things, but almost every day I go shopping. When I was 80, I got rid of my car. My daughter took it away. I think, well I will not do that anymore. That did not seem wise to me. Yes, and I walk every day to the grocery. That takes me more than an hour. Well, besides having to go shopping, I like to keep moving, I don't want to sit all the time watching television. So, that's what I also do. Well, that is a nice bonus, that you have the exercise."
(participant in interview)

Design phase – informant and advisor

In the design phase, identified values and requirements are translated into technical specifications for communicative and lucid prototypes in order to enable the par-

Table 1. Characteristics of participating people with dementia in the development of the *Decideguide*

Characteristics of participating people with dementia				
Participants in semi-structured interviews (n=23)				
Gender	Age	Education^{a)}	Type of dementia^{b)}	Marital status
8 Male	62-89 (M=80.4)	2 Low	13 AD	13 Married
15 Female		14 Medium	3 VD	7 Widowed
		7 High	5 MCI/D	3 Single
			1 PD	
			1 LBD	
Participants in focus group interviews at a day-care center (n=9)				
Gender	Age	Education^{a)}	Type of dementia^{b)}	Marital status
5 Male	68-86 (M=79.2)	3 Low	4 AD	5 Married
4 Female		4 Medium	1 VD	4 Widowed
		2 High	1 FTD	
			3 MCI/D	
Participants in focus group sessions with mock-up (n=12)				
Gender	Age	Education^{a)}	Type of dementia^{b)}	Marital status
8 Male	68-85 (M=80.0)	0 Low	3 AD	4 Married
4 Female		4 Medium	1 FTD	2 Widowed
		2 High	2 MCI/D	6 Unknown
		6 Unknown	6 Unknown	
Participants in usability tests (n=3)				
Gender	Age	Education^{a)}	Type of dementia^{b)}	Marital status
2 Male	68-85 (M=80.0)	0 Low	3 AD	2 Married
1 Female		1 Medium		1 Widowed
		2 High		
Participants in field study (n=4)				
Gender	Age	Education^{a)}	Type of dementia^{b)}	Marital status
3 Male	72-82 (M=77.5)	1 Low	2 AD	4 Married
1 Female		1 Medium	1 VD	
		2 High	1 LBD	

a) Low: primary/secondary school graduate; medium: high school graduate; high: college graduate. b) AD= Alzheimer's Disease; VD= Vascular Dementia; FTD= Fronto Temporal Dementia; MCI/D= Mild Cognitive Impairment/Dementia; LBD= Lewy Body Disease; PD= Pick Disease

Table 2. Participation of people with dementia in developing the *DecideGuide*. (phases and roles)

Phases of the CeHRes roadmap	Methods used for the <i>DecideGuide</i>	Roles of involvement (individual level) in Abma's participation ladder					
		Research subject	Infor-mant	Advisor	Referent	Inter-viewer	Co-re-searcher
Contextual inquiry	Consultation of patient organizations Systematic review	X					
Value specification	Interviews Focus groups		X				
Design	Focus groups Usability tests		X	X			
Operational-ization	Field study: interviews, observations		X	X			
Summative evaluation							

CeHRes = Center for eHealth Research and Disease Management; X = participation

ticipants to give feedback. Prototyping, cognitive walkthrough and usability tests support research activities in this phase.

The paper prototype that was developed on the basis of the user requirements was presented in focus group sessions to people with dementia. They were asked to comment on the sketches in general ('What is your first impression'), on the content ('Do you think that what this tool offers is relevant?' and 'Could this tool be helpful in making decisions?'), on its user-friendliness ('How easy is it to use the tool?'), and on the design and its attractiveness ('What do you think of what the tool looks like?'). In the second series of focus group sessions, the participants were asked to comment on the feedback of the first focus groups as well. During the usability tests, the participants were asked to complete tasks (e.g., log in with user name and password, send a message, respond to a message, fill in a questionnaire) and openly express what they were thinking. However, they were obviously not used to doing this. The researchers had to provide almost constant encouragement to get consistent verbal reactions.

People with dementia were fully able to provide researchers with comments on the sketches. The comments concerned the wording, use of color, amount of information, and the attractiveness. Furthermore, they provided them with advice asked and unasked for about improvements of the prototype. During the usability tests people with dementia performed the tasks well. They managed one task (sending and responding to messages) better than participants without dementia.

To conclude, in the design phase people with dementia not only answered researchers' questions, but, by giving comments and advice on the mock-up and the interactive prototype, people with dementia were more than information providers. They participated more actively by reflecting on findings in a way that matches the role of advisor on the patient participation ladder.

"Good afternoon madam...sounds so official. Please, more informal: e.g., Hello (first name)..." (participant in focus group session with mock-up)

Operationalization phase – information provider and advisor

In the operationalization phase, the technology is implemented in practice. This phase refers to the planning of actions and means, dissemination, adoption, and incorporation of the technology. Research activities in this phase are e.g. training and education to enable the use of the technology.

People with dementia and their care network members used the *Decideguide* in their daily lives. They received a written manual to support the use of the *Decide-Guide*. They answered the questions of the structured interviews at T₀, T₁, and T₂. Furthermore, they commented on the *DecideGuide* and its use during the field study. People with dementia appreciated the manual, but when problems occurred they phoned the researchers.

In short, the research activities of the field study matched the operationalization phase of the CeHRes roadmap. Compared to the roles in the patient participation ladder, the people with dementia participated as informants and advisors in this phase. They answered researchers' questions at T_0 , T_1 , and T_2 , and they commented on the use of the *DecideGuide*.

'Interviewer: "What did you think of using the DecideGuide?"

Respondent: "... in general: valuable and useful! In particular for myself and my entourage. A small group conversation is useful. Easy to use when problems arise. Talking freely was nice. A lot of contact with the case manager too. The tool should be used regularly, otherwise the effects fade off. At this moment, I still like the tool. That may become more difficult in future because of my memory." (participant in field study)

"Easy to log in. Starting up with logging in is difficult. It takes too much energy. But well, it should be safe of course." (participant in field study)

3.3 Research question 2: impact of involvement by people with dementia
From the analysis four themes arose concerning the impact of participation of people with dementia: influences on the content and design of the DecideGuide, motivation to participate, time investment, and the balance between challenge and concern.

3.3.1 Influences on the DecideGuide

Content of the DecideGuide

The people with dementia expressed their opinions and preferences in interviews and focus groups about decision-making topics. By expressing themselves individually and in groups, they contributed to the user requirements of the *DecideGuide*. For details see the paper by Span and her colleagues (2014a). Two sets of requirements were determined. The first set of user requirements consisted of topics that arose from problems experienced with decisions made and additional problems experienced. The topics that arose from problems experienced with decisions made concerned: social contacts, daily activities, mobility, safety, living, care, finances, and the future. The topics that arose from additional problems experienced concerned: decreasing autonomy of people with dementia, involvement of people with dementia, participants in decision-making, communication, lack of options, and timing of decisions. People with dementia expressed fewer problems than other network members, although they were fully capable to express what was important to them, e.g., autonomy and staying at home. This first set of user requirements was used to

decide on the content of the *DecideGuide*. The second set of user requirements concerned three domains of requirements the *DecideGuide* needs to facilitate: people involved and their roles (participation of people with dementia in decision-making, self-management and autonomy and the role of informal caregivers and professionals), timeline (anticipation and decision history), and information and communication. People with dementia specifically contributed to the following requirements: 'participation of people with dementia in decision-making', 'self-management and autonomy', 'anticipation', 'social contacts', 'mobility', 'living', and 'daily activities'.

'Interviewer: "Apart from keeping on living here, are there other things important to you?"

Respondent: "Well, yes, going your own way, if you want to watch television you watch, and if you want to listen to nice music for a while, then I will, then I can do those things, I don't have to ask anyone if it's OK. That independence, that is important. That is important to me, yes." (participant in interview)

Design of the DecideGuide

The first focus group of people with dementia took place in a day-care center in a large town. Some of the participants were relatively young and assertive. Although the group moderator of the day-care center was convinced that the participants' consent to video and audio recording was firm, they refused when the principal researcher asked for their consent again. They felt that they could speak more freely without recording. They were also very outspoken about the paper-based prototype session that was based on a fictive person. For some participants the number of sketches was too large to comprehend. The paper prototyping offered not enough guidance for them. Some participants found it difficult to comment on the text and questions in the prototype. They replied that they could not comment on the sketches because they did not know the person described (this person was fictive). Nevertheless, they provided feedback about the user-friendliness, the 'look and feel' of the *DecideGuide* and what the tool should offer in order to be usable and useful. In their opinion the mock-up included too many screens and all of the screens contained too much information. On the other hand, they liked the examples (e.g., about daily activities) that were given and although other network members thought that there were too many examples for people with dementia, they appreciated the number examples to choose from.

The participants of the second focus group also commented on the feedback of the first focus group session. These participants attended a day-care center in a fairly big town, and on average they were older than the first focus group. The presentation of the sketches on paper was reduced to six on the basis of the feedback from the

first focus group. The participants of this group had fewer problems with the fictive case than the first group. They also had fewer comments and enjoyed answering the questions.

‘Interviewer: “When you read that question, what did you think of it? Is it clear?”

Respondent: “Yes, but then I have to put myself in her place, that is difficult.” (participant in focus group session with mock-up)

‘Interviewer: “You typed some text and smileys...”

Respondent: “Those smileys, those were the most clarifying....without a few words they immediately give good results... It sometimes says more than some sentences...so I am in favor of including smileys.” (participant in usability test)

Three people with dementia participated in the usability tests for the first interactive prototype of the *DecideGuide*. All three consented and completed the test. These tests were done at home, and the participants were asked to complete certain tasks. The researcher who moderated the usability tests invited them to give feedback and started a discussion about various aspects of the tool. The feedback by people with dementia during the focus group sessions and the usability tests reflected their ‘here and now’ perspective, accuracy of language, and their thoughts about the graphical layout (Span et al., 2014b). The ‘here and now’ perspective was seen in their focus on concrete items in the present. In the question ‘how are you today?’ they did not like the word ‘today’ because it was too general. They stated that they could not answer that question because today has so many moments. They could only say how they felt ‘right now’. People with dementia were keen on accuracy of language. They commented on the wrong date in the tool and fine-tuned wording, e.g., ‘social contacts’ became ‘family and friends’, and ‘future’ was replaced by ‘important for now and later’. It was important for them that they were addressed by their first name rather than by Madam or Sir. Based on the feedback of people with dementia, the *DecideGuide* was adjusted and improved. In terms of lay-out, people with dementia preferred the foldable green menu bar rather than the white home page with the buttons unlike other participants. Icons used did not always clarify the meaning of the buttons.

“Yes... it will be...I wouldn’t know which pictures ... for ‘Deciding together’...well, yes there are two hands together...to be honest, that is not so clear to me. I prefer another picture. The same goes for ‘How are you’. On my computer, that picture is a sign that you can turn up or turn down the volume...” (participant in usability test)

3.3.2 Motivation to participate

People with dementia were motivated to participate. The main reasons for people with dementia to participate were to be useful by contributing to research activities and to contribute to a better quality of life for future dementia patients. Other reasons they gave for participating were: the importance of the research topic of making shared decisions, the IT tool as an aid (“technology is the future”) and the chance to try out whether an iPad would be a helpful tool for them (“What’s in it for me?”). People with dementia enjoyed learning new skills. They needed help to find out how the iPad worked, but enjoyed trying.

Two of the people with dementia who participated in the field study (Span et al., 2015) did so even though their spouses were reluctant. They wanted to be of use for as long as possible. They wanted to participate so future people with dementia could benefit. Moreover, they wanted to learn to use an iPad because this would probably be easier than learning to use a computer. These participants turned out to be the most active in using the *DecideGuide*. They were very motivated to try out the *DecideGuide* although it was sometimes difficult for them.

One person had some reading problems. He tried using the *DecideGuide*, but had to give up because of his eyesight. His spouse read to him what the network members wrote and what she had written. She also wrote his answers on the questionnaires for him. The spouse of another participant with speech problems spoke for him. This participant felt that his family members decided for him rather than with him. Therefore, he often kept quiet and accepted the situation. In the *DecideGuide*, he could give his own opinion.

“Research is important. Only by participating you forge ahead with the development of things. I am into technology. When there are technical aids then you should try them. It is a pity not to do it. As long as I can participate I will do so. That is useful...” (participant in usability test and field study)

“For the interest of research. More knowledge about dementia is important. Useful research. Nice that people come by on a regular basis....I want to be able to. It is good fun to use such a thing (iPad).” (participant in field study)

3.3.3 Time investment

The interviews and focus groups of people with dementia took more time than the interviews with other network members. This time was necessary for small talk and getting to know each other, for paying attention to the ongoing consent, and for

associative thoughts that came up in participants' minds before the research topics could be addressed. They were competent enough to participate in the interviews although they needed to be reassured that the researchers' visit had nothing to do with testing them but that the researchers were just interested in their opinions and experiences.

Prior to the focus group interviews, the principal researcher, therefore, attended the day-care center for 6 days to help people with dementia get familiar with the researcher (and vice versa). The people with dementia were happy to converse with the researchers, express their needs, and provide the researchers with useful and valuable information. Decision-making proved to be an abstract topic to talk about, despite its operationalization and the researchers' adjustments in the course of the interviews.

Furthermore, extra time and support was mandatory for all participating older adults, including the people with dementia and their spouses, to become familiar with the iPad and the *DecideGuide*. The structure of the *DecideGuide* appeared logical for the participants' children, but not for the participants (people with dementia and their spouses) aged 70 to 80 years. The tool was structured in too many steps and too many levels in some places, and it was not logical for older participants to navigate through those places. They needed extra guidance to get familiar with the structure of the *DecideGuide*. Thus, the principal researcher had to plan extra home visits.

3.3.4 Balancing between challenge and concern

In the development process informal caregivers, case managers and other professionals emphasized their concerns about the involvement of people with dementia. Furthermore, caregivers anticipated that the use of the *DecideGuide* would distress people with dementia, in particular because of the 'transparency' design principle. However, during the interviews, people with dementia showed no signs of distress. Some of them talked openly about their diagnoses. Others did not. They all enjoyed talking about what bothered them but they mostly associated their symptoms with their age rather than with their diagnosis.

"But well, I am not worried about it. And when I forget something, well, then I'll have to go once again, but no, I do not worry about it, no. Because, of my age, I think you should keep your peace." (participant in interview)

People with dementia appreciated the researcher's visits to the day-care center prior to the focus group interviews and the interest in their daily lives. During the focus group interviews they spoke freely about the topics and responded to each other – not always using many words, but they expressed themselves. For some

participants, talking about some topics was challenging emotionally. They were confronted with their diminishing abilities and autonomy. However, it was valuable for them to share these emotions, which go with dementia, and they experienced the group as a safe place. Participants were experts at elaborating on other things that were related to the topics already discussed. They differed in their ways of communicating problems. Some of them talked freely about their problems, others did not. Some participants experienced many problems, whereas others did not. Neither did these participants recognize the problems put forward in the interviews.

'Respondent: "I am not allowed to drive anymore because of my Alzheimer's. I don't like that."

All focus group members: "no!"

R: "Then you must let everything ... go"

Interviewer: "I see it bothers you, doesn't it?"

R: "Yes!"

I: "How long has this been the case?"

R: "Well, no, not so long.... But it is really saddening..."

I: "What exactly?"

R: "Well...you can't do anything on your own anymore. I am not to be trusted anymore in the street." (participants in focus group interview)

Some caregivers expected the usability tests with the *DecideGuide* to cause anxiety in people with dementia, but this was not the case. Two participants were laconic and showed no signs of distress. They had a 'We'll see what happens' attitude. The third participant was very keen on the tasks. "Am I doing it right?" This participant needed reassurance. During the test, these people with dementia were sometimes distracted and wanted to change the subject. Researchers gave them time to have their say and then tried to get them to refocus. Usually they cheerfully shifted their focus back to the test.

Furthermore, some distress was expected in the field study regarding the use of the *chat* function. This was based on the experiences one of the researchers, who played the role of the person with dementia in the cognitive walkthrough, had. This researcher got upset about how the other participants expressed themselves in the *chat* function and therefore feared for the experiences of people with dementia in the field study. However, the messages from other network members in the *chat* function of the *DecideGuide* did not cause the people with dementia any distress.

4. DISCUSSION

4.1 Summary of the results

The findings of this study show that people with dementia participated in various roles in four of the five phases of the CeHRes roadmap: as research subjects during the phase of contextual inquiry, as informants during the value specification phase, and as informants and advisors during the phases of design and operationalization. Their participation resulted in useful and unique feedback concerning the content and design of the *DecideGuide*. The *DecideGuide* was improved and altered on the basis of their feedback. Participants with dementia were intrinsically motivated to participate, wanted to contribute to dementia research for future dementia patients, and wanted to learn to use a tablet. Most of them enjoyed the research activities and liked learning new skills. Except for those in the focus group sessions, there was hardly any sign of upsets. However, meaningful participation takes time; time needed for small talk, for getting acquainted with the participant (and vice versa), and for building a trusting relationship.

4.2 Development phases and roles

The development phases of the CeHRes roadmap (i.e., contextual inquiry, value specification, design, and operationalization) guided researchers through the development step by step. The roadmap offered researchers methods they could employ in each phase, and enabled them to anticipate subsequent research steps. Moreover, the analyses using the roadmap showed that people with dementia were not directly involved in the first phase of the contextual inquiry. On the basis of memos and individual and group interviews about decision-making, the research topic of shared decision-making was expected to be difficult and abstract for people with dementia. This might have been the result of their indirect involvement in this phase and in developing the interview guide.

'Informant' and 'advisor' were the two roles among the six in Abma's participation ladder (i.e., research subject, informant, advisor, referent, co-researcher, and driving force) that people with dementia most often played. These roles are at the bottom and in the middle of Abma's patient participation ladder, respectively, and the people with dementia were not involved in the higher levels of referent, co-researcher, and driving force. However, their participation was meaningful; they gave useful information and feedback in the interviews, focus groups, usability tests, and field study. Some of their contributions were unique; they gave information and feedback that other participants did not.

The patient participation ladder presumes that higher levels lead to more and bet-

ter participation. Researchers debate this hierarchical aspect of the ladder. Tritter and McCallum's (2006) state that another type of user involvement is necessary in health care. They advocate a new approach that does more justice to the dynamic and evolutionary character of user involvement: it should be horizontal rather than vertical, and a mosaic rather than a ladder. This means that all levels are worthwhile and have equal value. As to which role is needed would depend on the phase of the research. Smit et al. (2011) also argued for this horizontal approach. The findings of this study underline these views. In this study, people with dementia acted as informants and advisors. These roles were suitable for the information that the researchers needed. However, the researchers decided when and how they required the people with dementia to be involved. Researchers will have to challenge themselves not to decide about participation for people with dementia, but with them, in close collaboration and in partnership.

As already mentioned, a valid measure of patient participation, e.g., a questionnaire, is not available (Tritter & McCallum, 2006; Visse et al., 2012). Such a measure can be helpful to raise researchers' awareness so that they consider people with dementia's participation before starting their research activities. Moreover, in retrospect, such a measure provides researchers with a tool to assess in which ways they actually involved people with dementia and whether their participation was meaningful. Valuable items for such a measure might be:

1. Time: is there sufficient time for building a relationship with people with dementia and for involving them in the development?
2. Decisions about participation (phases and roles): are people with dementia involved in these decisions?
3. Importance: have the contributions of people with dementia been significant for the research findings?
4. Engagement: how did the people with dementia experience their involvement?

4.3 Social inclusion, social participation, and reciprocity

Participation of people with dementia does not stand on its own, but depends on the interaction between the people involved. This interdependency of people with dementia, informal caregivers, and professionals needs to be acknowledged by all of them (Brannelly, 2006). It influences researchers' perceptions about dementia and their attitudes towards involving people with dementia in social life. It is very important for the participation of people with dementia that professionals see people with dementia as socially alive (Brannelly, 2011). In this study, the participating professionals and informal caregivers mainly focused on their concerns about such participation. Professionals and informal caregivers believed that it would be too

difficult for people with dementia to co-operate in this research, however important their participation may be. In this study researchers decided to ask the people with dementia themselves.

People with dementia liked being involved in this study. It gave them pleasure, and it was important to them to be useful by participating as long as possible and by contributing to a better quality of life for future dementia patients. In Cahill and her colleagues' study (2004), this sense of being useful and giving something back to people around them were reasons for people with dementia to report that their quality of life is good. Moreover, in our study, they provided researchers with information and advice. These reciprocal capacities of people with dementia contrast with van Gorp and Vercruysse (2012), Hsu (2007), and Gove (2012) who have found that there are still perceptions in society and among professionals that people with dementia are unable and unwilling to reciprocate, and even unworthy of social participation. These perceptions exclude people with dementia from social participation and need to be replaced with more positive ones. Vernooij-Dassen and colleagues (2011) state that focusing on people's strengths and wishes to give, rather than on their frailty, might help preserve their social inclusion, dignity, and quality of life. In this study, people with mild to moderate dementia were included, most of whom could express themselves well. Furthermore, researchers need to pay attention to non-verbal signs when vulnerable people are involved. This is especially important when people in more severe stages of dementia are involved (Hellstrom, 2007).

Perceptions of informal caregivers and professionals are important because people with dementia relate to them strongly. They are the key to inclusion and need to take responsibility by taking into account the opinions and preferences of people with dementia (Brannelly, 2011). Since there is a risk of social isolation and 'social death' for people with dementia (Sweeting & Gilhooly, 1997), professionals who cannot see people with dementia as socially alive and active cannot facilitate their personhood (Brannelly, 2011).

Encouraging and helping people with dementia to maintain their social contacts and remain active can contribute to their social inclusion and prevent their social isolation (Alzheimer Europe, 2012, 2014; Moniz-Cook, Vernooij-Dassen, Woods, Orrell, & Interdem, 2011). However, just encouraging them to participate is not enough to maximize their social inclusion. People with dementia need to have opportunities to reciprocate – this is crucial for meaningful social inclusion. Contrary to the findings of van Gorp and Vercruysse (2012), Hsu (2007), and Gove (2012) about society's and professionals' perceptions of people with dementia, this study shows that they can reciprocate. Reciprocation is very important to them so that they feel heard and that others in society value them. Participating in research may contribute to the social inclusion of people with dementia and may do away with the idea that people with dementia cannot meaningfully contribute to the external world.

4.4 Time

In this study the participation of people with dementia took time; time to make them feel comfortable, time for small talk, time to review the ongoing consent, and time to listen to their stories. People with dementia needed time to express themselves. Investing in a good relationship with people with dementia is necessary to facilitate a meaningful participation and to maintain dignity. For ongoing consent and for interviews taking time and adjusting to their pace and to their needs are advocated by Murphy et al. (2014) and Hellström et al. (2007).

Although increasingly more funders require that people with dementia participate as a condition for funding, the extra time that is necessary for their participation often is not taken into account. Researchers are responsible for a meaningful participation of people with dementia in research activities. However, funders can facilitate researchers' responsibility by counting in extra time for people with dementia to participate. This might help in avoiding a meaningless form of participation by people with dementia. It is important to realize that participation by vulnerable target groups like people with dementia requires time.

4.5 Limitations and strengths

This study has some limitations. The findings were based on a secondary analysis; the data used were not collected for the evaluation of participation. Moreover, the researchers involved in the development of the *DecideGuide* were also involved in assessing the ways in which people with dementia participated in developing it. This may have biased our findings in a more positive sense, although this is seen as a strength in secondary analysis (Heaton, 2004; Hinds et al., 1997). Notwithstanding its limitations, the strength of this study lies in its rich and varied data, careful analysis, and the use of theoretical models. This enhanced the rigor of the study.

5. CONCLUSION

In this study, people with mild to moderate dementia participated in designing the *DecideGuide* in most phases of developing it, but mainly as informants and advisors. Their participation from the beginning may result in a better, shared understanding of and commitment to the research topic. This is necessary for a sound development process.

People with mild to moderate dementia can give unique feedback, and it is important to them to be significant to others. They are well able to reciprocate, and

this is important to them. Participating in research activities may contribute to social inclusion of people with dementia and to their quality of life. Researchers can facilitate their social participation by asking them to participate in research and aiming for partnership. However, researchers have to take the necessary time to achieve meaningful participation by people with dementia.

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