

## Developing an Interactive Web Tool, the DecideGuide, to Facilitate Shared Decision Making in Dementia Care Networks: Lessons Learned

Marijke Span, Carolien Smits, Leontine Groen-van de Ven, Jan Jukema, Marike Hettinga  
Windesheim University of Applied Sciences  
Zwolle, The Netherlands  
m.span@windesheim.nl, chm.smits@windesheim.nl,  
lm.groen-vande.ven@windesheim.nl,  
js.jukema@windesheim.nl, m.hettinga@windesheim.nl

Myrra Vernooij-Dassen  
IQHealth Care and Department of Primary Care, Kalorama  
Foundation, Radboud Alzheimer Centre  
Nijmegen, The Netherlands  
myrra.vernooij-dassen@radboudumc.nl

Jan Eefsting  
EMGO+ Free University Medical Centre of Amsterdam,  
The Netherlands  
j.eefsting@zgjiv.nl

**Abstract**—An interactive web tool, the DecideGuide, is developed to support case managers in facilitating shared decision making in care networks of people with dementia. The DecideGuide is developed in collaboration with the end users: people with dementia, informal caregivers, and case managers. The development consisted of five sub studies. In retrospection, reflections are made on these sub studies. Lessons learned concerned: the importance and value of involving people with dementia in the development of assistive technology such as the DecideGuide, the importance of involving people with dementia from the start, the importance of taking time for people with dementia, and the importance of being aware about the role of end users from the very beginning. Moreover, developing an interactive tool for end users with different capacities and interests requires attuning to the most vulnerable end user group of people with dementia; just ask them rather than decide for them. This paper provides an overview of the lessons learned in the development of the DecideGuide.

**Keywords**- dementia; decision making; assistive technology; participatory design

### I. INTRODUCTION

The voice of people with dementia is often ignored [1][2]. Relatives and professionals tend to shield people with dementia because of the cognitive decline. This is often done with the best intentions. As a consequence of this shielding attitude, people with dementia are not always involved in decision-making about their own situation [3][4]. When the experiences and wishes of people with dementia are not taken into account, it is difficult to make decisions that are attuned to their needs. Although relatives tend to decide for people with dementia rather than with them, the research shows that people with dementia can express their needs and experiences, even in an advanced stage of dementia [3][5].

Decision-making in dementia is complex because of the multiple participants involved who have different capacities and interests and the progressive cognitive decline that adheres to the disease dementia [6]. Well-known decreasing abilities address memory, route planning, behavior change, and orientation. As we all get older, the chance that dementia will affect us increases. Predictions about this increase of dementia worldwide range from 66 million in 2013 to 114

million in 2050 [7][8]. Life expectation of people with dementia after diagnosis runs between 6-10 years. During this period people with dementia and their relatives have to face many problems and decisions [9][10][11]

Shared decision making (SDM) has its roots in the clinical encounter. It is an approach that involves patients in making medical decisions in collaboration with their professionals [12]. Moreover, shared decision making results in increased autonomy [4] and well-being [13] of both the person with dementia and the informal caregiver. It gives a voice to people with dementia. Shared decision making is often supported by paper or web based tools.

This paper concerns the development of an interactive web tool to facilitate shared decision making in dementia care networks, called the DecideGuide. The DecideGuide and its development is a part of a major research program on shared decision making in care networks of people with dementia aiming to improve professional care and thus contributing to dementia care practice. Besides developing an interactive web tool, the research program focuses on developing theory building and competency descriptions for case managers [14].

This study has an iterative participatory design process. We involved end users and particular people with dementia [15] in developing a user-friendly and usable IT application. Involving people with dementia in the development of supportive IT applications results in better and user-friendlier applications [15][16]. Involvement of people with dementia is necessary; it enables researchers to gain insight into views, needs, and experiences of people with dementia [3][4][17][18].

In this paper, we aim to gain insight into the development of the DecideGuide, which is an interactive web tool to facilitate shared decision making in dementia by looking back on the development process. Our research question is: what lessons can be learned of the design and development process, and the involvement of people with dementia?

The outline of the paper is as follows: Section II explains the DecideGuide, Section III describes the methods used in the sub studies, in Section IV the results of the different development phases are briefly presented, Section V describes the lessons learned, and Section VI ends with the conclusion.

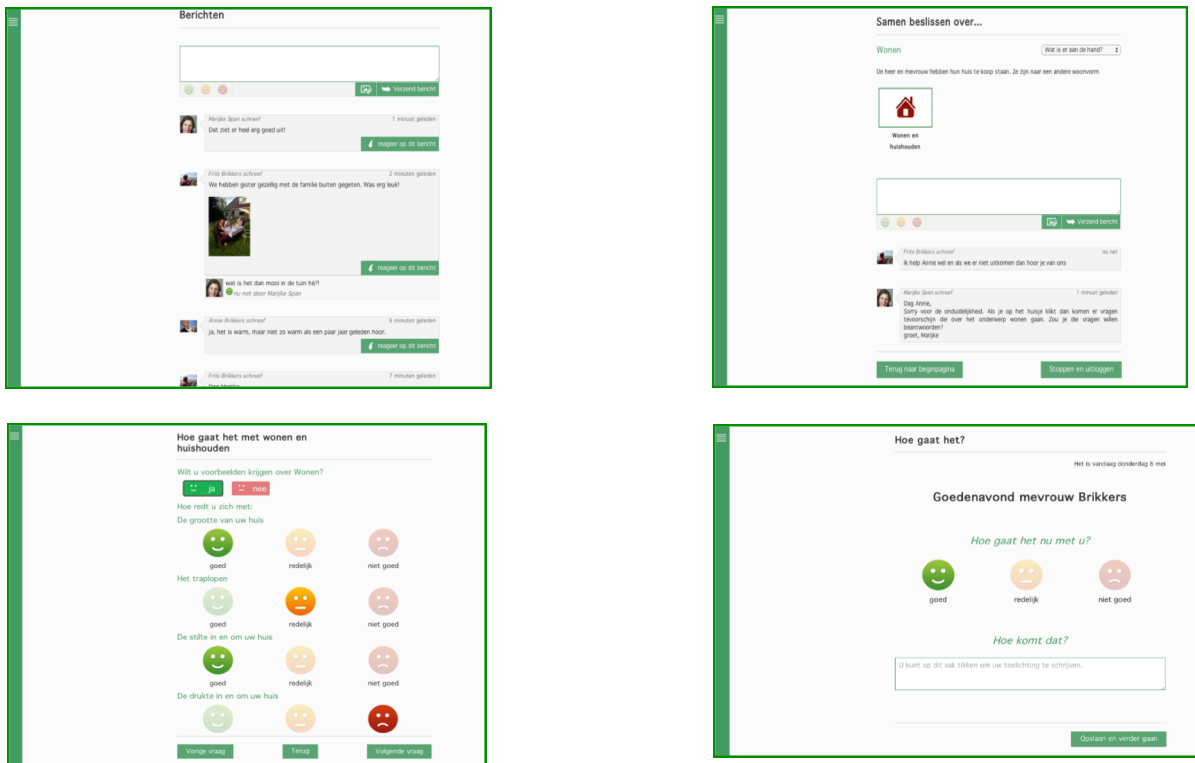


Figure 1. Final layout of three pillars of the DecideGuide (screen view for the person with dementia). Clockwise starting top left: chat function (belonging to the first pillar), deciding together (second pillar), individual opinion “How are you right now?” and individual opinion in questionnaire with examples (both belonging to the third pillar) [21]

## II. THE DECIDEGUIDE

We developed the DecideGuide, which is an interactive web tool facilitating shared decision making in care networks of people with dementia. People with dementia, informal caregivers and case managers communicate in this tool with each other in making shared decisions.

The DecideGuide has three functions: 1) a *chat function* where network members can communicate with each other, 2) a *deciding together* part that supports step by step decision-making, and 3) an *individual views* part, where network members can give their individual opinion about eight dementia related themes (Fig. 1). All participants have an individual login and attend the tool on their own or after an alert of the case manager. The DecideGuide is a safe and shielded web tool that is accessible via tablet, a laptop or a computer.

## III. METHODS

In this paper we look back on the development trajectory of the DecideGuide with a bird’s-eye view. We look back at the development process and the involvement of people with dementia. The development consisted of five sub studies: (1) a systematic review of literature about involvement of people with dementia in the development of supportive IT applications, (2) identifying user requirements based on needs and wishes of end users, (3) determining the design reflected on (5) the participation of people with dementia in

developing the DecideGuide. Table I provides a brief overview of the methods of the sub studies.

We used the Center for eHealth Research and Disease Management (CeHRes) roadmap for the development of the DecideGuide, because this approach connects a Human Centered Design with eHealth Business Modeling and emphasizes the importance of involving all stakeholders to develop sustainable innovations [19]. The CeHRes roadmap offers a holistic framework consisting of five phases: contextual inquiry phase, value specification phase, design phase, operationalization phase, and summative evaluation phase.

## IV. RESULTS

Consecutively, we will present the general study findings, and conclusions and reflection of the four steps of the development briefly per study. Then, findings addressing the participation of people with dementia will be presented and discussed.

### A. Systematic literature review

1) *General findings [15]:* From a list of 893 relevant citations, 26 publications could be included. The findings suggest that most researchers acknowledge the importance of involvement of people with dementia in the development but they differed in how they involved people with dementia. Most people with dementia were mainly involved in the first phases of the development process, the explorative and

TABLE I. CHARACTERISTICS OF METHODS OF SUB STUDIES OF THE DEVELOPMENT OF THE DECIDEGUIDE

	Development process of the DecideGuide: sub studies				
	1. Systematic review	2. Identifying user requirements	3. Determining the design	4. A 5-month field study	5. Participation of people with dementia: case study
<b>Research questions</b>	How are people with dementia involved in the development of supportive IT applications?	1) What topics can be identified for an interactive web tool facilitating shared decision-making in dementia? 2. What additional needs and preferences regarding an interactive web tool facilitating shared decision making in dementia can be identified?	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?	1) How do end users value the user friendliness, and the user acceptance and satisfaction of the tool, and 2) how do end users value the DecideGuide as tool in decision-making processes?	How participated people with dementia (phase, role, and impact) during the design and development of the DecideGuide?
<b>Participants</b>		People with dementia (n=19), informal caregivers (n=31), case managers (n=24), and experts (n=14).	People with dementia (n= 12), informal caregivers (n= 8), older adults (n=3), case managers (n= 7) and experts (n=3).	Four dementia care networks (n = 20) consisting of people with dementia (n=4), informal caregivers (n=13), and their case managers (n=3).	People with dementia who participated in the sub studies 1-4 (n=48)
<b>Data collection</b>	A systematic search was conducted using Cochrane Library, PubMed, PsychInfo, EMBASE, and CINAHL, concerning the involvement of people with dementia in the development of supportive IT applications.	50 semi structured interviews with end users Eight separate focus group interviews with end user groups Expert consultation Two multi-disciplinary workshops	Two focus group sessions with mock-ups with all end user groups. Cognitive walkthrough with experts. Individual usability tests with three individuals of all end user groups	Structured interviews at t0,t1, t2 Observations of case managers' home visits Log files in tool Log book	Use of data gathered in sub studies 1-4: Semi structured interviews (n=23) Four focus groups (n=18) Usability tests (n=3) Pilot study (n=4) Log book
<b>Analysis</b>	Content analysis focused on involvement characteristics: phase of involvement, methods used to involve, role, and impact of involvement.	Content analysis was applied to the data addressing the research questions.	The five steps of framework analysis were used. Analysis focused on the three levels of the CeHRes assessment of design quality: system, content, and service quality.	Content analysis was applied to the data and focused on: 1) how the end users valued the user friendliness, and user acceptance and satisfaction, and 2) how end users valued the DecideGuide as tool in decision-making processes.	Secondary analysis, using the patient participation ladder of Abma and the phases of the CeHRes roadmap.

technical development phases. People with dementia played mainly the role of study objects and informants (n = 24) rather than being co-designer (n=2).

2) *Conclusions and reflections*: People with dementia can participate in the development of supportive IT applications and they provide useful feedback that leads to more user friendly and usable IT applications. The findings of the review confirmed our intention to involve people with dementia in all phases of the development, despite their declining capacities and despite the opinions of informal caregivers and professionals. In order to know what is important to people with dementia, we have to involve them unless they refuse to participate.

### B. Identifying user requirements

1) *General findings [20]*: Two sets of user requirements were identified. The first set was based on experienced problems and decisions of people with dementia, informal care givers, and case managers addressing: social contacts,

daily activities, mobility and transport, safety, living, future, care, and finances. The second set of user requirements was based on additional needs and preferences of participants addressing: participation of the person with dementia in the decision-making, insight into the decision history, anticipation of possible future problems and decisions, and the degree of self-management and autonomy preservation of the person with dementia.

2) *Conclusions and reflections*: The iterative participatory approach – individual interviews followed by two sequential focus groups per target group – helped us to identify two sets of user requirements. Decision making in dementia care networks concerns mainly problems of the well-being of people with dementia and their informal caregivers rather than more care related problems. The views of all people involved were of importance to achieve a well-funded set of user requirements. We invested much time in individual interviews with people with

dementia, informal caregivers, and case managers and separate focus groups per target group to enable participants to speak freely. This provided us with useful feedback. People with dementia mentioned fewer problems than the other participants but they described values that were important to them, e.g., independency and social contacts. This could be due to a possible fear that reporting problems may have undesirable consequences with respect to their autonomy.

All participants found it hard to describe requirements for a supportive SDM tool. They could not imagine how such a tool should look like. Beforehand, we expected this for people with dementia, but it proved also to be difficult for both informal caregivers and case managers. Discussing requirements for a supportive tool to facilitate SDM seemed to be too abstract for participants.

### C. Determining the design of an interactive web tool, the DecideGuide

1) *General findings* [21]: The design of the interactive web tool, the DecideGuide, arose from four iterations. These iterations were based on feedback of all end users groups. The different participants experienced weaknesses that addressed mainly the system quality: user-friendliness of the tool (e.g., too many screens and too much information per screen, operating a touch screen, unclear interface, meaning of buttons), unclarity of navigation (in screens and between screens) and persuasiveness of the design (presentation of information, use of icons, size of icons/smiley's). Weaknesses addressing the content quality concerned the accuracy of wording and relevance of the content. Experienced strengths concerned the possible future extensions, monitoring caregivers' well-being, use of smileys and the green interface color. Disagreements of participants regarding design issues addressed the number of screens and examples, use of smileys, and the design rationale of open communication and transparency.

People with dementia provided us with detailed and unique feedback about their focus on the present, the 'here and now' of their time perception; a careful use of language; and a pleasant graphical layout.

2) *Conclusions and reflections*: Designing an interactive web tool for people with different capacities and interests is challenging but possible. All perspectives were included with special attention for the most vulnerable target group of people with dementia. The specific and detailed feedback of people with dementia was very valuable and made their contribution unique. However, other participants doubted whether the tool would be useful and usable for people with dementia.

From the start informal caregivers and case managers emphasized their concerns about the participation of people with dementia regardless of the phase of the study. They thought that participation would be too difficult and intrusive for people with dementia. Besides their concerns, we asked

people with dementia themselves about their willingness to participate. We wanted to ask them instead of deciding for them. People with dementia were open to participate. They mentioned no objections and showed no signs of distress. Paper prototyping (mock-ups) was difficult for them and confirmed findings of other researchers [22]. We chose a fictive person with dementia for this session because we thought that it would be less intrusive for them. But they commented that they found the session difficult because they could only speak and decide for themselves, rather than for the fictive person presented on paper. It confused them. The fictive person was not a problem for informal caregivers and case managers. Nevertheless, the paper prototype session proved also to be difficult for them. They found it hard to imagine from paper how such an interactive web tool could look like.

### D. Field study: using the DecideGuide in daily life

1) *General findings*: Preliminary findings of the field study show that the user-friendliness of the DecideGuide needs improvement, in particular for older adults (70+) including people with dementia. The deciding together part provided insufficient guidance and the navigation in the user interface needs further simplification. The user acceptance and satisfaction were sufficient: all participants appreciated the easy way of communicating in the chat function, and the option to express individual views. Participants felt more involved and shared more information with each other about daily life issues. Informal caregivers and case managers appreciated the DecideGuide as tool in decision-making: it structured their thoughts and provided a structure for making decisions.

2) *Conclusions and reflections*: The use of the DecideGuide is feasible in dementia care practice but the navigation needs further refinement. The DecideGuide has meaningful impact on its users: it stimulates people with dementia and their care networks in communicating more frequently with each other, opens difficult issues to discussion, takes into account all perspectives, and leads to more involvement of informal caregivers and case managers in the daily lives of people with dementia.

The current generation of older adults of whom most are not familiar with computers needs support to use IT applications. Including personalized 'nice to haves' like an agenda, photo gallery, or daily paper to the tablet can help to make the use of a tablet more attractive for this target group. Also the participation of more (younger) people in the network stimulates the interaction in the network and therefore the activities of the older participants. We did not expect the 'chat function' to be such a success as network members experienced it. This way of communicating with each other and sharing daily life issues/information within the network was less common than we expected. It proved to be of great value for participants, in particular for informal caregivers and case managers.

### E. Participation of people with dementia in developing the DecideGuide

1) *General findings:* People with dementia participated in most phases of the CeHRes roadmap [19] and in different roles of Abma's patient participation ladder [23]: during the contextual inquiry phase in the role of research object, during the value specification phase as information provider, and during the design and operationalization phase as advisor. Their participation resulted in unique feedback leading to a more attuned version of the DecideGuide.

The impact of participation of people with dementia on themselves as persons addressed their intrinsic motivation to participate in the development; their enjoyment in learning new skills, their wish to be of use for research activities as long as possible, and their wish to contribute to a better quality of life for future dementia patients.

We invested much effort in involving people with dementia in the development. Taking time is a key for meaningful inclusion of people with dementia e.g., taking time for small talk before research activities, taking time to get to know them better, taking time during research activities, and taking time for an ongoing consent to be sure about their voluntary participation [24]. Besides, a safe environment is important e.g., their home or the day care center they are attending.

2) *Conclusions and reflections:* We involved people with dementia in the same phases of the development as informal caregivers and case managers and we listened carefully to them. We involved people with dementia mainly as information providers and advisors. We chose for this place on the participation ladder because we wanted to gain experience in involving a vulnerable target group like people with dementia. A lower place on the participation ladder would have resulted in less useful feedback. In a subsequent study, we might aim for involving people with dementia as co-designers. But a higher place on the participation ladder does not automatically lead to more participation. More researchers stress the importance of a horizontal participation ladder rather than a vertical one: availability of different roles dependent on which role is suitable for the situation is more important than reaching higher levels on the participation ladder [25][26].

However, as participation of people with dementia is not self-evident, we challenged ourselves, all participants and in particular people with dementia, to participate meaningfully in the development of an interactive web tool that facilitates shared decision making for people with different capacities and interests. In our research the role of advisor was a suitable and valuable role and resulted in meaningful participation of people with dementia.

Nowadays, many research proposals are assessed on participation of patients. Participation of patients is time consuming and in particular participation of vulnerable patient groups. Time is scarce in research and might lead to patient participation on paper, and thus becoming a sham. Participation of people with dementia in research is

important to attune to their needs and to give them a say, but investing in meaningful inclusion of people with dementia might do more justice to this target group than reaching for higher steps on the patient participation ladder.

### V. LESSONS LEARNED

- The CeHRes roadmap helped is in offering a structured way to develop the DecideGuide. It provided us with criteria to assess the activities in the different phases.
- Informal caregivers and case managers do not always have a good view of people with dementia's preferences.
- People with dementia can give unique and valuable feedback that differs from the feedback of other participants.
- Spending time with people with dementia and taking time for small talk supports them in expressing themselves.
- Asking people with dementia what they like, what they want, and if they want to participate and how sounds plausible, but requires attentiveness, time, and dedication of researchers. Deciding for people with dementia is a pitfall despite good intentions (e.g., *we thought* a fictive person in the mock-ups would be less intrusive, but we were wrong).
- A meaningful participation of people with dementia requires involving them in a very early phase in research activities so they really have a say in what will be investigated and which role they will play.
- Older adults (70+) need more support in order to get familiar with a tablet and the DecideGuide.
- More participation does not automatically lead to better participation.
- Aiming for meaningful inclusion of people with dementia in research might do more justice to people with dementia than trying to achieve a higher step on the participation ladder.

### VI. CONCLUSION

An interactive web tool for people with dementia, their informal caregivers, and case managers was developed to facilitate shared decision making in dementia care networks. Developing an interactive web tool, for participants with different capacities and interests is challenging. It requires open communication and attuning to the most vulnerable end user group of people with dementia because they are easily overruled. This includes balancing between the benefits of people with dementia's contribution and the impact on their well-being.

### REFERENCES

- [1] H. Wilkinson, "Including people with dementia in research: methods and motivations". In: The perspectives of people with dementia, research methods and motivation. London: Jessica Kingsley, 2002.

- [2] N. Savitch and P. Zaphiris, "Accessible websites for People with Dementia: a Preliminary Investigation into Information Architecture," in ICCHP, 2006, p. 8.
- [3] M. von Kutzleben, W. Schmid, M. Halek, B. Holle, and S. Bartholomeyczik, "Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia," *Aging & Mental Health*, vol. 16, April 2012, pp. 378-390.
- [4] S. L. Dupuis, J. Gillies, J. Carson, and C. Whyte, "Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services," *Dementia*, vol. 11, 2011, pp. 427-452.
- [5] J. Whitlatch and H. Menne, "Don't forget about me. Decision making by people with dementia," *Journal of the American Society on Aging*, vol. 33, 2009, pp. 66-71.
- [6] R. M. Epstein and R. L. Street, "Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness," *The Annals of Family Medicine*, vol. 9, September 1, 2011, pp. 454-461.
- [7] M. Prince, R. Bryce, and C. Ferri, "World Alzheimer Report 2011," 2011. Available at: <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>. Last access date 10-12-2014.
- [8] C. Ferri et al., "Global prevalence of dementia: a Delphi consensus study," *Lancet*, vol. 366, 2005, pp. 2112-2117.
- [9] G. Livingston et al., "Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK," *BMJ*, vol. 341, (Aug 18 1)c4184, 2010.
- [10] M. Zwaanswijk, A. P. A. v. Beek, J. Peeters, J. Meerveld, A. L. Francke, and S. Van Beek, "Problems and needs of informal caregivers of persons with dementia: a comparison between the initial stage and subsequent stages of the illness process." ["Problemen en wensen van mantelzorgers van mensen met dementie: een vergelijking tussen de beginfase en latere fasen van het ziekteproces"], *Tijdschrift voor Gerontologie en Geriatrie*, vol. 41, 2010, pp. 162-171.
- [11] G. van der Roest et al., "What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services," *International Psychogeriatrics*, vol. 21, 2009, pp. 949-965.
- [12] G. Elwyn, A. Edwards, and P. Kinnersley, "Shared decision-making in primary care: the neglected second half of the consultation," *British Journal of General Practice*, vol. 49, 1999, pp. 477-482.
- [13] H. L. Menne, S. S. Tucke, C. J. Whitlatch, and L. F. Feinberg, "Decision-Making Involvement Scale for Individuals With Dementia and Family Caregivers," *American Journal of Alzheimer's Disease & Other Dementias*, vol. 23, 2008, pp. 23-29.
- [14] C. Smits and J. Jukema, "Shared decision making in care networks of older adults with dementia. A research program to professional support of shared decision making in care networks of older adults with dementia", 2010.
- [15] M. Span, M. Hettinga, M. J. F. J. Vernooij-Dassen, J. Eefsting, and C. Smits, "Involving People with Dementia in the Development of Supportive IT Applications: a Systematic Review," *Ageing Research Reviews* vol. 12, 2013, pp. 535-551.
- [16] F. J. M. Meiland et al., "Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European Rosetta project," *International Psychogeriatrics*, vol. 26, 2014., pp. 769-779.
- [17] K. Cubit, "Informed consent for research involving people with dementia: A grey area," *Contemporary Nurse*, vol. 34, 2010, pp. 230-236.
- [18] L. Nygård, "How can we get access to the experiences of people with dementia? Suggestions and reflections," *Scandinavian Journal of Occupational Therapy*, vol. 13, 2006, pp. 101-112.
- [19] J. E. W. C. Van Gemert-Pijnen et al., "Introducing a holistic framework for eHealth technologies," *Journal of Medical Internet Research*, vol. 13 (4):e111, 2011.
- [20] M. Span et al., "Towards an Interactive Web Tool that Supports Shared Decision Making in Dementia: Identifying User Requirements," *International Journal On Advances in Life Sciences*, 2014, no 3&4, in press.
- [21] M. Span et al., "An interactive web tool to facilitate shared decision making in dementia: design issues perceived by caregivers and patients". *International Journal On Advances in Life Sciences*, 2014 no 3&4, in press.
- [22] M. Span et al., "Developing a Supportive Tool to Facilitate Shared Decision Making in Dementia. Involvement of End Users in the Design Phase," *The Sixth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2014) IARIA*, March 2014, pp. 253-256. ISBN: 978-1-61208-327-8
- [23] P. Riley, N. Alm, and A. Newell, "An interactive tool to promote musical creativity in people with dementia," *Computers in Human Behavior*, vol. 25, May 2009, pp. 599-608.
- [24] T. A. Abma, C. A. C. M. Pittens, M. Visse, J. E. Elberse, and J. E. W. Broerse, "Patient involvement in research programming and implementation," *Health Expectations*, 2014. doi: 10.1111/hex.12213
- [25] K. Murphy, F. Jordan, A. Hunter, A. Cooney, and D. Casey, "Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies," *Dementia*, January 8, 2014.
- [26] J. Q. Tritter and A. McCallum, "The snakes and ladders of user involvement: Moving beyond Arnstein," *Health Policy*, vol. 76, 2006, pp. 156-168.
- [27] C. Smit, T. van der Valk, and K. Wever, "Fundamental research and patient organizations: a surprising combination! [Fundamenteel onderzoek en patiëntenorganisaties: een verrassende combinatie!]," *Badhoevedorp* 2011.