
CeHRes Roadmap to Improve Dementia Care

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Abstract

Dementia and technology, how do they go together? Technology might be a solution to support health and well-being for patients. Although promising, a lot of technologies are not used due to higher cost than expected, ineffective implementation, and technologies that do not work or help people in a positive way. To improve the adoption and use of technologies for health and well-being, we created a roadmap to guide the process of development, evaluation, and implementation (van Gemert- Pijnen et al. 2011). The roadmap is based on reviews of existing frameworks for eHealth and prior research about development, design,

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and implementation and applied in several research and development projects (van Gemert-Pijnen et al. 2013). In this chapter we elaborate on the use of the CeHRes roadmap for dementia care. First, we will describe the CeHRes roadmap and its principles for development, then we present a case study to demonstrate how the roadmap was used in practice, and finally we will reflect upon the case study by means of lessons learned.

Keywords

Dementia • eHealth • Development

CeHRes Roadmap to Improve Dementia Care

Dementia and technology, how do they go together? Technology might be a solution to support health and well-being for patients. Although promising, a lot of technologies are not used due to higher cost than expected, ineffective implementation, and technologies that do not work or help people in a positive way. To improve the adoption and use of technologies for health and well-being, we created a roadmap, to guide the process of development, evaluation, and implementation (van Gemert-Pijnen et al. 2011). The roadmap is based on reviews of existing frameworks for eHealth and prior research about development, design, and implementation and applied in several research and development projects (van Gemert-Pijnen et al. 2013). In this chapter we elaborate on the use of the CeHRes roadmap for dementia care. First, we will describe the CeHRes roadmap and its principles for development, then we present a case study to demonstrate how the roadmap was used in practice, and finally we will reflect upon the case study by means of lessons learned.

CeHRes Roadmap, Model, and Principles

The CeHRes roadmap is a practical approach to guide professionals (designers, developers, project managers) and researchers in the development and implementation of eHealth technologies. The roadmap entails five different phases to explore and test how an eHealth technology can be perfectly adapted to the target group and successfully implemented in practice (Fig. 1).

The Five Phases of the Roadmap

Contextual inquiry is geared toward identifying and describing the stakeholders' (patients, caregivers/health workers, health insurers) needs and problems. This phase also focuses on selecting those stakeholders who are most likely to benefit from the development of eHealth technology. The objective is to identify the weak and strong points of the current situation (health and well-being), to inquire the needs of stakeholders to improve health and well-being, and to identify regulations and

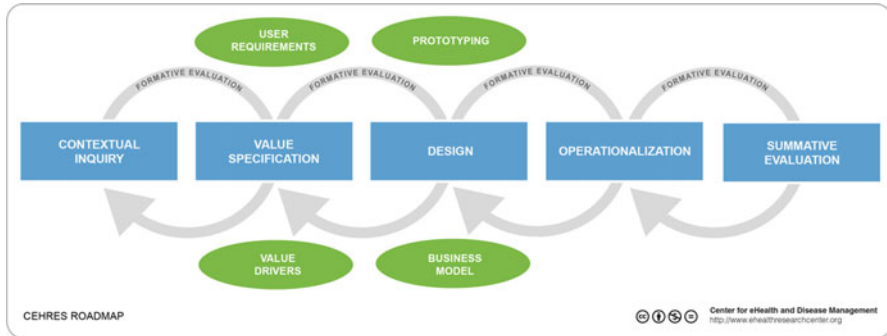


Fig. 1 CeHRes roadmap

conditions that should be taken into account (the context) to implement an eHealth technology. In this phase several activities can be conducted to investigate the context for development (see www.eHealthWiki.org). Important for successful implementation, a project management team should be established to organize meetings between developers and researchers to synchronize the content and system of an eHealth application and to schedule the participation of different stakeholders during the development process.

Value Specification

The value specification phase builds on the results of the contextual inquiry. The stakeholders identify the added values (economical, medical, organizational etc.) that they want to achieve by means of a technical solution for the improvements in health and well-being. These values can be ranked in order to create a feasible technology and to set conditions for implementation (see www.eHealthWiki.org). The values will be translated by the project management team into requirements (user, usage) to design the content and system of the application. These requirements can be formulated as a value map to discuss with stakeholders how a technical solution can contribute to the values to be achieved. For example, to support home care in a safe way for people with dementia, sensor technology can be a solution to alarm family or caregivers in case of a dangerous situation. In a value map stakeholders can discuss the cost and benefits of home care technology for frail people and the conditions for implementation. They can rank the values to set priorities for implementation from the perspectives of patients, caregivers, and those who pay for and maintain the technologies.

Design

A user-centered design can be created with the involvement of end users (patients, families, caregivers etc.). The value map with requirements will be translated into mock-ups, prototypes for the content and system. The prototypes (from paper to technology) will be tested, using scenarios that represent the use in practice of a certain technology. For example, in the case of dementia, several technologies can support health and well-being: technologies that support monitoring sleep/waking

rhythms, walking, and eating behaviors; sensor technologies that provide alarms and signals in case of dangerous situations; or coaching technologies to support interaction between users (e.g., patients-caregivers). For example, PAL4 (©Focus Cura) is a touch screen that allows people with dementia to look at their diary and provides video contact with family and caregivers and the “Chatterbox”, a game supported by technology to increase social interaction. During the design phase the project management organizes usability testing rounds with several mock-ups representing different kinds of solutions (monitoring and/or coaching technologies). For the design of mock-ups, usability principles and persuasive technology models (e.g., the Persuasive System Model (Oinas-Kukkonen and Harjumaa 2009)) can be used to examine users’ preferences for the presentation of the information and the format of technology (mobile, PC, etc.) and to identify factors that can increase the motivation to use the technologies in practice (van Gemert-Pijnen et al. 2013).

Operationalization

This phase focuses on activities to introduce and implement technology in healthcare. The project management team develops a business model with conditions for implementation (timing, activities, actors, budget) and an introduction program to embed technology in practice. For example, to implement sensor systems at home, the caregivers and family should be trained to understand the signals and data provided by these sensor technologies to know whether the patient needs help and to plan the treatment program.

Evaluation

To assess whether a technology fits with the stakeholders’ values and end users’ needs, formative evaluation rounds are conducted during the development phase and finally, for summative evaluation, to measure the effects on behavior, health condition, and healthcare organization.

For an overview of activities that can be conducted during the five phases, see www.eHealthWiki.org and “improving eHealth” (van Gemert-Pijnen et al. 2013). The roadmap is based on user-centered design principles, persuasive design strategies, and business modeling. The integration of a user-centered design approach, with a stakeholder-driven procedure *during* development, enables a sustainable implementation of technologies in healthcare. In our view development of eHealth technologies is more than creating a tool to support people. eHealth development can be considered as a participatory design process, a process of co-creation between end users and stakeholders to guarantee a fit between technology and the way of living and working. This co-creation process is coupled with continuous and iterative cycles for evaluation (formative evaluation) to know whether technology can contribute to improve health and well-being and what barriers hinder the implementation. Therefore, implementation is not a post design step, but interwoven with development of a technology. As such, eHealth development is not an ad hoc activity, but a structural approach to set the conditions for changing healthcare using technology.

A Case Study: The DecideGuide

The DecideGuide is an interactive Web-based system to support shared decision-making in care networks of people with dementia. Through this system people with dementia, their informal caregivers, and case managers (and/or other professionals involved) can communicate with each other in making shared decisions about care and well-being. The DecideGuide enables participatory design people with dementia, their informal caregivers, and case managers participate in the design to tailor the guide to their needs. The case manager deliberates with the person with dementia and the informal caregivers about the usage of the DecideGuide. All groups have an individual login and use the system on their own or after the case manager alerts them. The aim of the DecideGuide is to give voice to people with dementia as they are often not involved in decision-making about their own health and well-being. Therefore, the DecideGuide has three functions: the first function, *Messages*, is a chat function that enables users (at a distance) to communicate with each other. The second function, *Deciding together*, supports decision-making step by step. The third function, *Individual opinion*, enables users to give their individual opinions about dementia-related topics, e.g., care, living, daily activities, finances, mobility and transport, family and friends, safety, and future. It particularly supports giving voice to the person with dementia. The DecideGuide, a safe and shielded technology, is available for tablets, laptops, and computers (Span et al. 2014a) (Fig. 2, 3, 4, and 5).

Contextual Inquiry

The DecideGuide was developed in an iterative participatory design process. Involvement of all end users in the development process was considered as essential, as this results in better and more user-friendly systems (Span et al. 2013). The CeHRes roadmap was used because of its holistic approach and emphasis on involvement of all stakeholders.

The project started with consulting stakeholders like dementia experts and patient advocates such as the Dutch Alzheimer Association of whom many had a seat in the consortium. The consortium consisted of relevant actors in the field of dementia, like patient and caregivers via the national and regional Dutch Alzheimer's association, the national center of expertise for long-term care, case managers' network, researchers, and representatives of regional dementia care institutions. They were asked about the problems they experienced and expected needs regarding decision-making. Then, we conducted a systematic literature review focusing on how people with dementia are involved in the development of supportive IT applications. Results show that involvement of people with dementia is not self-evident and that involving them in all phases of the development increases the user-friendliness and usability of IT applications (Span et al. 2013).

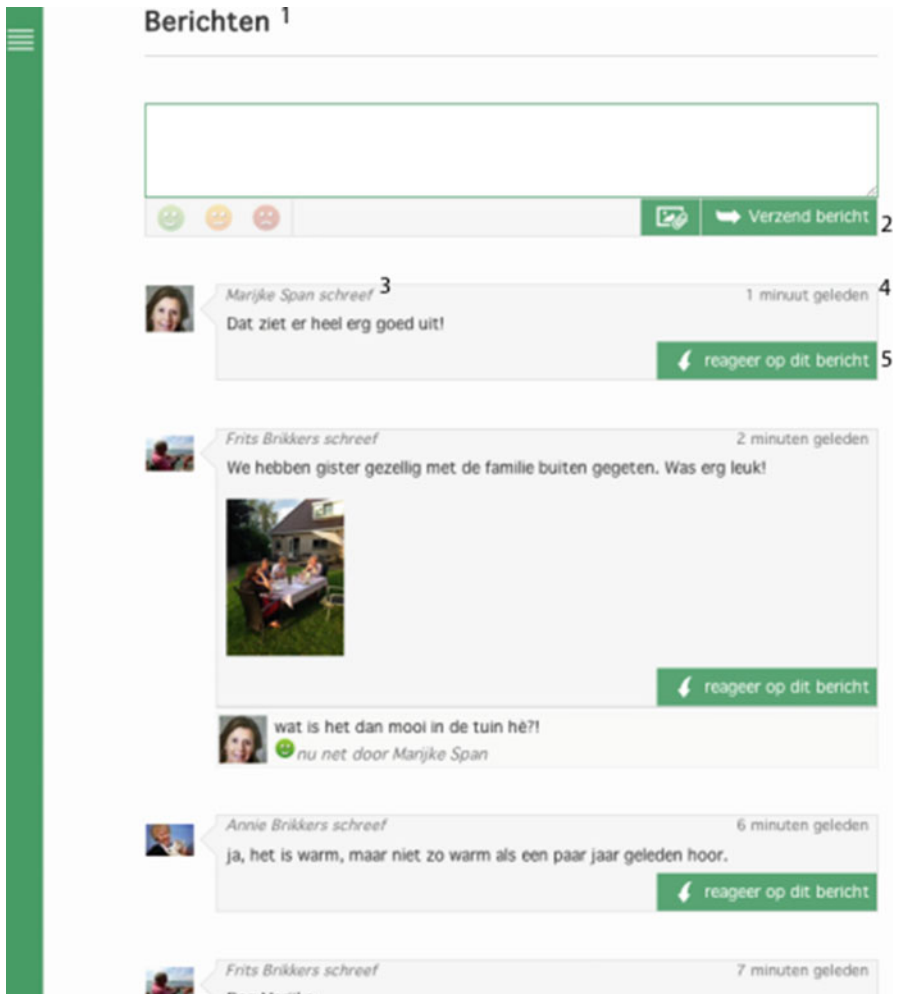


Fig. 2 Chat. (1) Messages (2) ‘Send message’ button (3) Network member Marijke Span wrote (4) Time message was posted (5) ‘Respond to this message’ button


Value Specification

In a stakeholder meeting the goals and values regarding the research and development program were discussed. The overall goal of the research program for the consortium was to improve dementia practice by supporting case managers in facilitating shared decision-making in care networks of people with dementia. Nevertheless, members of the consortium also focused on their goals and values that sometimes differed in content and tempi. For the case managers’ organization, it was important the program would result in practical tools. Representatives of the Dutch Alzheimer Association focused on participation of people with dementia and

Samen beslissen over...¹

Wonen² Wat is er aan de hand?³

De heer en mevrouw hebben hun huis te koop staan. Ze zijn naar een andere woonvorm


Wonen en huishouden⁴

Verzend bericht

Frits Brikkers schreef nu net
Ik help Annie wel en als we er niet uitkomen dan hoor je van ons

Marijke Span schreef 1 minuut geleden
Dag Annie,
Sorry voor de onduidelijkheid. Als je op het huisje klikt dan komen er vragen tevoorschijn die over het onderwerp wonen gaan. Zou je die vragen willen beantwoorden?
groet, Marijke

Terug naar beginpagina⁵ Stoppen en uitloggen⁶

Fig. 3 Deciding together. (1) Deciding together about... (2) Living (3) Decision-making phase 'What is going on?' (4) Questionnaire 'Living and housekeeping' (5) Back to home page button (6) Logout button

informal caregivers and attuning to their needs. The national center of expertise for long-term care (Vilans) aimed for the dissemination of the insights on shared decision-making in dementia care networks and implementation of the interactive Web tool. The researchers focused on case management, communication within the networks of people with dementia, self-management, and autonomy of people with dementia and their informal caregivers.

The end users who participated had their own interests. Case managers were in need for practical support regarding decision-making in their daily dementia practice

Hoe gaat het?¹

Het is vandaag donderdag 8 mei²

Goedenavond mevrouw Brikkers³

Hoe gaat het nu met u?⁴

goed redelijk niet goed

Hoe komt dat?⁵

U kunt op dit vak tikken om uw toelichting te schrijven. ⁶

Opslaan en verder gaan ⁷

Fig. 4 How are you right now. (1) How is it going? (2) Date (3) Good evening Mrs. Brikkers (4) How are you right now? Fine, pretty, not so fine (5) Why is that? (6) Writing an explanation (7) Save and continue button

that is not time consuming. Informal caregivers were in need for support in the difficult decisions they had to make with or without the persons with dementia. For people with dementia it was important to understand the needs for themselves and future people with dementia.

Design

The next activity was identifying user requirements the system should address. Semi-structured individual interviews ($n = 50$) were undertaken with people with dementia, their informal caregivers, and case managers about decision-making

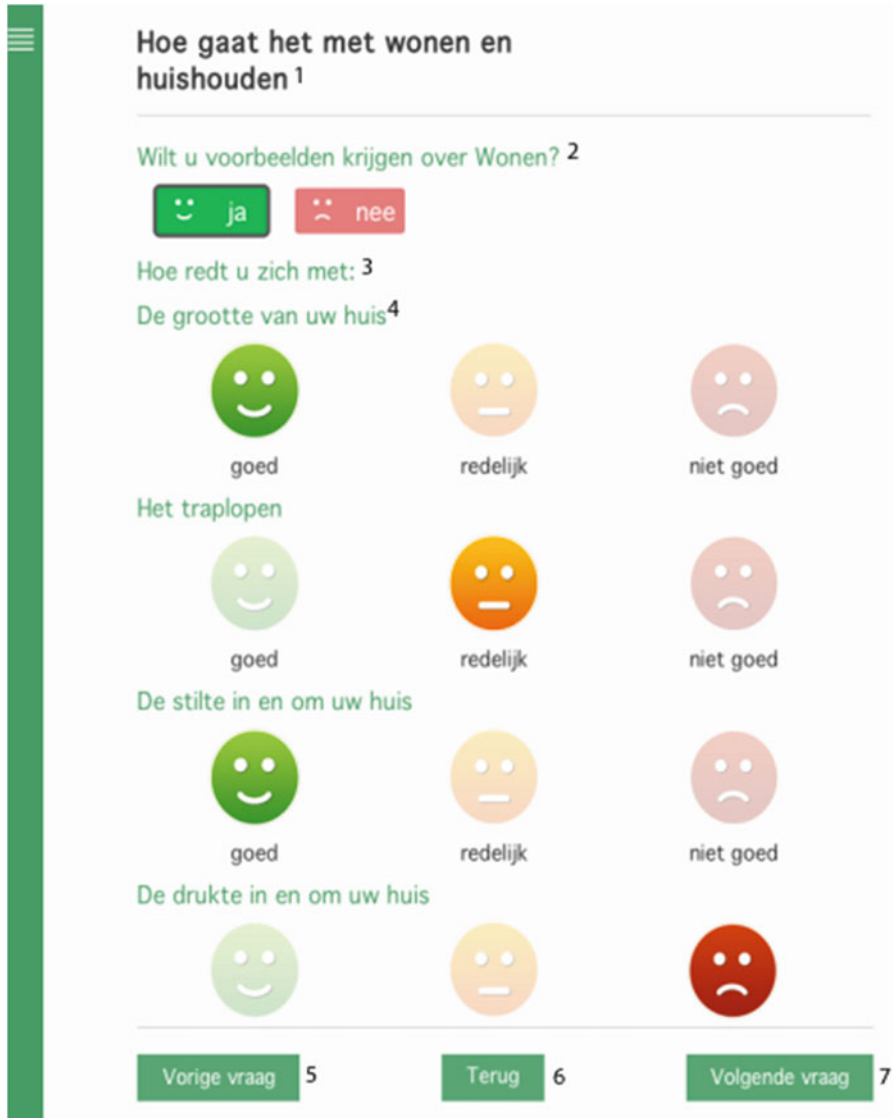


Fig. 5 Individual opinion. (1) How are living and housekeeping (2) Do you want examples about living and housekeeping? (3) How do you deal with (examples are given) (4) The size of the house, stairs, silence inside and outside the house. . . (5) ‘Previous question’ button (6) ‘Back’ button (7) Next question button

topics. Consecutively, in separate focus groups ($n = 34$), the three end user groups and a group of dementia experts ($n = 13$) were asked to check the results of the interviews, to add items that were missing in their opinion, and to express requirements a supportive system should address (Span et al. 2014b). In this phase the decision was made for a partnership with an external software developer.

Based on the results of the interviews and focus groups, mock-ups of the system were developed. The mock-ups, a paper-based prototype consisting of 11 screens, was presented in separate focus group sessions to people with dementia, their informal caregivers, and case managers in two consecutive rounds ($n = 27$). A first iteration was made before the second focus group session. Based on the feedback and comments of the end users of both focus group rounds, in a second iteration a first interactive prototype of the system was developed. This interactive prototype, the DecideGuide, was then tested by experts ($n = 3$) in a cognitive walk-through. Based on the experiences of the experts, a third iteration was made before end users tested the system. In individual usability tests with a think aloud protocol case managers, older adults, informal caregivers, and people with dementia tested the DecideGuide ($n = 12$). Their feedback resulted in a fourth iteration of the DecideGuide. Finally, a design checklist of the roadmap was used to assess the quality of the system, content, and service of the design.

Operationalization

The system was used in a 5-month pilot study. Four care networks of people with dementia ($n = 19$) used the DecideGuide on an iPad in their daily lives. Care networks consisted of persons with dementia, their informal caregivers, and case managers. Except for two persons with dementia who participated in the usability tests, the network members were not familiar with the DecideGuide. People with dementia, their informal caregivers, and case managers were interviewed at the start, midway, and at the end. Moreover, observations are made of visits at home and memos and field notes are recorded in a log book. With these activities the impact of the DecideGuide was evaluated. Furthermore, barriers and facilitators for a successful implementation in daily practice of dementia care networks were inventoried.

Two manuals, one for case managers and one for the other participants, were developed that explain the steps of shared decision-making and the possibilities of the DecideGuide. During the development trajectory the project team developed a shared decision-making training that was provided for case managers, nurses, and other professionals working with people with dementia.

Summative Evaluation

Based on the findings of the pilot study, the DecideGuide will be adjusted and an effect study with the DecideGuide will be conducted.

Reflection on the Case Study

We reflect on this case study via lessons learned to provide recommendations for future development projects in the field of dementia.

Lessons Learned

- Involvement of *end users* appeared complicated. Nevertheless, it is essential to involve end users from the beginning of the development and to listen to their opinions and experiences, although older adults and people with dementia need more time to express themselves than other stakeholders. Involvement of people with dementia is complicated because they might have problems with expressing their problems and needs. Standard questionnaires to ask people with dementia about their needs, feelings, and thoughts are hard to use (Nijhof 2013). Criteria for involvement of people with dementia in the development process can be: willingness to learn something, MMSE or other scores related to the phase of dementia, phase of receiving care, eHealth literacy, and expected support from family or caregivers (Nijhof 2013). Caregivers should also be asked about their willingness to use eHealth and their experiences in using eHealth for frail people. From several dementia projects we know that caregivers face problems when using computers or mobile devices in healthcare. They lack adequate education and skills, and in most cases implementation (education, training) is not scheduled as part of their jobs (Nijhof 2013).
- Involvement of *stakeholders* to assess the conditions for implementation was time consuming but valuable. Interviews, observations with caregivers, patients, case managers, management, and work documents (protocol, treatment plans, care pathways) provided the information needed to implement an eHealth system and to set up a realistic implementation plan (time, budget, training, and responsibilities for the maintenance of the eHealth system) (van Gemert-Pijnen et al. 2013; Nijhof 2013). For example, in an ADL project using sensors to measure daily life activities of people with dementia (eating, sleeping, walking etc.), caregivers and family were not able to interpret the sensor data and the data provided by the sensor was not transferable to their treatment goals and plans. This resulted in a non-usage of high cost-effective systems. To avoid such situations, stakeholder meetings, during the early stage of development, are necessary to discuss the values to be achieved and the feasibility of the derived goals to improve health and well-being. In the case study a lot of time (15 weeks for the interviews, focus groups) was invested in identifying goals and requirements with stakeholders and in particular to identify needs of the end users. Although time consuming, these stakeholder meetings resulted in agreement on the goals and requirements to achieve with the DecideGuide. A document with goals and system requirements was developed that was recognized by all stakeholders. This document guides the process of *value creation* among stakeholders and can be used as a first draft for the implementation plan.
- *Prototyping and testing* with end users provide feedback from different perspectives (caregivers, patients, etc.). During the *design phase* several methods were applied to improve the design step by step. The use of mock-ups in the focus group sessions was difficult and confusing for most of the people with dementia. Nevertheless, it resulted in valuable feedback. In the cognitive walk-through, experts (researchers) tested the interactive prototype. Remarkably, the difficulties

experts experienced with regard to the functionalities of the DecideGuide (chat, communication) were not confirmed by people with dementia in the pilot. For example, the expert who played the role of the person with dementia in a chat with two other experts as informal caregiver and case manager experienced the chats as rather confronting. The experts perceived the chat as patronizing patients with dementia, talking about instead of talking with the patients, while “real” patients experienced no problems with the communication at all. This indicates how difficult it is to imagine what patients feel and think and how important it is to include real patients in prototyping.

- To verify the *quality* of the content and system of the DecideGuide, a *guideline* (Nijland 2011, Chap. 5) was used that provides criteria referring to the five phases of the CeHRes roadmap. This guideline should not be used as a checklist to be ticked but as an aid to discuss which research activities and criteria are relevant in each phase of development. The project management team can prioritize what activities and criteria should be taken into account and what activities and criteria are less relevant. For example, items like interoperability of devices, credibility, and completeness of information were considered less relevant for the DecideGuide compared to aspects like learnability and persuasiveness of the content.
- *Project management* is needed to schedule the formative evaluation rounds and research activities (Nijland 2011). The development process of the DecideGuide was delayed because of differences in work dynamics of researchers and designers of the software company. Designers and developers (researchers, caregivers, etc.) work in different tempi and they use a different vocabulary about design. To understand each other, a value map with goals to be achieved and the derived requirements (for system design) can guide the management of a project in health technology development. Important for the operationalization is to discuss the ownership and maintenance of eHealth technologies. The stakeholders of the DecideGuide committed themselves to the implementation of the system in the involved care networks. The consortium was the owner of the content of the DecideGuide and the software company was the owner of the system. An arrangement was made that these two parties could not change the DecideGuide without consulting each other. The same was agreed regarding the maintenance of the DecideGuide. An agreement on ownership and maintenance is needed to be able to update the content and system. The agreement made by the consortium and software company to split the responsibilities might be reasonable, but in practice this can hinder the accuracy and flexibility of the system because of the differences in priorities and the lack of an adequate business model for updating content (who pays for what kinds of updates?).
- To avoid technical discussions, a manual for using technology can be created from the perspective of users (Nijhof 2013). In particular, such a manual can be helpful to clear up differences in priorities (time, interest) between involved stakeholders. For example, in our case the researchers and designers of the system had different priorities in realizing the system, which prolonged the operationalization of the DecideGuide.

- The stakeholders agreed on the *values* to be achieved, e.g., improving dementia care practice, participation of people with dementia in the development (deciding with rather than deciding for them), and supporting self-management and autonomy of people with dementia and their informal caregivers. However, more attention is needed to business modeling from the beginning of the project. The responsibilities for introduction (training) and responsibilities for technology (maintenance) should be discussed during the value specification to develop a realistic budget case. In the DecideGuide the IT partner for instance, as one of the stakeholders, was not involved at the start of the project to make clear agreements on maintenance tasks. One of the problems with technology is the cost-benefit ratio, for example, it is important to decide how many users are needed in a certain time period to benefit from a home care technology compared to traditional care (Nijhof 2013).
- To be cost effective, a technology can entail different functionalities that can become gradually available. Basic functionalities of the technology can be used at the start for all users and be expanded later on based on *evaluations of the usage* (via logdata). Evaluation is not a fixed end; real-time usage data are important to understand the uptake and impact of a technology on daily life and healthcare practice. Evaluation is an iterative and cyclic activity and starts with the contextual inquiry. To understand the fit between users and technology, logdata can be collected. This requires a log protocol (Van Gemert et al. 2014; Sieverink 2014) to set the conditions for monitoring use and users and to intervene during the period of introduction. This logdata protocol should be incorporated in the system; algorithms should be developed to collect data during usage to measure adherence and dropouts, to predict the impact of usage on outcomes, and to identify user profiles (Nijland 2011; Van Gemert et al. 2014). An informed consent from end users is needed to get agreement to monitor users of technologies.

In the end, to create a fit between technology and people with dementia, a user-centered design is a prerequisite but not sufficient to develop technologies that work, help, and are cost effective. Project management and a stakeholder-driven approach are needed to develop sustainable technologies. Education and training are crucial for caregivers, family, and patients to avoid technologies that overshoot the mark and that make no sense for frail people. The CeHRes roadmap and accompanied tools (eHealth wiki) can be used to create a fit between dementia and technology. To share knowledge and to improve interventions for health and well-being, the eHealth wiki can be expanded with information supplied by project teams involved in developing technologies.

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