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To cite this article: Marijke Span, Marike Hettinga, Leontine Groen-van de Ven, Jan Jukema, Ruud Janssen, Myrra Vernooij-Dassen, Jan Eefsting & Carolien Smits (2017): Involving people with dementia in developing an interactive web tool for shared decision-making: experiences with a participatory design approach, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2017.1298162](https://doi.org/10.1080/09638288.2017.1298162)

To link to this article: <http://dx.doi.org/10.1080/09638288.2017.1298162>



Published online: 12 Mar 2017.



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ORIGINAL ARTICLE

## Involving people with dementia in developing an interactive web tool for shared decision-making: experiences with a participatory design approach

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### ABSTRACT

**Purpose:** The aim of this study was at gaining insight into the participatory design approach of involving people with dementia in the development of the *DecideGuide*, an interactive web tool facilitating shared decision-making in their care networks.

**Method:** 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 group interviews ( $n=18$ ), usability tests ( $n=3$ ), and a field study ( $n=4$ ). Content analysis was applied to the data.

**Results:** Four themes showed to be important regarding the participation experiences of involving people with dementia in research: valuable feedback on content and design of the *DecideGuide*, motivation to participate, perspectives of people with dementia and others about distress related to involvement, and time investment.

**Conclusions:** People with dementia can give essential feedback and, therefore, their contribution is useful and valuable. Meaningful 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.

### ARTICLE HISTORY

Received 19 July 2016  
Revised 23 December 2016  
Accepted 19 February 2017

### KEYWORDS

*DecideGuide*; assistive technology; Alzheimer; participatory design; consumer involvement

### ► IMPLICATIONS FOR REHABILITATION

- People with dementia can contribute meaningfully to the content and design and their perspective is essential for developing useful and user-friendly tools.
- Participating in research activities may contribute to social inclusion, empowerment, and quality of life of people with dementia.

## Introduction

Participation of people with dementia in research is not self-evident [1–3], although awareness and relevance about including the experiences of people who live with dementia increase [4–6]. Informal caregivers and professionals tend to shield people with dementia, often with the best intentions [5]. Researchers' reasons for exclusion are e.g., that participation may be too difficult and/or too stressful for people with dementia. Researchers may also feel that they lack expertise about involving people with dementia in research [1]. Although these reasons may apply to some people with dementia and in specific situations, exclusion does no justice to the experiences and capabilities of others. It may result in sub-optimal research findings [7] and subsequently in inadequate IT applications [8]. Moreover, research shows that people with dementia, even people in advanced stages of dementia, can express their needs [9] and preferences [10] and that even near caregivers may not have a clear insight into people with dementia's values and preferences [11].

Involving people with dementia in research might be challenging, particularly in the later stages of the illness. Issues that need to be addressed for meaningful participation are consent and decision-making capacity [2]. Researchers have different perspectives on these issues. Meulenbroek et al. [12] advocate that an adequate consent procedure in dementia research (e.g., double consent) is as important as the research design. This includes a combination of the use of a capacity instrument with knowledge about the person's history. On the other hand, Cubit [13] emphasizes the challenge of seeking and obtaining informed consent of people with dementia in a moral and ethical way without the use of a capacity instrument. Dewing [1] also advocates an inclusionary consent regardless of legal capacity as people with dementia should be treated as persons regardless of their cognitive capacity. To promote inclusion in research in meaningful ways, Dewing [1] developed a method (process consent) that includes people with changes in their cognitive capacities in research. It consists of five aspects: background and preparation; establishing

a basis for capacity and other abilities; initial consent; ongoing consent monitoring and; feedback and support. Murphy et al. [2] focused on strategies for maximizing the inclusion of people with dementia in qualitative research. She developed a guide, CORTE, to acquire consent. It consists of four areas that need to be addressed: gaining consent, maximizing responses, telling the story, and ending on a high. As people with dementia often experience capacity instruments as threatening, these stepwise approaches of seeking and gaining informed consent may help researchers to involve people with dementia appropriately and meaningfully in research activities.

Involving people with dementia in decision-making about their own situation is important as family caregivers report better quality of life, less depression, less negative strain, and more understanding of the values of the person with dementia [11,14]. Excluding people with dementia from decision-making is sometimes voluntary because they do not want to participate. In that case it is their decision not to participate. Sometimes they are not given the chance to participate, even if they are perfectly able to participate in decision-making about their own situation [15].

To facilitate shared decision-making in the care networks of people with dementia, an interactive web tool, the *DecideGuide*, was developed [16,17]. Shared decision-making is an approach that facilitates the involvement of patients in making care decisions together with their clinicians [18,19]. Shared decision-making increases patient autonomy and satisfaction with the overall decisions [7]. 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 meaningful participation of people with dementia in research activities is challenging, this study focuses on involving them in the development of the *DecideGuide*. The aim of this

study was at gaining insight into the participatory design approach of involving people with dementia in the development of the *DecideGuide*, an interactive web tool facilitating shared decision-making in their care networks. The research question of this study is: What are the experiences with the participatory design approach of involving people with dementia in the development of the *DecideGuide*?

Materials and methods

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 [20,21]. 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 on the development steps leading to the *DecideGuide* was undertaken. The data with a rich and varied nature consisted of transcripts of semi-structured interviews and focus groups, field notes, observational records, and a log book [22,23]. These data were collected by the principal researcher assisted by other researchers of the team developing the *DecideGuide*.

The case

The *DecideGuide*, a responsive web tool for supporting shared decision-making in a dementia context, was developed and refined in four iterations (Figure 1) on the basis of feedback from intended users: people with dementia, informal caregivers, and case managers [24].

The design principles of the *DecideGuide* are threefold. First, we aimed for transparency in order to reduce feelings of

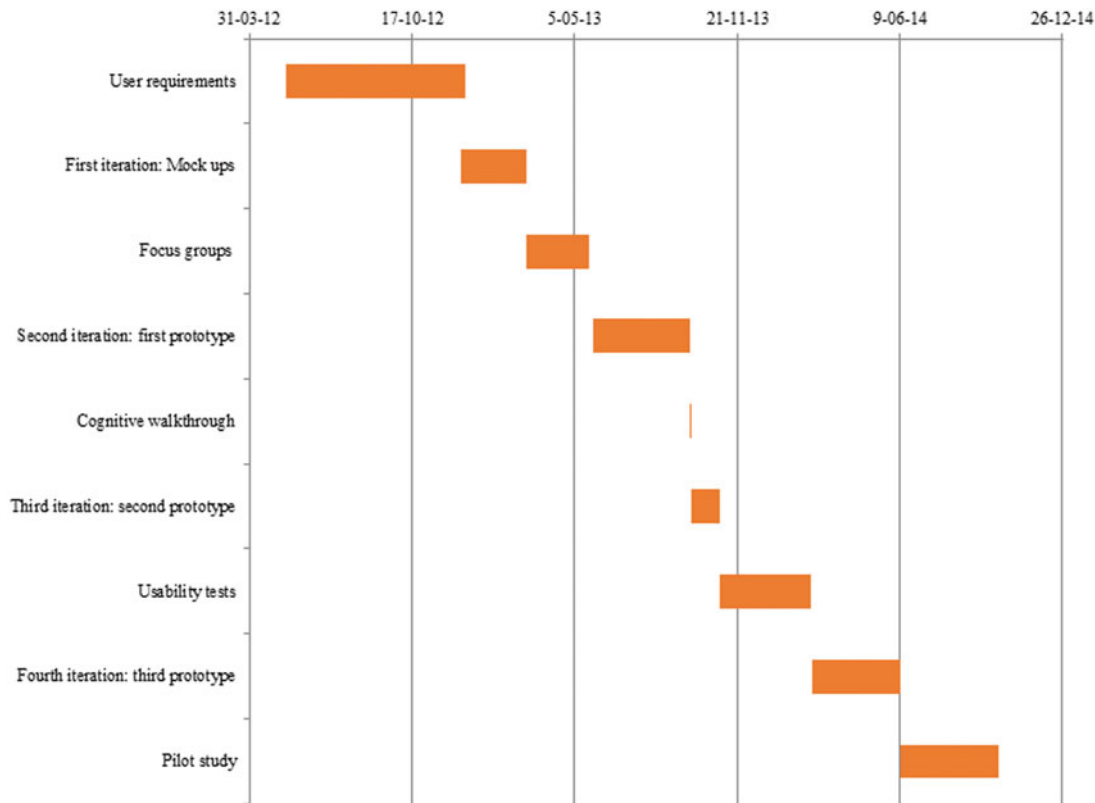


Figure 1. Timeline of designing the *DecideGuide*.

suspicion, e.g., that people with dementia, due to the condition, often harbor [25]. Second, we aimed for open communication and information to ensure that all network members share the same information. The third aim was at giving a voice to people with dementia as their opinion is often neglected [26]. 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 (Figure 2). The first, *Messages*, is a chat function and supports transparency. The chat functionality 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 secure 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 users (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 [17].

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.

### Recruitment of participants

People with mild to moderate dementia were recruited in three different ways: by case managers, by contacts in nursing homes and daycare centers, and on the website of the Dutch Alzheimer's Association (see Table 1 for characteristics). As we wanted to highlight people with dementia's experiences and perspectives, inclusion was determined by their ability of having a (group) conversation with the researchers rather than by a cognitive capacity instrument (e.g., MMSE) [4,5]. 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 2–4 on Reisberg's global deterioration scale, which excluded people with severe dementia [27]. 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

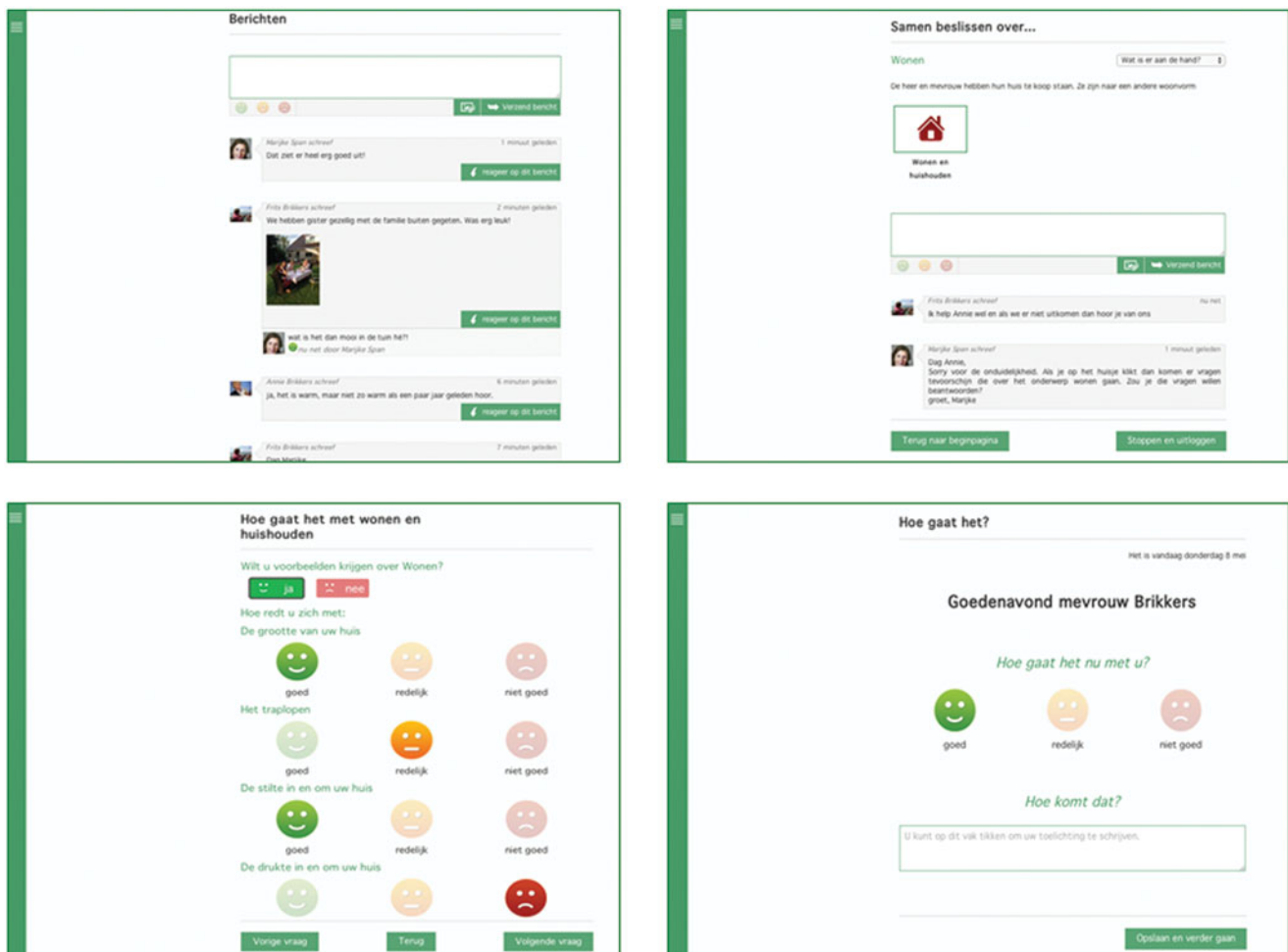


Figure 2. Final layout of the *DecideGuide* (screen view for the person with dementia). Clockwise starting top left: chat function, deciding together function, individual opinion function "How are you right now?" and individual opinion in questionnaire with examples.

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

ID	Gender of PWD	Age of PWD	Type of dementia <sup>a</sup>	Marital status	Education <sup>b</sup>	Living arrangements
<i>Semi-structured interviews (n = 23)</i>						
1	Man	82	VD	Married	Low	Home for the elderly
2	Woman	82	AD	Widowed	Medium	Nursing home
3	Woman	83	LBD	Single	Medium	Home for the elderly
4	Man	77	AD	Married	High	Nursing home
5	Woman	83	MCI/D	Widowed	Low	Community dwelling
6	Woman	62	VD	Married	Medium	Nursing home
7	Woman	Unknown	PD	Married	High	Community dwelling
8	Man	80	AD	Widowed	Medium	Community dwelling
9	Woman	74	AD	Married	High	Community dwelling
10	Man	Unknown	AD	Married	Medium	Community dwelling
11	Woman	79	MCI/D	Married	Medium	Community dwelling
12	Woman	80	VD	Married	Medium	Community dwelling
13	Woman	84	Unknown	Widowed	Medium	Community dwelling
14	Man	70	AD	Married	High	Community dwelling
15	Woman	89	AD	Widowed	Medium	Community dwelling
16	Woman	87	AD	Widowed	Medium	Community dwelling
17	Man	83	Unknown	Married	Low	Community dwelling
18	Woman	73	AD	Single	Medium	Nursing home
19	Man	86	Unknown	Widowed	Medium	Community dwelling
20	Woman	89	AD	Single	Medium	Community dwelling
21	Woman	87	AD	Married	Medium	Community dwelling
22	Woman	Unknown	AD	Married	Medium	Community dwelling
23	Man	78	AD	Married	Medium	Nursing home
<i>Focus group interviews at a day care center (n = 9)</i>						
1	Woman	79	AD	Married	Low	Community dwelling
2	Man	86	MCI/D	Widowed	High	Community dwelling
3	Man	77	VD	Married	Low	Community dwelling
4	Man	80	MCI/D	Married	Medium	Community dwelling
5	Man	68	FTD	Widowed	Low	Community dwelling
6	Woman	81	MCI/D	Widowed	Medium	Community dwelling
7	Man	78	AD	Married	Medium	Community dwelling
8	Woman	80	AD	Widowed	Medium	Home for the elderly
9	Woman	84	AD	Married	High	Home for the elderly
<i>Focus group sessions with mockup (n = 12)</i>						
1	Woman	85	AD	Widowed	High	Community dwelling
2	Woman	80	MCI/D	Married	Medium	Community dwelling
3	Man	85	AD	Married	High	Community dwelling
4	Man	69	FTD	Married	Medium	Community dwelling
5	Man	80	AD	Married	Medium	Community dwelling
6	Woman	81	AD	Widowed	Medium	Community dwelling
7	Man	Unknown	Unknown	Unknown	Unknown	Community dwelling
8	Man	Unknown	Unknown	Unknown	Unknown	Community dwelling
9	Woman	Unknown	Unknown	Unknown	Unknown	Community dwelling
10	Man	Unknown	Unknown	Unknown	Unknown	Community dwelling
11	Man	Unknown	Unknown	Unknown	Unknown	Community dwelling
12	Man	Unknown	Unknown	Unknown	Unknown	Community dwelling
<i>Usability tests (n = 3)</i>						
1	Man	72	AD	Married	High	Community dwelling
2	Man	82	AD	Widowed	High	Community dwelling
3	Woman	79	VD	Married	Medium	Community dwelling
<i>Field study (n = 4)</i>						
1	Woman	81	AD	Married	Medium	Community dwelling
2	Man	82	AD	Married	High	Community dwelling
3	Man	72	LBD	Married	High	Community dwelling
4	Man	75	VD	Married	Low	Community dwelling

PWD: person with dementia.

<sup>a</sup>AD: Alzheimer's disease; VD: vascular dementia; FTD: Fronto temporal dementia; MCI/D: mild cognitive impairment/dementia; LBD: Lewy body disease; PD: Pick disease.<sup>b</sup>Low: primary/secondary school graduate; medium: high school graduate; high: college graduate.

participants. These characteristics were checked by researchers when they first met with the people with dementia recruited. If necessary informal caregivers gave additional information.

### Consent procedure

Special attention was paid to the informed consent of people with mild to moderate dementia to be sure of their voluntarily participation. This included investing in their ongoing consent [5].

People with dementia received written and oral information about the research activity, and were asked for their consent. Their initial 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. Effort was put in highlighting the individual experiences of people with dementia. This was not always self-evident



for the couples, but after explaining the importance of the individual views they agreed.

### 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 [28]. Data triangulation was used to strengthen the validity of the findings [29]. 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. The research group consisted of researchers specialized in care for older people, dementia experts and IT experts.

The data were collected in three steps: determining the content of the tool, determining the design of the tool, and testing the tool in daily practice.

#### Step 1: determining the content of the tool

To determine the content of the interactive web tool semi-structured interviews were used to identify the needs and preferences of people with dementia [29]. 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 [29]. The semi-structured interviews aimed at identifying difficulties and decisions that people with dementia encounter. The interviews lasted 30–60 min; they were audiotaped and transcribed verbatim. The interview topics included problems experienced, decisions, personal values, and involvement of people with dementia in decision-making [30].

Next, to enhance data richness two focus groups were organized where participants were invited to discuss the results of the interviews and to make additions to the problems experienced and decisions made [31,32]. One group consisted of four persons with dementia, the other of five. Both groups attended a daycare center. Two researchers moderated the focus group interviews, which lasted 1–1.5 h each. The principal researcher (Marijke Span) led the focus groups and used an interview protocol to direct the discussion about experienced problems. The second researcher assisted the principal researcher.

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

#### Step 2 determining the design of the tool

To determine the design of the interactive web tool a mockup (a paper-based prototype) of the *DecideGuide* was developed. This mockup was based on the results of the semi-structured interviews and the focus group interviews [24,28]. The mockup was presented in two 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 daycare center. The mockup 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, six sketches were presented to the focus group of four. Both focus group sessions lasted 1–2 h. The principal researcher (Marijke Span) 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 to identify possible user problems [33], 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 [28,34]. 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 min. The think-aloud method was used to identify thoughts and feelings of participants while using the prototype [35]. 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 (Marijke Span) moderated the usability tests and asked the participants to complete some tasks. Another researcher (Ruud Janssen) 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.

#### Step 3 testing the tool in daily practice

To test the *DecideGuide* in their daily lives four people with dementia and their care networks (19 participants in total) took part in a five-month field study. This study focused on evaluations of the user-friendliness of the tool, of participants' contentment with the tool, and how they valued the tool for decision-making. They worked with the *DecideGuide* on a daily basis on an iPad for five months. Participants were recruited via case managers. Several home visits preceded the actual participation to get acquainted. During the first visit, the principal researcher explained the study 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 the use of the *DecideGuide* on an iPad. The researcher explained things and participants were given a hardcopy instruction manual. 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 3–6 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 focusing on if and how they used the *DecideGuide*.

### Analysis

Content analysis was used for the primary analyzes [29]. To determine the content of the *DecideGuide* (step 1) the transcripts were

read and reread by two researchers who then coded fragments in the interview transcripts describing problems encountered and decisions made in the networks. The two researchers discussed the codes until consensus was reached. The list of codes was then discussed in the research group. Next step was developing categories of problems and decisions by grouping the codes into meaningful clusters using Affinity Diagramming [33]. In designing the *DecideGuide* (step 2), framework analysis was used to analyze the quality of the design in terms of system, content, and service [36,37]. The data of the field study (step 3) were analyzed using content analysis. The primary analyzes were conducted by two researchers and discussed within the research group. Disagreements were discussed until consensus was reached.

For this study, a secondary analysis of the data was conducted with a focus on involvement of people with dementia in the development [22,23]. The data were content-analyzed by reading and re-reading the transcripts while focusing on participation of people with dementia [20]. The codes that originated from the data were then grouped into meaningful clusters using affinity diagramming [33]. This secondary analysis was conducted by two researchers (Marijke Span and Ruud Janssen) who were familiar with the data. The principal researcher (Marijke Span) started the coding process and the second researcher (Ruud Janssen) assisted and checked the initial coding process. Disagreements were discussed till consensus was reached. Both researchers are experienced qualitative researchers who are aware that their personal and professional perspectives or experiences influence the data analysis, which was regularly discussed. Steps in the development and analysis were discussed within the research team to enhance intersubjectivity.

### Participants' characteristics

For the semi-structured interviews to identify user requirements (step 1), 30 people with dementia and their care networks were reached of whom 23 consented to participate (Table 1). 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 daycare 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 (step 2), 20 people with dementia in two daycare 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 (step 3), six people with dementia, and their care networks were approached. 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.

### Ethical considerations

The institutional review board of the regional ethics committee of Isala Clinics gave written approval for the study (number: 10.11113) and a careful informed consent procedure was followed (see section Consent procedure).

### Results

This section describes the experiences with a participatory design approach of involving people with dementia in the development of the *DecideGuide*. Four themes were identified: (1) valuable feedback on content and design of the *DecideGuide*, (2) motivation to participate, (3) perspectives of people with dementia and others about distress related to involvement, and (4) time investment.

#### Valuable feedback on content and design of the *DecideGuide*

People with dementia provided valuable information and unique feedback on the content and design of the *DecideGuide* that otherwise would have been missed out. Based on their feedback adjustments were made to the *DecideGuide*.

Regarding the content of the tool people with dementia expressed fewer problems than other network members, but they were fully capable to express what was important to them, e.g., autonomy and staying at home. Their information was used for the first set of user requirements to decide on the topics for the content of the *DecideGuide*: social contacts, daily activities, mobility, safety, living, care, finances, and the future. Moreover, issues were identified related to the decision-making process: decreasing autonomy of people with dementia, involvement of people with dementia, participants in decision-making, communication, lack of options, and timing of decisions.

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.'" (respondent 8 in semi-structured interview, Table 1)

In the design phase people with dementia provided not only information and advice to improve the design of the *DecideGuide*. During the first focus group people with dementia were very outspoken about the paper-based prototype session that was based on a fictional 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 fictional). 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 mockup 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 of examples to choose from.

The participants of the second group had less 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.'" (respondent nine in focus group session with mockup, Table 1)

"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.'" (respondent three during usability test, Table 1)

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. 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 a simple 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 ..." (respondent two during usability test, Table 1)

### **Motivation to participate**

People with dementia were motivated to participate in the several stages of the development. The main reasons for people with dementia to participate were (1) to be useful by contributing to research activities, (2) to contribute to a better quality of life for future dementia patients, and (3) give one's opinion. 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 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.

Some participants discussed the ongoing consent. They had given their consent at the start and in their opinion that was enough. They experienced it a bit as patronizing that the researcher asked them on a regular basis if they still consented.

"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 ..." (respondent 2 in field study, Table 1)

"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)." (respondent 1 in field study, Table 1)

### **Perspectives of people with dementia and others about distress related to involvement**

In the development process informal caregivers, case managers and other professionals expressed some 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." (respondent 1 in semi-structured interview, Table 1)

People with dementia appreciated the researcher's visits to the daycare 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 emotionally. They were confronted with their diminishing abilities and changes in 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.'" (respondent 8 in focus group interview, Table 1)

Some caregivers expected the usability tests with the *DecideGuide* to cause anxiety in people with dementia, but this was not the case. Two participants responded laconically 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 of 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.

### 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. The participants 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.

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 70–80 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.

## Discussion

### Summary of the results

This study focused on participation experiences in developing the *DecideGuide*. Four themes were identified: valuable feedback to

content and design, motivation to participate, perspectives of people with dementia and others about distress related to involvement, and time investment. The participation of people with dementia in the development resulted in valuable and unique feedback concerning the content and design of the *DecideGuide*. The *DecideGuide* was improved and altered on the basis of their feedback. This type of feedback takes time; time needed for small talk, for getting acquainted with the participant (and vice versa), and for building a trusting relationship. 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. There was hardly any sign of upsets although distress of the person with dementia was the main concern of informal caregivers and professionals. A careful consent procedure is pre-requisite for meaningful inclusion of people with dementia in research.

### Consent

A careful and stepwise consent procedure was followed by the researchers. That resulted in clarity of people with dementia's intention to participate. Researchers have an essential role in the consent procedure; their personal moral character is the most important protection for human research subjects [13]. To ensure that people with dementia's dignity and respect was maintained, the consent procedure was discussed regularly in the research team and in the later stages checked with the strategies of Murphy et al. [2]. There was no doubt in the research team whether to include people with dementia, only how to include them best, as Hellström advocated earlier [4].

The consent procedure was for some participants too careful and raised questions about why they had to confirm their participation again. They felt a bit patronized because they had given their consent beforehand. This was also recognized by Murphy et al. [2]. Getting to know the person is important to understand a person's needs and attuning the consent procedure to the individual needs.

### Social inclusion and social participation

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 [38]. It influences researchers' perceptions about dementia and their attitudes towards involving people with dementia in social life. For the participation of people with dementia it is therefore important that professionals see people with dementia as socially alive [39]. In this study, the participating professionals and informal caregivers expressed their concerns about such participation.

People with dementia were motivated to participate and 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 [40], 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 [41], Hsu [42], and Gove [43] 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 et al. [44] 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.

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 [39]. Since there is a risk of social isolation and "social death" for people with dementia [45], professionals who cannot see people with dementia as socially alive and active cannot facilitate their personhood [39].

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 [46–48]. 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. 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.

### 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. In order to facilitate learning, people with dementia plead for an early introduction of new tools regarding their stage of dementia. This is confirmed by findings of Boman et al. [49]. 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. [2] and Hellström et al. [4].

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.

### 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 [22,23]. Notwithstanding its limitations, the strength of this study lies in

its rich and varied data and a careful analysis. This enhanced the rigor of the study.

### Conclusions

In this study, people with mild to moderate dementia participated in developing the *DecideGuide*, an interactive web tool to facilitate shared decision-making in dementia care networks. People with mild to moderate dementia are motivated to participate in research, they can give valuable and unique feedback, and it is important to them to be able to reciprocate the efforts others make and to be significant to others. 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.

### Acknowledgements

The Dutch Foundation Innovation Alliance (SIA RAAK [Regional Attention and Knowledge Circulation] PRO), Zorgpalet Hoogeveen (Residential care organization for older adults) and Windesheim University of Applied Sciences funded this study.

### Disclosure statement

The authors report no declarations of interest.

### Funding

The Dutch Foundation Innovation Alliance (SIA RAAK [Regional Attention and Knowledge Circulation] PRO), Zorgpalet Hoogeveen (Residential care organization for older adults) and Windesheim University of Applied Sciences funded this study.

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