An Interactive Web Tool to Facilitate Shared Decision Making in Dementia: Design Issues Perceived by Caregivers and Patients

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Abstract—The aim of this study is to identify design issues (both weaknesses and strengths) that should be considered for designing a user-friendly design of an interactive web tool that facilitates shares decision making in care networks of people with dementia. Our research questions are: 1) What design issues can be identified? and 2) What is the unique contribution of people with dementia to the design? This study, with its iterative participatory design based on the CeHRes roadmap included six separate focus group sessions with people with dementia, informal caregivers, and case managers; a cognitive walkthrough with researchers; and usability tests with case managers, older adults, informal caregivers, and people with dementia. The design issues were: a screen design based on pleasant and harmonious colors, the use of clear and uniform buttons throughout the interface, the use of multiple-choice questions with smileys as answering options, a foldable menu bar that is closed (for people with dementia) or open (for caregivers) by default, and the incorporation of a chat function that specifically keeps all end users involved in a conversation. The specific and detailed contribution of the participants with dementia dealt with their focus on the present, accuracy of language, and the graphical layout. However, other participants doubted whether the tool would be useful and usable for people with dementia. Designing a user-friendly, interactive web tool for people with different capacities, interests, and perspectives is challenging. People with dementia contributed uniquely to the design of the web tool. A pilot study will show whether the doubts of some of the participants are valid.

Keywords- dementia, shared decision making, participatory design, assistive technology, interactive web tool.

I. INTRODUCTION

Designing an interactive web tool to facilitate shared decision making (SDM) in care networks of people with dementia is complex because of the progressive character of dementia and the multitude of people involved in the decision making process namely, the person with dementia, informal caregivers, and case managers [1][2]. In a prior study we identified user requirements for such a tool: decision-making topics that the tool should address and additional needs and preferences of all concerned [3][4]. In the present study, we focus on the design of such an interactive web tool – a design that aims to do justice to people with dementia in decision making.

Dementia is characterized by progressive cognitive decline. Decreasing abilities address memory loss, route planning, behavior change, and orientation problems. Dementia is a disease that is affecting increasingly more people worldwide: the prediction is from 66 million in 2030 to 115 million in 2050 [5][6]. The life expectancy of people with dementia after diagnosis is 6 to 8 years. During this period, people with dementia and their loved ones are faced with many decisions related to care and well-being, e.g., can or should the patient drive a car, walk alone outdoors, start day care, or be admitted to a nursing home [7][8]. These decisions, often overloaded with emotions, change the situation of people with dementia continuously. Dementia is not a linear process, and the change in capacities of people with dementia influences their position in decision making [9][10].

The decision making of many people challenges the traditional view of shared decision-making. Shared decision making (SDM) has its origin in the clinical encounter between the clinician and the mentally able patient who decide about one medical question. The decision is mainly based on analytical thinking [11]. Shared decision making is an approach that involves patients in making medical decisions to the extent that they want to and that emphasizes the collaboration between professionals and patients [11][12]. Shared decision making increases patient autonomy and empowers the patient [13]. This could also benefit people with dementia who are capable of expressing their

needs [13] and preferences [14]. Unfortunately, their participation in decision-making processes [13][15], research [16] and IT development trajectories [17] is not common.

In designing an interactive web tool to facilitate SDM in care networks of patients with dementia, we have to take into account the two-fold complexity just described, i.e., the progressive character of dementia and the multitude of people involved, all of whom have different capacities and interests in decision making. Because of this, we included all the groups in the designing to create a shared perspective; not only the groups of informal caregivers and case managers, but also the group of people with dementia [18]. The last group is the most vulnerable group in this context. The views of people with dementia are in danger of being overlooked. Caregivers tend to shield them or speak for them rather than with them [19]. Spending time with people with dementia and confirming that their contribution is worthwhile helps to include them in research [16]. This is necessary to better understand their needs and preferences [13].

An additional reason for involving them in the design is the progressive character of dementia that sets them apart from average web users. They have problems using a "one size fits all" computer design [20]. Several researchers have provided evidence-based design criteria for designing for people with dementia: creating easy orientation [21][22]; using familiar cues; making everything legible and distinctive [23]; choosing touch screens, large-format screens, and large font sizes; keeping text to a minimum; assuring a hypermedia structure with limited options for selection and an attractive design [24]; and using tablets [25]. These criteria ensure a dementia-friendly design of IT tools in general.

Thus, the current body of knowledge includes knowledge of design criteria that the final product must meet. It does not, however, provide knowledge of how to design an interactive SDM web tool or what the challenges will be. This design process has to deal with the two-fold complexity as well. Therefore, we aim to identify design issues (strengths and weaknesses) that have to be taken into account in a design for a user-friendly interactive web tool for SDM in care networks for people with dementia. The research questions read:
1) What design issues can be identified for a user-friendly interactive web tool that helps people with dementia with shared decision making?
2) What is the unique contribution of people with dementia to the design?

II. METHODS

In our study with its iterative, participatory design, we consider the involvement of all types of end users, but particularly people with dementia [17], as one of the key factors for developing a user-friendly and usable interactive web tool. We used the Center for eHealth Research and Disease Management (CeHRes) roadmap for the tool because this approach connects a human centered design with eHealth business modeling and emphasizes the importance of involving all those concerned to develop sustainable innovations [26]. The roadmap helps developers structurally integrate interactive web tools in health care and involves the participants in all phases of the development. The CeHRes roadmap offers a holistic framework consisting of five phases:
1) Contextual inquiry: gathering information from the environment where the technology will be implemented
2) Value specification: defining requirements based on participants' values
3) Design: translating these values and requirements into technical specifications and requirements for communicative and lucid prototypes in order to enable the participants to give feedback
4) Operationalization: implementing the technology in practice
5) Summative evaluation: determining the effects of the technology on behavior, health and organization.
This paper describes how the third phase of the CeHRes roadmap was applied to the design of an interactive web tool facilitating SDM in care networks of people with dementia: the *DecideGuide*. We used focus group sessions, a cognitive walkthrough, and usability tests to address both research questions.

A. DecideGuide

The DecideGuide is an interactive tool for people with dementia, informal caregivers and case managers to communicate with each other in making shared decisions. The design principles of the DecideGuide are transparency, open communication and information, and giving voice to people with dementia. The DecideGuide incorporates three perspectives: those of people with dementia, informal caregivers, and case managers. The case manager deliberates with the person with dementia and the informal caregivers whether to use the DecideGuide. All participants have an individual login and use the tool on their own or after they are alerted by the case manager. The DecideGuide has three pillars. The first pillar, *Messages* is a chat function that enables users (at a distance) to communicate with each other. The second pillar, *Deciding together* supports decision making step by step. The third pillar, *Individual opinion* enables users to give their individual opinions about dementia-related topics and their circumstances. It particularly supports giving voice to the person with dementia (Fig. 1). The DecideGuide, a safe and shielded web tool, is available for tablets, laptops, and computers.

The DecideGuide was developed in a process consisting of four iterations (Fig. 2). Fig. 3 illustrates the iterative development with the changes made in the chat function. These included using buttons (forward and back) instead of arrows, simplifying the menu bar, changing the position of menu bar, using colors, adding notifications, and providing an option to fold or expand the menu bar. All these changes were made in accordance with the feedback from users.

B. Focus group sessions with mock-ups (first iteration)

Firstly, separate focus group sessions were organized with intended end users, including people with dementia,
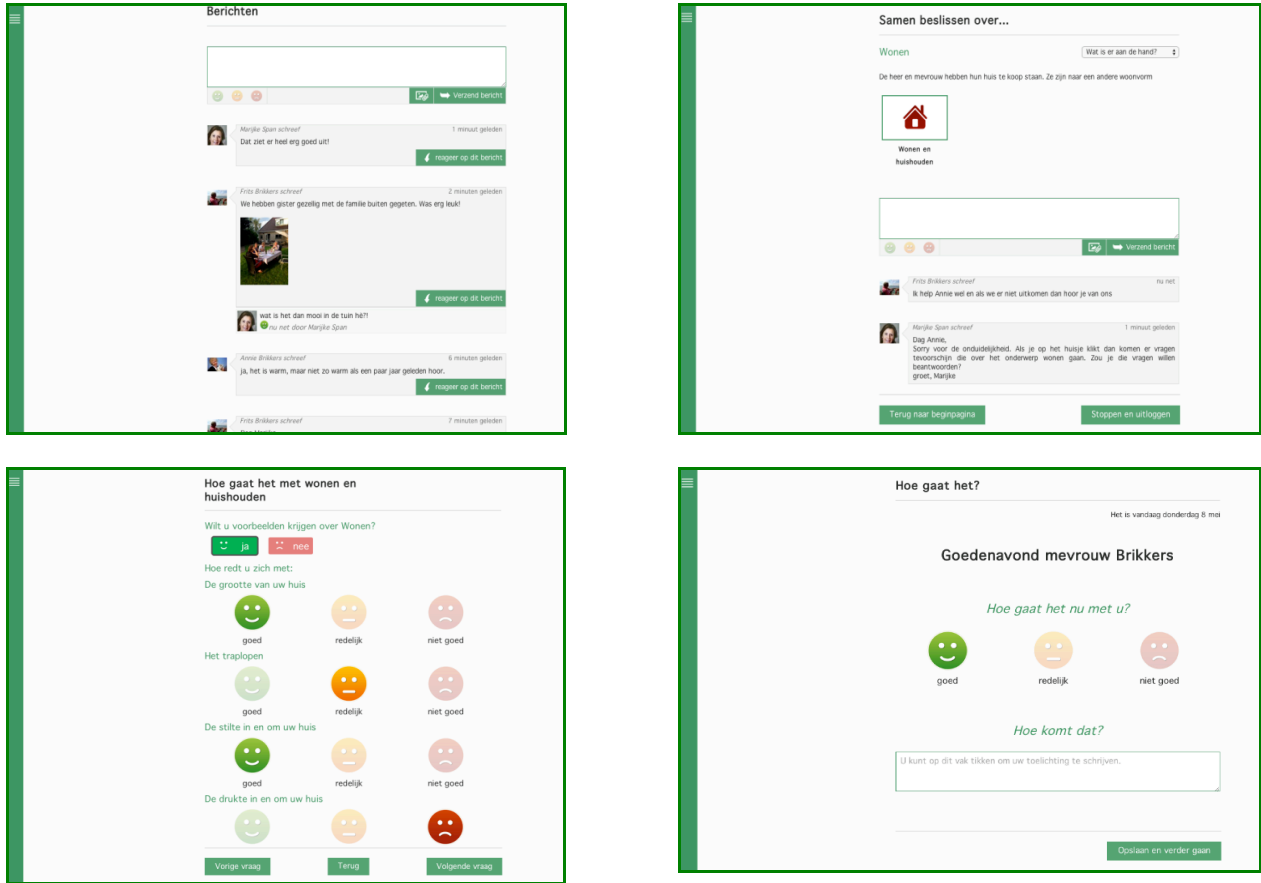
Figure 1. Final layout of three pillars of the DecideGuide (screen view for the person with dementia). Clockwise starting top left: chat function (belonging to the first pillar), deciding together (second pillar), individual opinion "How are you right now?" and individual opinion in questionnaire with examples (both belonging to the third pillar).
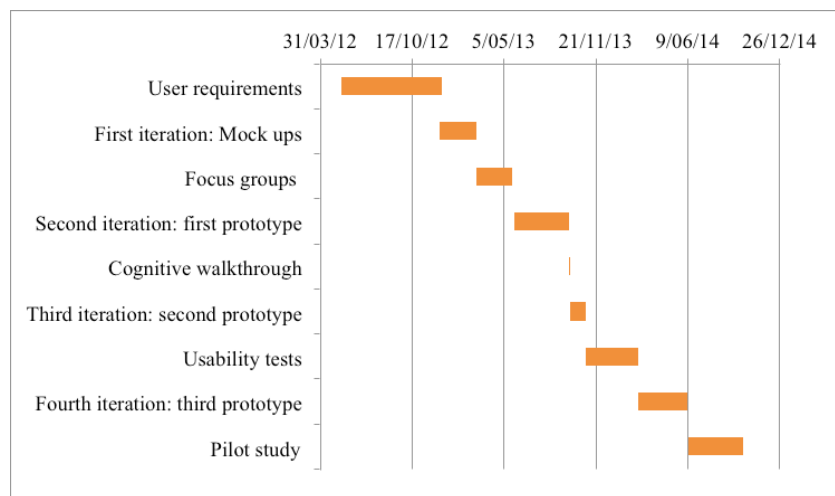

Figure 2. Timeline of designing the DecideGuide.

informal caregivers, and case managers. The goal of these focus group sessions was to receive comments and feedback about the first mock-ups, that is sketches on paper of the user interface of the DecideGuide.

People with mild to moderate dementia were recruited from two daycare centers. Informal caregivers were recruited from residential homes and the Dutch Alzheimer Association. Case managers were recruited from regional case managers' networks. All participants gave their written informed consent. We paid special attention to the informed consent of people with dementia because of their vulnerability. To be sure of their voluntary participation we invested in an ongoing consent [16]. We invested in time for social talk and getting to know each other, checked the consent of people with dementia during their participation after their initial consent, and emphasized the importance of their participation. The investigators watched over any signs, non-verbal or otherwise, of discomfort or restlessness of people with dementia. In such a case, the participant was given ample opportunity to quit.

Twenty-seven end users participated in the six focus group sessions (Table I). The two separate focus group sessions with people with dementia and informal caregivers took place in two rounds. They consisted of six and four participants, respectively, with different participants in each round. The participants of the second-round focus groups commented both on the mock-ups and the feedback of the first round of focus groups. Two focus group sessions with case managers took place with the same group of seven participants. The principal researcher, assisted by another researcher or designer, moderated the focus groups.

The mock-ups of the DecideGuide included 11 sketches on paper. The mock-ups, based on user requirements [3][4], were presented in the focus groups [26]. End users were asked to comment on the different sketches in general (What is your first impression?) content (Do you think what this tool offers is relevant? or Could this tool be helpful in making decisions?), user-friendliness (What do you think of the usability of the tool?) and the attractiveness of the design (What do you think of the look and feel of the tool?).

The focus group sessions lasted 1 to 2 h and were audio taped and transcribed verbatim, except for one focus group with people with dementia in round 1. Although the participants agreed to recording the interview before the meeting, they refused when the meeting was about to begin. They felt they could speak more freely without the session being recorded. Field notes of this interview were taken.

The five steps of framework analysis were used to analyze the focus group interview transcriptions: becoming familiar with the data, identifying a thematic framework (identified themes showed similarities to an existing framework), indexing (coding with thematic framework), charting (rearranging thematic framework if necessary), and mapping and interpretation (explanation of the findings) [27]. We used the CeHRes assessment of design quality which was adapted from the CeHRes roadmap. It consisted of three levels for assessing the quality of design: system quality (user-friendly, safe technology), content quality (understandable and meaningful content) and service quality

(adequately provided service) [28]. We used the CeHRes assessment of design quality because it addresses various aspects of eHealth design quality that are based on several studies.

C. Cognitive walkthrough (second iteration)

Secondly, the first interactive prototype was built on the basis of the feedback for the mock-ups: the DecideGuide. This prototype was tested in a cognitive walkthrough session with the researchers to identify possible user problems and evaluate the usability of the DecideGuide [18][28][29].

Three of the research team tested the DecideGuide on a tablet in a 2-h role-playing session in a usability lab. First the participants tried the tool on their own, without any instruction. Then they performed tasks in a think-aloud session [29]. The session was video and audiotaped, and field notes were taken. The principal researcher and developer supervised the session. The analysis focused on the three levels of the CeHRes assessment of design quality: system, content, and service quality.

D. Usability tests (third iteration)

Thirdly, on the basis of the results of the focus group interviews and the cognitive walkthrough, we tested the usability with the adapted interactive prototype of the DecideGuide on a tablet [28][29]. The goal of these usability tests was to further refine the DecideGuide into a prototype that was robust enough to be used in a pilot study [29]. Three to five usability tests are required to identify most of the bugs [30][31]. The total number of usability tests was 12: three for the case managers, three for the informal caregivers, and three extra usability tests with older adults before the three usability tests with people with dementia were done. The participants were asked to perform tasks (e.g., log in with their user names and passwords, send a message, respond to a message, and fill in a questionnaire). The think-aloud method was used to identify their thoughts and feelings while they used the prototype [32]. The usability tests were video and audiotaped, and field notes were taken. The principal researcher moderated the usability tests with the assistance of another researcher.

Firstly, three case managers who participated in the development tested the DecideGuide together in a session that lasted 2 h. They tried out the DecideGuide on their own and then tried some tasks. Secondly, after adjusting the DecideGuide on the basis of the usability tests with case managers, three older adults recruited from a sounding board of the department *Care innovation for older adults* at a university of applied sciences tested the DecideGuide individually. They tested the DecideGuide with the login of people with dementia in a 1-h session in a usability lab. We chose this approach to find out whether the DecideGuide was "bug free", user friendly, and suitable for people with dementia to test. Thirdly, three informal caregivers recruited by participating case managers tested the DecideGuide. These individual sessions also took place in a usability lab and lasted about 1 h. Fourthly, three community-dwelling people with dementia (Reisberg score: 2-4) recruited by participating case managers tested the DecideGuide on a
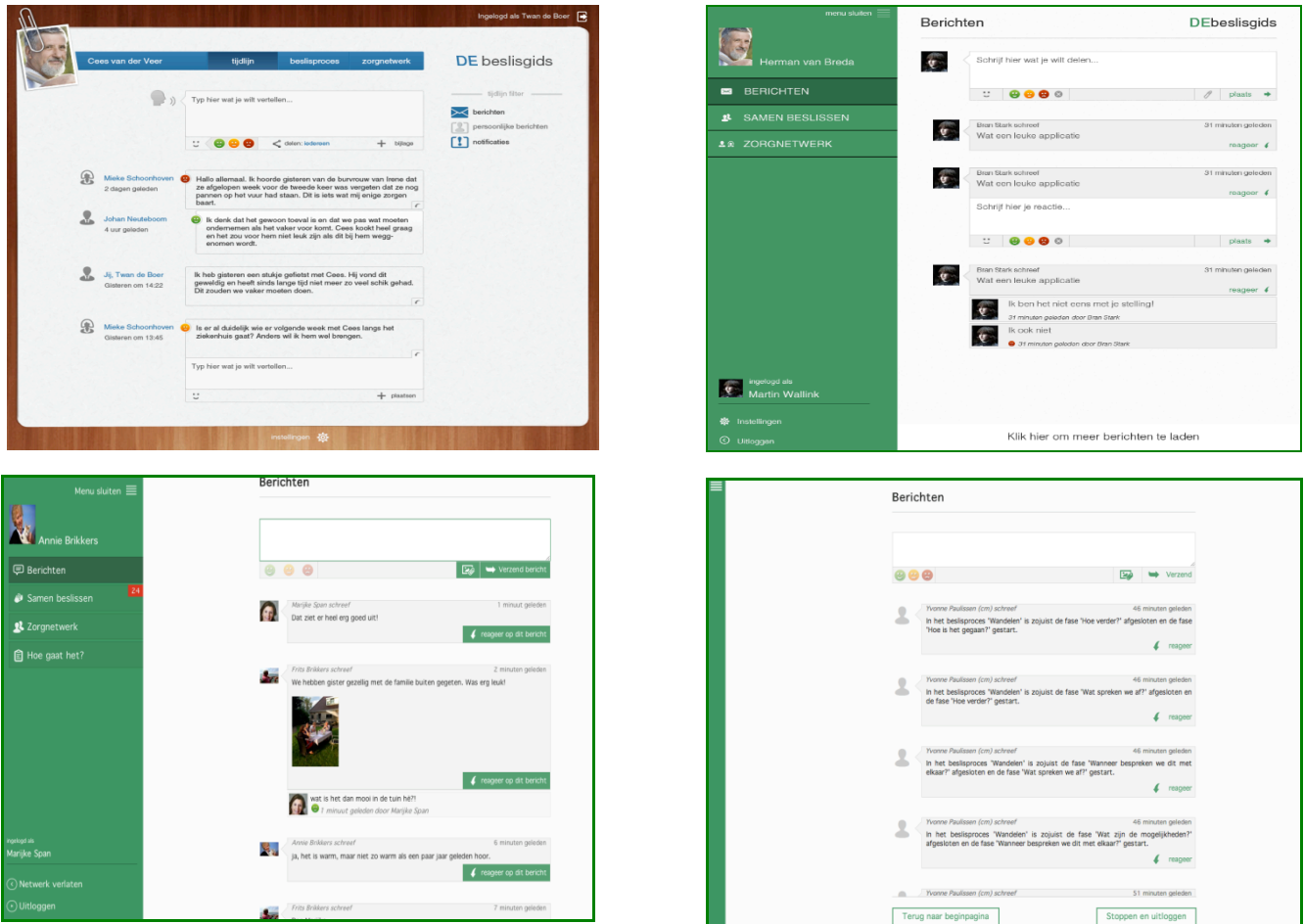
Figure 3. Iterative development of the chat function of the DecideGuide.
Clockwise starting top left: mock-ups, 1st prototype, 2nd prototype, 3rd prototype.

TABLE I. CHARACTERISTICS OF FOCUS GROUP SESSIONS

Focus group session	Round 1	Round 2
PWD[a]	6 people commented on 11 sketches (screen views of PWD).	
PWD		6 people commented on 6 sketches and gave feedback about the first focus group
ICs	4 people commented on 11 sketches (screen views of ICs)	
ICs		4 people commented on 11 sketches and gave feedback about the first focus group
CMs (same people in both rounds)	7 people commented on 4 sketches (screen views of CMs)	7 people commented on 15 sketches (screen views of CMs, PWD, and ICs)

[a]PWD= people with dementia, CMs= case managers, ICs= informal caregivers

tablet at home. These sessions lasted between 30 and 60 min. Based on the feedback from those who participated in the usability tests, a fourth and final prototype was developed

that will be evaluated in a pilot study. Analysis focused on the three levels of the CeHRes assessment of the design quality of system, content, and service. The principal

researcher analyzed the transcripts to identify design issues that could be added to the CeHRes assessment. The researcher who assisted with the usability tests verified the analysis.

III. RESULTS

All 39 respondents who agreed to participate completed their participation (Table II). There were no dropouts. The respondents were motivated and enjoyed their participation.

A. Research question 1: design issues

1) Focus group sessions

The focus group sessions resulted in feedback that addressed mainly the system quality, particularly the user-friendliness (e.g., too many screens, with too much information per screen) and design style (e.g., presentation of information and use of icons; Table III). Regarding the quality of the content, unclearness, and difficulty of the terms were reported, particularly in the "deciding together" part. Textual refinements were made: wording of decision-making themes and questions, as well as spelling and accuracy of the date. Only case managers commented on the quality of service. They described the tool as very useful in facilitating SDM in in care networks of people with dementia, but they doubted whether the tool would be useful for people with dementia. They thought that using the tool was too difficult for them to be able to participate adequately.

2) Cognitive walkthrough

The cognitive walkthrough with three researchers resulted in feedback mainly about system quality. Many bugs were found (buttons that did not react or were missing and partly black screens). Moreover, navigation issues and user-friendliness issues came up. Feedback about the content quality focused on the presentation of content (unclear icons and questions). The researchers emphasized the usefulness of the tool for informal caregivers and case managers but they doubted whether the tool would be useful for people with dementia. Moreover, the researchers doubted whether people with dementia would benefit from the open communication in the chat function. They felt that communication in the chat mode was too intrusive for people with dementia. The cognitive walkthrough focused mainly on the interaction between users.

3) Usability tests

Design issues arising from the usability tests were mainly about system quality: user-friendliness (e.g., operating a touch screen, unclear interface, navigation within a screen and between screens, purpose of buttons, and software bugs) and design style (e.g. smileys too small, questionnaires too long, and way of addressing people). The design issues concerning the content quality were: accuracy (e.g., unclear use of language, missing words), relevance (e.g., the content of the tool was too difficult for people with dementia and phases of decision making were irrelevant in some user interface elements), and comprehensibility (e.g., questionnaires were too difficult and confrontational for

people with dementia). The design issues identified in service quality addressed mainly the usefulness of the tool. The only way the tool can be useful for people with dementia in the informal caregivers' and case managers' view, is by starting to use the tool early in dementia.

The strengths were the possibility of future extensions ("nice to haves" e.g., a skype function, a personal calendar, and alerts), the monitoring of informal caregivers' well-being, colored smileys as answer options, the use of the green for the main interface color, and the examples that are given (Table III).

4) Differences in participants' opinions about design issues

The participants agreed about many design issues (Table III). Nevertheless, there were some differences of opinion. Firstly, in the focus group sessions, informal caregivers and case managers were of the opinion that the tool should consist of fewer screens and fewer examples with smileys. The people with dementia agreed about the screens but not about the examples – they liked them and wanted even more examples to choose from. We reduced the number of the screens and expanded the examples (that is, we added more examples per theme and also examples for possible solutions).

Secondly, in the focus group sessions, some informal caregivers and people with dementia called into question the use of smileys. They were afraid the smileys would be too childish. Others liked them; they found them as easy, clear, and appealing. We decided to continue the use of smileys because of their simplicity and clarity. Moreover, we wanted to design the screens as similarly as possible for both informal caregivers and people with dementia in order to rule out causing possible feelings of inferiority among people with dementia when designing two different views. The usability tests later showed that all participants indeed liked the use of examples and smileys.

Thirdly, from the beginning, informal caregivers and case managers said that they needed a separate communication channel without the person with dementia where they could speak freely about the situation. The people with dementia did not mention such a need. We decided not to create such a channel and adhere to the design rationale of the DecideGuide based on principles of SDM: open communication and transparency. The results of the upcoming pilot study will show whether or not this transparency can be maintained.

Fourthly, informal caregivers and case managers said that the DecideGuide was too difficult and the chat function too intrusive for people with dementia. They questioned transparency as design rationale for the tool. They were convinced that the design rationale was very nice and desirable, but also very confrontational for people with dementia. They said that transparency tends to decrease the distrust of people with dementia, but may increase their restlessness. In the role playing during the cognitive walkthrough, researchers had similar considerations. The researcher who played the role of the "person with dementia" disliked what others said via the chat function, took this as a personal attack, and even wanted to stop using the tool. The

TABLE II. CHARACTERISTICS OF PARTICIPANTS

Total number of participants of focus groups and usability tests (n = 39)			
Characteristics of focus group participants (n = 27)			
	People with dementia (n = 12)	*Informal caregivers (n = 8)*	*Case managers (n = 7)*
Gender	8 Male 4 Female	1 Male 7 Female	6 Female 1 Male
Age in years	69-85 (M = 80.0) 6 Unknown	53-83 (M = 67.6)	38-60 (M = 48.8)
Educational level	0 Low 4 Medium 2 High 6 Unknown	0 Low 2 Medium 6 High	6 High
Type of dementia	3 Alzheimer's disease 1 Front temporal dementia 2 Mild cognitive impairment/dementia 6 Unknown		
Reisberg scale	2-4		
Marital status	4 Married 2 Widowed 6 Unknown		
Relation to person with dementia		6 Spouse 1 Daughter 1 Friend	
Caregiving was experienced as		3 Heavy 4 Medium	
Experience as case manager			1 <1 year 3 1-5 years 2 >5 years

[a]Low = primary or secondary school graduate, medium = high school graduate, high = college graduate

Characteristics of usability test participants (n = 12)			
	Case managers (n = 3)	*Informal caregivers (n = 3)*	*Older adults (n = 3)*	*People with dementia (n = 3)*
Gender	3 Female	2 Female 1 Male	2 Female 1 Male	1 Female 2 Male
Age	42, 50, and 62 years	61, 65, and 74 years	62, 63, and 67 years	72, 79, and 82 years
Type of dementia				3 Alzheimer's disease
Reisberg scale				3–4
Educational level[a]	3 High	2 Medium 1 High	1 Medium 2 High	1 Medium 2 High
Electronic equipment *(computer, laptop, tablet, smartphone)*	3 Computer 1 Tablet 3 Smartphone	2 Computer 3 Laptop 2 Tablet	3 Computer 1 Tablet	2 Computer 1 Tablet 1 nothing
Experience with computers *(years)*	10–15 years	7–15 years	5–25 years	1–5 years
Software and networks used *(Word, Excel, Power Point, Email, Internet, Social media)*	3 Email 3 Internet 3 Word 3 Power Point 3 Excel 2 Social media	3 Email 2 Internet 2 Word	2 Email 2 Internet 3 Word 1 Excel 1 Power Point	2 Email 1 Internet 1 Word 1 Nothing
Assessment of one's own IT capacities *(excellent, good, moderate, or poor)*	2 Good 1 Excellent	2 Moderate 1 Good	3 Moderate	1 Moderate 2 Poor

[a] Low = primary or secondary school graduate, medium = high school graduate, high = college graduate

informal caregivers believed that the only chance for successfully using the tool was starting to use it in the early stages of dementia. The people with dementia did not comment on how other participants would view the tool, except for one remark. When the person filled in the questionnaire about one of the eight dementia related themes, "daily activities", he wondered how his answers could be relevant for the case manager. The pilot study will show whether the participants' concerns are justifiable.

5) CeHRes assessment of design quality

Data analysis showed that most of our design issues fit into the structure of the CeHRes assessment of design quality (Table IV). These design issues did not cover all the items of the CeHRes assessment. The items that did not seem applicable to our interactive web tool included efficient search functionality (A1e), and design persuasiveness (A3c,d) addressing system quality; evidence-based information (B2), language and ethnicity (B6), and disclosure (B7) addressing content quality; and responsiveness (C2), reliability (C5), and credibility (C6) addressing service quality. Other items were simply not mentioned by the participants: technical support (A1h), and safety and technical security (A2b-d). Moreover, some design items that were mentioned did not fit into the CeHRes framework: items lacking in the system such as "absence of extra answer option button" and benefits (usefulness) of using an interactive web tool such as "learning from the tool", and "pleasure in using the tool". We added them as 1j *Completeness* (system quality) and 7 *Perception*: 7a *Learning* and 7b *Pleasure* (service quality) respectively (Table IV).

B. Research question 2: the unique contribution from people with dementia to the design of the interactive web tool

All end users contributed to one or more items of the system, content, and service quality of the design (Tables III and IV). Informal caregivers contributed to most items; the case managers and people with dementia, to fewer items. The people with dementia were very well able to give their opinions in the focus group sessions and the usability tests. Their feedback given for the two focus group sessions addressed mainly the system and content quality (Table III). We honored their feedback in the design in as far as it did not conflict with the design rationale of the interactive web tool. The people with dementia liked participating: it gave them pleasure and they liked learning new things such as using an iPad and the DecideGuide. Without their feedback, we would have missed their focus on the present (i.e., the "here and now" of their perspective) and their preferences about careful use of language and a pleasant graphical layout. We discuss each of these unique contributions below.

1) Focus on the present

The feedback of the people with dementia addressed concrete items in the present. They did not reflect on possible future items, or on the web tool in a more abstract way, or on the perspective of other participants the way informal caregivers and case managers did. They just focused on the assignments researchers asked them to do and to comment on. This focus on the "here and now" is reflected in their specific feedback.

When answering the first question of the web tool, "How are you today?" in the focus group, someone commented: "Do you know how long today is? I cannot tell you how I feel today. Today has so many moments. I only can tell you how I feel right now. But that can be totally different in a few hours. So please ask me: How are you

right now?" We changed the formulation of this question according to their proposal.

A fictive case was used in the sketches of the mock-ups for the focus group sessions because we thought that a fictive case would be less confrontational for people with dementia. This was a misjudgment: it was apparently difficult for people with dementia to answer the questions: "I cannot answer this question because I do not know this person. He is not familiar to me. I can only answer for myself". All other participants in the focus group sessions also had difficulties with the mock-ups. They found it difficult to imagine what the interactive web tool could look like.

The people with dementia were relaxed and very well able to accomplish the tasks in the usability tests and to give their opinions. Moreover, for the tasks of "send a message to the network members" and "respond to the message of the case manager" in the chat, they were the only participants who accomplished these tasks without assistance.

2) Careful use of language

The people with dementia gave very specific and detailed feedback about the tool's user-friendliness and presentation of content of the tool. Fine-tuning and accuracy of text were important to them. They gave feedback about the wrong date on the screen shots and proposed synonyms for some themes (e.g., "family and friends" rather than "social contacts"). They did not like the name of the theme "future": "future…. future?....there is no future….". We therefore changed this theme to "important now and later". Sometimes, the people with dementia prevented researchers from oversimplifying wording. When we were searching for a simple synonym for the theme "mobility" only the people with dementia did not agree. "Mobility" was fine and clear, but should be augmented with "transport". This resulted in the theme "mobility and transport".

The people with dementia were the only people who commented on form of addressing them in the tool. It was important to them that they were called by their first names rather than their surnames: "I am not a sir/madam…just call me by my first name. That's who I am".

They wanted to answer questions very precisely. Several times they discussed the three answering options with smileys: "good", "don't know or neutral", and "not so good". Although they liked the limited options available, the meaning of these options did not reflect their answers. They preferred an extra button with "moderate". Their reactions included: "I don't know what to answer; no smiley reflects my opinion well enough. I would like another button".

3) Pleasant graphical layout

The informal caregivers, case managers and older adults argued that the screens had to be as simple as possible for people with dementia. They liked the green menu bar at the left side of the screen rather than the white buttons on the homepage. However, in their opinion, the homepage without the menu bar was enough for people with dementia. They liked the green color of the design, but emphasized their wish for more contrast. Buttons should be distinctive enough. They liked green buttons with white letters rather

TABLE III. CeHRes ASSESSMENT OF DESIGN QUALITY: WEAKNESSES AND STRENGTHS

Mock-ups of the focus group sessions			
CeHRes assessment of design quality		*Weaknesses*	*Strengths*
System quality	User-friendliness	*Navigation structure and ease of use* Too much screens for people with dementia. CM and PWD Too much information on screens. IC) Screens are too lively for people with dementia. PWD and IC Letters too small (not all PWD agreed) Messages in timeline with chat become a big mess. CM	*Nice to haves* Adding things such as a personal calendar (personalized part in tool for case managers, linking with home technology, skype function). CM and IC Alerts for daily activities (taking medication, eating, etc). IC and CM
	Design persuasiveness	*Lens for design* All network members view all messages because the tool is based on transparency and open communication. This is not always advisable for people with dementia. CM Too many examples with too many colors. IC Use of smileys is a bit childlike. IC *Presentation of content* Use of smileys is clear but not really nice. PWD Attention to use of red in tool. Red smiley is similar to feeling unwell. Using red for a theme can also suggest danger. IC Use of colors in messages is not distinct enough. CM and IC	Monitoring well-being is important. IC Use of red, orange, and green for smileys is nice. IC
Content quality	Accuracy	Date and year are incorrect. PWD The terms are not specific enough: How are you today? PWD	
	Comprehensibility	Use of some terms is not clear enough and too difficult e.g., options and pros and cons of options. PWD	
	Relevance	Open questions are less attractive than questions that also offer examples. Tool is too directive. PWD	
Service quality	Perceived usefulness	The tool is very useful for facilitating SDM in care networks of people with dementia, but how useful will it be for people with dementia? CM	Tool is directive: easy to use because you do not have to invent answers by yourself. IC

Cognitive Walkthrough with researchers			
CeHRes assessment of design quality		*Weaknesses*	*Strengths*
System quality	User-friendliness	*Navigation structure/ease of use* Unclear login Use of smileys in chat function is unclear Adding a smiley is impossible Unclear whether message or smiley has been sent Unclear navigation structure Questionnaires are incomplete and unclear "Deciding together" is unclear Giving one's individual opinion is unclear to PWD Too difficult for PWD Notification for new messages is lacking	*'Nice to haves'* Notifications for new activities in tool Separate communication possibility for IC and CM?
	Design persuasiveness	*Lens for design* All network members view all messages because the tool is based on transparency and open communication. This is not always advisable for PWD *Presentation of content* Use of gray in "Deciding together" does not contrast enough Use of icons is unclear Content of questionnaires differs a lot	Monitoring well-being is important for IC Overall color (green): nice and restful Use of red, orange and green for smileys is nice
Content quality	Accuracy	Questionnaires are incomplete	
	Comprehensibility	Use of some terms is not clear enough and too difficult, e.g., options and pros and cons of options Use of decision phases is too difficult for PWD	
	Relevance	Use of decision phases is too difficult for PWD	
Service quality	Rerceived usefulness	Tool is very useful in facilitating SDM in care networks of PWD but how useful will it be for PWD?	

PWD = People with dementia; IC = informal caregiver; CM = case manager

TABLE III (CONTINUED)

Individual usability tests		
CeHRes assessment of design quality	*Weaknesses*	*Strengths*
System quality — User friendliness	*Navigation structure and ease of use* Call into question: tool user friendly for PWD? CM, IC, OA Operating the touch screen (tapping; scrolling; keyboard). PWD, IC, OA Log in difficulties for PWD and OA Interface is not clear enough (buttons too small; too close together, use of color not distinctive enough, font size too small, not enough answer options. PWD, IC, OA Meaning of some buttons and UI elements is unclear (text on buttons, length of questionnaires, automated messages, adding smileys to messages. PWD, IC, OA Software bugs (buttons do not react, black surface). PWD, IC, CM, OA Navigating within the screen (meaning of buttons; where to start? PWD, A Navigating between screens (partly absence of "back" button and "go on", going back in tool is unclear. PWD, IC, CM, OA Absence of extra answer option button A1j. PWD, IC	Combination of icons and buttons is nice Notifications for new messages
System quality — Design persuasiveness	*Lens for design* Call into question: design tool suitable for PWD? (use of color [less white, more green; more contrast]; too much text; drop down menu). CM, IC *Presentation of content* Smileys in chat too small; mismatch icon and text? PWD, IC Presentation of information (dosed offering of questionnaires; type of questions does not suit every user). IC, CM, OA Addressing users (PWD: I am not Sir, but just John. Just call me by my first name). PWD	Green color: restful and nice. All Predominantly quiet screens: nice. All Use of smileys is good (all): it says more than a number of sentences. PWD Monitor question for IC as start question is appreciated a lot by IC. IC
Content quality — Accuracy	Use of language is unclear: sentences are incorrect; words are missing. IC	
Content quality — Relevance	Called into question the relevance and difficulty of content for PWD. CM, IC Doubts about relevance of UI elements (mentioning phase of decision-making for PWD and IC? CM	Appreciation of monitor question for IC. IC Questionnaires are relevant: both open and closed questions as well as examples with smileys. IC, CM, OA Examples are nice. PWD, IC, OA
Content quality — Comprehensibility	Questionnaires are too difficult and too confrontational for PWD? IC, CM Unclear UI elements ("Deciding together"; drop down menu). IC, OA	Questionnaires and smileys are clear. IC, OA
Content quality — Completeness	UI element ("Messages" screen too complicated. IC	
Service quality — Usefulness	Called into question: the usefulness of tool for PWD (starting early in dementia process). CM, IC Called into question: personal contact versus digital contact. IC Called into question: transparency in tool versus confrontation for PWD. CM	Tool is fun. IC Examples in tool are supporting. PWD, IC, OA Tool helps thinking about things; offers handles for discussing things. IC, OA Reducing difference in information of IC nearby and at distance. IC Tool contributes to appreciating IC.
Service quality — Social dynamics	Unclear what happens with information in tool. IC	
Service quality — Psychological influence	Tool is too confronting for PWD. CM Careful way of writing is necessary. IC, OA, CM	
Service quality — Perception		Learning from tool (and iPad). PWD Pleasure. PWD, IC, CM, OA

PWD = people with dementia; IC = informal caregiver; CM = case manager; OA = older adults; UI = user interface

than the opposite that other participants liked. Moreover, some people with dementia liked the menu bar. We honored the preferences of the people with dementia in coloring all buttons into green and giving them the choice of viewing the menu bar folded or expanded (Fig. 4).

IV. DISCUSSION

In this study, we have identified design issues (weaknesses and strengths) for an interactive web tool facilitating shared decision making in care networks of people with dementia and its twofold complexity: the progressive character of dementia and the multitude of people involved.

The weaknesses were mainly in the quality of system: user friendliness (too many screens and too much information), unclear navigation (in screens and between screens), and design style (use of colors, smileys, and graphical layout). The weaknesses in the content of the design were the relevance of the content and the accuracy. The strengths

TABLE IV. PARTICIPANTS' CONTRIBUTIONS TO THE DESIGN OF THE INTERACTIVE WEB TOOL, THE DECIDEGUIDE

CeHRes assessment of design quality			Focus group sessions and usability tests				Cognitive walkthrough
			Case managers	*Older adults*	*Informal caregivers*	*People with dementia*	*Researchers*
A. System quality	1. User friendliness	a.Ease of acces	x	x	x	x	x
		b.Ease of use	x	x	x	x	x
		c.Absence of technical errors	x	x	x	x	x
		d.Clear navigation structures	x	x	x	x	x
		e.Efficient search functionality					
		f.Efficient feedback channels	x	x	x		
		g.Push factors	x		x	x	x
		h.Technical support					
		i.Readability of text		x	x	x	x
		j.Completeness		x	x	x	
	2.Safety & technical security	a.Privacy& confidentiality					x
		b.Encryption					
		c.Authentification					
		d.Interoperability					
	3.Design persuasiveness	a.Lens for design	x	x	x	x	x
		b.Presentation of content	x	x	x	x	x
		c.Observation					
		d.Conditioning					
B. Content quality	1. Accuracy			x	x		
	2. Evidence based						
	3. Relevance			x	x	x	x
	4. Comprehensibility			x	x	x	x
	5. Completeness			x	x	x	x
	6. Language and ethnicity						
	7. Disclosure						
C. Service quality	1. Usefulness			x	x	x	x
	2. Responsiveness					x	x
	3. Social dynamics					x	x
	4. Psychological influence		x			x	x
	5. Reliability						
	6. Credibility						
	7. Perception	a. Learning				x	x
		b. Pleasure		x	x	x	

An X means that the target group commented on this item; an empty cell means that the target group made no comment

included possible future extensions, monitoring informal caregivers' well-being, the use of smileys, and the green interface color. The participants' disagreements about the designing issues of the DecideGuide included the numbers of screens and examples, the use of smileys, the design rationale of the SDM-based DecideGuide open communication, transparency, and giving voice to people with dementia. The people with dementia gave detailed and unique feedback that focused on the present, careful use of language, and a pleasant graphical layout.

A. Design process

We used an iterative participatory approach to develop the DecideGuide. In a prior study user requirements were identified for the interactive web tool [3][4][33]. These user requirements all have been given a place in the final interactive prototype.

We conducted usability tests with older adults to check whether the prototype was robust enough for people with dementia to do the test. We did not want them to drop out because of an unreliable prototype. The older adults' feedback was relevant, but the feedback of the people with dementia was the most important for the DecideGuide. This is in line with Riley and colleagues' [35] conclusion. In contrast to Riley and colleagues [35], we used paper prototyping for all end users; they did not because it was less effective for older adults and therefore not useful for people with dementia. In our study, paper prototyping seemed to be difficult for all the participants. Nevertheless, it led to useful feedback in the design process. Nygård and Starkhammar [36] identified difficulties in the use of every day technology for people with dementia (e.g., in handling the technology and limitations of knowledge and personal condition). In our study, we recognized the knowledge limitations; nevertheless, this difficulty was not a problem thus far.

The CeHRes assessment of design quality was helpful. We used it as a checklist afterwards and for categorizing the issues. Nevertheless, some categories seem to show an overlap (e.g., ease of use/A1b and clear navigation structure/A1d) and/or are difficult to distinguish from each other (e.g., relevance/B3 and usefulness/C1). Since no descriptions were offered, we had to interpret the subcategories of the framework ourselves. Furthermore, not all subcategories were relevant to an interactive web tool like the DecideGuide (e.g., efficient search functionality and interoperability). Some categories and subcategories could not be filled because the participants did not give feedback about them. These empty cells in Table IV suggest that such items were irrelevant, but items such as "technical support" and "safety and technical security" are certainly important for a web tool like the DecideGuide. Did we have a blind spot for these empty cells? Were the questions we asked good enough? We used the CeHRes assessment of design quality evaluative, after all iterations were finished. Using this assessment in advance and as a formative checklist during the development might have been helpful in the timely identification of a blind spot and the meaning of the empty cells. It enables researchers to reflect on the result of an iteration and add leading questions for the next iteration to

be sure all items are discussed. Further, there are no items about the perception of end users in the current version of the CeHRes assessment of design quality. More and more helpful IT applications for vulnerable older adults are being developed due to the growth of this target group [37][38]. In order to ensure that the perspective of vulnerable people has been taken into account, a criterion could be added to the CeHRes assessment: perception.

B. Participation of people with dementia

In a prior review, Span and colleagues [17] concluded that participation of people with dementia in developing assistive technologies is not self-evident. The involvement of all end users, and particularly people with dementia themselves, is important in developing a useful and user-friendly tool for people with dementia. A recent study about the European Rosetta project (designing assistive technology for people with mild to severe dementia) confirms this [34]. In our study, the caregivers were positive about including people with dementia, but most caregivers had a biased view of the ability of people with dementia to use an interactive web tool and to participate in research. Nevertheless, the caregivers' assumptions that the usability tests would be too difficult for people with dementia proved to be wrong. Moreover, most caregivers said that web tools would be more appropriate for the coming generation of people with dementia than the current one. Only a few participants had no opinion and said, "first ask people with dementia". Deciding for people with dementia instead of asking them to participate excludes people with dementia. This approach seems to be in line with studies that exclude people with dementia – whether deliberately or not – on the basis of "shielding" (caregivers tend to shield people with dementia from participating because they are afraid of exposing them to possible stressful situations) [39][40] or "difficulty" (caregivers think that people with dementia cannot participate because it is too difficult for them) [41][42]. In both cases, caregivers decide for people with dementia rather than with them.

We included people with dementia in the design process just as we did the other participants. The people with dementia were asked to participate and give feedback in the same way as the informal and formal caregivers. This resulted in a tool that takes account of the wishes of people with dementia: use of the first name, asking how they feel "right now", use of examples to hit upon an idea, and the use of smileys that are not childish at all, but nice and handy. Awareness of the importance of involving people with dementia in the design is crucial in order to develop a useful and user-friendly web tool. This is in line with Hanson and colleagues [43] and Robinson and colleagues [44], who emphasize the importance of collaborating with people with dementia in the development of an IT application from the beginning.

In our study, the people with dementia were very well able to give detailed comments about the interactive web tool. In verbalizing their comments they related them directly to their personal views, not to those of the other participants. Our people with dementia seemed to live and comment more in the "here and now", unlike the other participants, who

took the future into account. This is illustrated by the question "How are you today?" that we changed to "How are you right now?" on the basis of their comments. The other participants seemed to think more abstractly about and for people with dementia. Replacing people with dementia with others to represent their perspective is therefore unsatisfactory. None of the other participants made comments that were identical or similar to those of the people with dementia. The "here and now" comments of the people with dementia therefore have added value. Their contribution is unique and requires careful inclusion of them in designing a web tool for them.
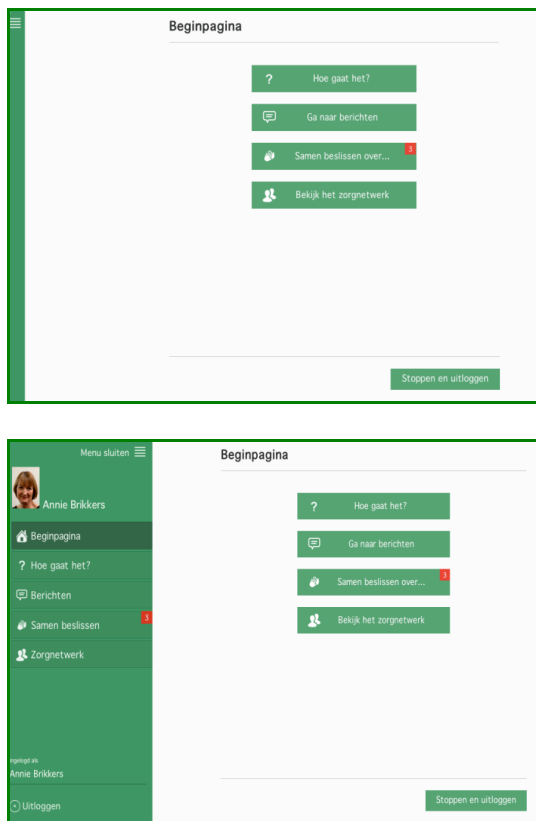
Figure 4. Folded and expanded menu bar

C. Limitations and strengths

This study has some methodological limitations. The first limitation concerns the participating people with dementia. Most of them had a high level of education. Further, the case managers recruited most of them; in other words, although they could have registered on their own, they did not. These two facts may have influenced the findings in this study positively.

The second limitation lies in the location of the usability tests. Older adults, informal caregivers, and case managers took the usability test in a skills lab at the university. Particularly the older adults and informal caregivers showed some stress and hasty behavior at the beginning of the test. They overlooked things on the screens. The people with dementia took the usability tests at home. They all were relaxed and showed no signs of stress. This discrepancy between the people with dementia and the others was unexpected, but may have been caused by the differing environments.

The strength of this study lies in its iterative, participatory approach. The interactive web tool was developed step by step with maximum participation of all end users. Different methods at the individual and group levels were used to enable end users to speak for themselves and also to challenge them in encounters with others. We explored the end users' views thoroughly, and we listened carefully to the people with dementia.

V. CONCLUSIONS

Designing an interactive web tool that facilitates SDM in care networks of people with dementia, for participants who have different capacities and interests, is challenging. Design issues included a screen design based on pleasant and harmonious colors, the use of clear and uniform buttons throughout the interface, the use of multiple-choice questions with smileys as answering options, a foldable menu bar that is closed (for people with dementia) or open (for caregivers) by default, and the incorporation of a chat function that specifically keeps all end users involved in a conversation. All viewpoints were included in the design process, with special attention to the most vulnerable participants – the people with dementia. Their specific and detailed contribution was their focus on the present, the accuracy of language, and the graphical layout. Their feedback about the design was therefore unique and very valuable. However, other participants doubted whether the tool would be useful and usable for people with dementia. A pilot study will show whether these doubts about the value of the tool for people with dementia are valid.

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