

## 5. Supportive technologies for people with dementia: a closer look into an interdisciplinary field

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Technologies can support people with dementia to live a safe, happy and independent life at home. These supportive technologies have a variety of purposes, such as support in day-to-day activities (e.g., reminder systems, item locators) and safety (e.g., sensors, localization systems). There are also technologies with a focus on engaging in meaningful activities (e.g., reminiscence, lifelogging) as well as training and fun (e.g., serious games). Furthermore, there is a focus on supporting communication (e.g., video calling and text messaging), information and screening (e.g., websites) (Evans, Brown, Coughlan, Lawson, & Craven, 2015). Iterative co-design with end-users is needed to ensure high accessibility, relevant benefits and satisfactory use of these supportive technologies. Nevertheless, most of the abovementioned developments lacks frequent co-design cycles and people with dementia are scarcely involved in the design process of technology development (Suijkerbuijk et al., 2019).

Various scientific disciplines are involved in researching and developing supportive technologies. These disciplines range from psychology and neuroscience to design and engineering. The disciplines differ in their research paradigm and design approaches in developing, designing and evaluating technology. In this chapter we take a closer look at the methods and materials that are used for active involvement of people with dementia in research and development of supportive technologies. We provide insights from different Active and Assisted Living (AAL) development projects (FreeWalker and eWare) that exemplify these multidisciplinary projects. In addition, we share the insights gained from in-depth interviews with researchers from the different worlds. We conclude with a discussion on how the challenges of multidisciplinary collaborations might stand in the way and what could be ways forward to give people with dementia their desired role in the development of meaningful supportive technologies.

## 5.1 Active involvement of people with dementia in technology development

Earlier literature reviews, mainly focused on research done in healthcare settings, highlight how important it is to involve people with dementia and their informal caregivers in the development of new supportive or assistive technologies (Meiland et al., 2017; Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013; Topo, 2009)). The most common type of involvement, which occurs in the evaluative phase, results in insights in the effectiveness, usefulness and acceptability of the developed devices. In the majority of these reviewed studies, people with dementia have had a rather passive role in the development, at best serving as an object of study or informant. Few studies found in the medical and healthcare databases (Cochrane library, PubMed, EMBASE, and CINAHL database) report on the involvement of people with dementia throughout the entire development process of technology, e.g. as a continuous equal partner or co-designer. Co-design is defined by Sanders and Stappers (2008) as the “creativity of designers and people not trained in design working together in the design development process” (p. 2). This working together on equal grounds stimulates collaboration and serves to enhance the qualities of all partners involved. The lack of this creative working together in the development of supportive technology is noteworthy since co-design practised from the start of the development process can have an impact with positive, long-range consequences on the user experience of the eventual design outcome (Sanders & Stappers, 2008). Co-design with people with dementia can yield an enhanced sense of control in participants (Hanson et al., 2007) and can ultimately lead to a more empathic understanding of the user group (Lindsay et al., 2012). Empathic understanding enables designers and developers to gain relevant and intimate user insights needed for more meaningful and suitable technology development. However, involving people with dementia as co-designers in the development can be challenging due to the characteristics of the syndrome, which might vary between the different types of dementia with different behavioural, cognitive and emotional consequences. Being a co-designer might require certain levels of sensory, cognitive and motoric abilities to be part of the process that includes methods and tools to acquire contextual knowledge and to create and visualise new viable solution ideas together with others. These aforementioned skills decrease for a person with dementia (Hendriks, Slegers, & Duysburgh, 2015) and this could result in insecurity about one’s own capabilities and therefor conflicts equality in partnerships. The large variety among people with dementia adds to the overall challenges of successful co-design with this user group, as different people might need different methods of participation.

### 5.1.1 Involving people with dementia in development of technology: methods and materials

There is still a lack of specific knowledge about the research methods and materials needed to actively involve people with dementia in the entire development process of supportive technologies. Although we have to be precautious about method-ism in this field, as the different contexts of design research with different people living with dementia cannot result in a generic methodology (Hendriks, 2019), it is important to share insights gained from the use of different methods and materials over the entire process of technology development.

The review of Suijkerbuijk et al. (2019) showed that there is a growing number of research projects that aim to develop supportive technologies for people with dementia. Compared to earlier work (Span et al., 2013), there is an increase in studies eliciting an active involvement of people with dementia. By adding studies from the HCI and Design fields, the review by Suijkerbuijk and colleagues outlined a more balanced view on where in the development process people with dementia can be involved. Not only are people with dementia able to evaluate technology, they can also play an important role in the generative phase of development to steer the design of supportive technology earlier in the process. There is considerable attention in the HCI community for designing with people living with dementia (Rens Brankaert et al., 2019; Lazar et al., 2018; Morrissey, Lazar, Boger, & Toombs, 2017). The HCI community moves the research focus away from considering medical

concerns only, towards a broader view including context, values and the situatedness of technology use. Involving people with dementia as co-designers in the development of technology is deemed challenging, but not impossible. However, even with the update and expansion in this review, what is generally missing are extensive reports on the methodology and evaluation of the experiences of people with dementia themselves. This makes appreciation and further improvement of active involvement and co-design difficult.

## 5.2 Examples of supportive technology development

Designers, researchers and developers with different backgrounds, different languages, different motives and different ways of working need to collaborate in the process of developing supportive technologies in order to create solutions that are desirable, feasible and viable. This complex collaboration creates obvious difficulties that sometimes seem to stand in the way of prioritizing the voice of the end-user in the development process. This might result in low acceptance and usefulness of currently available supportive technologies (Evans et al., 2015) and eHealth in general (Wouters et al., 2018). What follows in this chapter are stories of two AAL projects in which the authors are and were actively involved; FreeWalker and eWare. These projects exemplify the challenges experienced in collaboration within development projects.

### 5.2.1 Working within an international and multidisciplinary project team

Within the project 'FreeWalker' ("<https://www.freewalker-aal.eu>," n.d.), a European consortium of eight partners from 3 different countries (Austria, Switzerland & The Netherlands) is working together to develop a dynamic GPS-based safety zone for people with dementia and their (in)formal carers.

A project like FreeWalker is based on a proposal with a workplan developed ahead of the pre-design and generative phases. This implies that the project goals, main functionalities of the supportive technology, and evaluation methodology are defined to a great extent at the project start. Although the project intentions are positive and iterative co-design is key, R&D projects based on funding can in principle never truly start with end-users needs. There are two interesting project phases to share for the purposes of this chapter: first, the involvement of the primary end-users, 'people with dementia', and second the requirements analysis phase within an interdisciplinary consortium.

In FreeWalker, people with dementia are not involved in the pre-design and generative phases and will take part in the evaluative phase whenever FreeWalker has already been developed. It is debatable to what extent it is necessary to include people with dementia in the design of GPS soft- and hardware, however the implications of the technologies on their lives can be quite significant. FreeWalker can enlarge the freedom of movement, but also limit the perception of freedom due to tracking and localization functionalities. Overall, the person with dementia has no control over the dynamic safety zone and the algorithm deciding the shape and size of the zone. A big part of the project was assigned to the challenges in the technical development. As the application might be very abstract to actual end-users, the consortium faced troubles with actually involving people living with dementia in the concept development, as to stay on the time planning from to original proposal.

Another interesting phase to share is the end of the requirements phase. Once requirements have been gathered in multiple co-design rounds with formal and informal carers, it transpires that not all requirements can be met, due to incompatibility with any or all of the following constraints: Project goals; Time or funding; Technical feasibility; and Cultural / National differences in needs and potential market. By rating requirements on these constraints via a MoSCoW analysis (Clegg & Barker, 1994), with Must-have, Should-have, Could-have, and Would-have functionalities, a ranked list can be made with functionalities that can be developed within the project constraints. The MoSCoW process is transparent and the interdisciplinary consortium partners can have their vote based on their perspective. Yet, there is limited room for end-user involvement in this process and it can devalue the

end-users' needs whenever incompatible with e.g., the predefined project goals and/or available funding.

### **5.2.2 From generative to evaluative phase**

The goal of the eWARE project ("<https://aal-eware.eu/wp/>," n.d.) is to introduce a novel eco-system to support the wellbeing of people with dementia and their informal carers. In the project, existing supportive technologies are integrated and adapted for people with dementia who live alone at home (about 70% of people affected by cognitive impairments). These supportive technologies include a lifestyle monitoring system and social support robotics which together ought to provide context relevant responses in daily living (Zwierenberg et al., 2018). Four different end-user organizations in four different countries are taking part in the project.

In the generative phase of the project, it was mostly informal and formal carers that were involved (Casaccia et al., 2019), as the participating end-user organizations found it difficult to ask people with dementia to contribute this early in the process. It was doubtful if people with dementia could express their needs in respect to the integration of lifestyle monitoring and social robots. Some of the needs that were generated in the generative phase, were categorized as Would-have functionality (as the MoSCoW analysis was also used in this project to prioritize requirements). Partners in the project decided that it was outside of the scope of the integration of the two systems. They did not seem to be the most relevant requirements at that phase of the project. However, during the alpha trials in the evaluative phase it appeared that people with dementia needed additional functionalities to start and keep motivated in using the eWare system. For example, the social robotic as a stand-alone has functionalities such as playing the radio. This was deliberately left out of the eWare project, as to simplify the scope of the project. The participants from the test did mention they wanted more interaction and more fun elements. It was decided to frame the functionalities of the system differently in the remainder of the project (the eWare system is not given reminders, but compliments).

In this project, there are different researchers deploying the research that has to be done according to the project proposal. Research partners with a medical background were very eager to put a clinical test to the questionnaires. Within the project meetings, a lot of time was spent to discuss this. From the care-organization perspective this was not desirable as this would impact the requirement phase and it was expected that it would demean the experiences of participants with the eWare system. Furthermore, the researchers from HCI did not see how these insights would help the further developments of such system. To find a way of valuing the individual perspectives of the participants but also find a measure to get some outcomes on effectiveness, the research partners decided to use the Goal Attainment Scale (Turner-Stokes, 2009). This is a measure which uses a personal situation and standardizing it together with research participants. The standardized measures can be used to see the effect for all participants. With this measure, different research perspectives could be combined. The Goal Attainment Scale is currently used in the remainder of the project.

## **5.3 Challenges in active involvement according to researchers in the field**

In order to further elaborate on our own experienced challenges in involving people with dementia in the development of supportive technologies, we conducted in-depth interviews in 2018 with eleven Dutch researchers. We used a convenience sampling method by inviting existing contacts. To further understand the interdisciplinary field, we aimed for a wide variety in the experiences of the interviewed researchers. These differed in fields (from design, to engineering, to psychology) and in years of experience (from 1-year PhD to 9 years of being a professor). Interviews ( $n=11$ ) lasted

approximately 1 hour and were recorded with permission and transcribed verbatim. The semi-structured interviews covered three questions:

- 1) What are the experiences of the researchers with different methods and materials used to involve people with dementia?
- 2) What are the most valuable lessons that researchers gain from working in collaborative projects to develop supportive technologies for people with dementia?
- 3) How do researchers obtain and share relevant knowledge within this field?

For this chapter we decided to focus on the outcomes of the first two questions only.

### 5.3.1 Experiences with different research methods and materials

All interviewed researchers state that they involve people with dementia multiple times throughout their projects. Four researchers explicitly mention a specific iterative approach (e.g. co-design) that they aim for in their projects. It is a shared insight that keeping people with dementia involved throughout a project is challenging and time-consuming (keeping in contact with participants, also outside of research activities) but highly relevant for the development of meaningful supportive technologies. One of the researchers mentioned that people are not asked to participate in the entire project from the start, as this might be experienced as overwhelming and therefore discouraging. This highlights one of the challenges in continuous involvement of people with dementia. From the interviews we gain several insights that have been shared in previous work as well (Astell et al., 2009; Rens Brankaert, Ouden, & Brombacher, 2015; Hendriks, 2019; Mayer & Zach, 2013) such as the fact that interviews and focus groups should have a clear time constraint in order to not overburden participants with dementia. Below we highlight a number of specific new insights.

Several researchers highlight the importance of using existing knowledge, for example by doing literature reviews ( $n=6$ ). One of the researchers spoke about a large needs study that her research group performed. In that study, a total of 236 interviews with people with dementia were conducted and the outcomes of this large study has been the foundation of all subsequent development projects for this research group. However, one of the researchers with a design background pointed out that not all relevant information can be gained from reading literature. One of the biggest challenges that more interviewees referred to is the translation of everyday needs to market-ready solutions for a larger group of people. This is an important phase in the design practice and might be experienced by researchers from different backgrounds as a non-scientific black box. Furthermore, it is of interest how this relates to the involvement of the people living with dementia themselves within this phase of the design process. Do they take part as equal partners, as precondition for co-design, and is that even possible?

With respect to materials used in research, interviewees explain that a variety of prototypes were tested throughout their projects. The fidelity of these prototypes ranges from paper prototypes in the generative phase to fully functional prototypes in the evaluative phase. In line with previous research (Orpwood et al., 2004) it is pointed out that it is very important to think carefully what to test with people with dementia, maybe even more than when testing with users without cognitive problems. However, the reasons given by our interviewees are diverse. One of the researchers talked about the importance of problem-free testing. Since this researcher uses a regular group of enthusiastic people with dementia, which meets frequently in order to increase the accessibility of new innovations for the user group, she noticed that the group became reluctant to test new versions of prototypes when they had experienced troubles earlier on. This might be a relevant insight when thinking about including the same users over the course of one or multiple projects.

Other reasons for reconsidering testing prototypes with people with dementia, is that some prototypes of technologies can be quite harmful and risky to the end-user when tested in real life contexts (such as navigation support systems). Other prototypes might be too costly so that only few people can be included in real-life testing. All of the above reasons need consideration during prototype testing with people with dementia and can influence the outcomes of formative evaluations.

One of the recurring themes in the interviews is researching the effectiveness of supportive technologies for people with dementia. The interviewees that talk about quantitative measurements ( $n=5$ ), all underscore that randomised controlled trials are not feasible in projects developing technology, even though this is still a common part of many project proposals. Not only do funding agencies still ask for trials with a large group of people, dementia care organizations also want to know whether technology truly supports the life of people with dementia and assists informal and professional carers. However, the time for setting up an effect study cannot be incorporated within the mean of three years that is common in supportive technology development projects. In addition to that, the traditional RCT-designs do not fit within the field of technology; technology always needs updates and randomising by way of a placebo is nearly impossible. This opens up the debate on how to dynamically approach an outcome such as effectiveness, as the earlier example within the eWare project shows. One of the researchers mentions that more anthropological research to fully understand how technology can be supportive in the everyday lives of people with dementia creates more relevant rich data that will help the field to move further. More research on how to hand-over such experiences is highly relevant (Smeenk, Sturm, Terken, & Eggen, 2018).

### 5.3.2 Working in multidisciplinary teams to develop supportive technologies

As involving people with dementia throughout a project is regarded as an essential prerequisite for successful technology development, the entire team should be open to investing time in this. One of the researchers states that the involved researcher needs to have a certain intrinsic motivation to work from the perspective of users and create positive outcomes in their lives and that of relevant others. This is helpful for convincing other stakeholders (such as developers) in the team as well as the research participants. People with dementia and their informal caregivers are more willing to share their insights when researchers are enthusiastic. Three of our interviewees explicitly mention that developers should be open to all sorts of outcomes during the project, as the approach of iterative human-centered design can create unexpected outcomes. One researcher describes: *“Sometimes these development projects give interesting insights about older adults without the actual technology being valuable. For technical partners this can be regarded as a failed project. That cannot be the case, we do not want to stimulate a technology-push.”* In addition to that, developers should at least have some interest in the user group as well.

Interviewees explained that maybe more than in the development of non-technological interventions, project partners are very dependent on each other. Developers and designers have very different skills to some of the involved researchers. This makes it difficult to fully understand the capabilities and resources needed before the actual start of a project, in particular when the design brief is more open. Also, the aims of different project partners can vary, for example, between researchers and designers. Two design researchers that we interviewed explained that there is always a need for finding a balance between doing reliable research activities (lowering the variables) and getting actual practical insights (in the context of use) to steer the development and design in the right direction. In the case of involving people with dementia, it is also highly relevant to not overburden the participants and adapt the methods to the situation at hand. Another example of different aims between partners is that of SMEs or business partners and designers, as was also discussed in the FreeWalker example earlier in this chapter. Overall, our interviewees underscore the importance of having a business partner for developing viable outcomes. However, in the pre-design and generative

phase of technology development there is a high need for creativity which, to one of the interviewees, can be affected when thinking about costs early on.

Two researchers defined solutions on how to overcome the differences between partners involved in the development of supportive technologies. One of the interviewees explained the process of educating each other throughout the project in the common paradigms and methods that are used in their own discipline. This might lead to more interdisciplinary team work. Close collaboration, by literally sitting and working next to each other, is deemed necessary to integrate research, design, business and development. Another solution given in our interviews is to actually involve people with an interdisciplinary profile (such as Human-Computer Interaction professionals) who can facilitate the communication between dementia researchers and technology developers, since translating insights from research into technology development goes beyond simply understanding each other.

Despite the intention to actively involve people with dementia iteratively throughout a project, the different researchers from the field experience similar challenges, such as researching needs and translating these into actual designs and first prototypes, as well as when and how to involve people with dementia within this process. The difficulties in funded projects with different partners and with different aims are highlighted by the project examples given earlier in this chapter concerning actual human-centered design developments and studying the effectiveness of the developed supportive technologies. This is also reflected in work by Span and colleagues (2017) who argue that funders should consider the extra time required for meaningful participation of people with dementia within these complex projects.

## 5.4 Implications for future research in co-designing supportive technologies

The increasing number of people with dementia worldwide creates a need for meaningful support in independent living and overall well-being in daily life. Large national and international programs for developing supportive technologies reflect the growing interest in the potential of technologies to improve dementia care, although the uptake of these technologies is still limited to technologies such as lifestyle monitoring (see, Zwierenberg et al., 2018). There seems to be a mismatch between products and the (real) needs and abilities of people with dementia. Active involvement of people with dementia is complex, due to the characteristics of the dementia syndrome, the sparseness of knowledge on useful research methods and materials and the inherent multidisciplinary work that accompanies these development projects.

The projects described in this chapter further exemplify the abovementioned difficulties. To apply for funding and to align a consortium of partners with different backgrounds and from different countries and cultures, a detailed proposal is needed before the start of a project. This inherently affects the balance within the project between users on the one hand and designers and researchers on the other, as people with dementia usually do not partake in the writing of project proposals. Although funding agencies, such as ZonMw in the Netherlands (ZonMw, n.d.), increase the use of panels of users to review proposals, how to include all sorts of people with dementia within these referent pools remains largely unknown. Designers and researchers within the field should therefore try to find suitable ways of including people in pre-project phases.

Furthermore, when defining user requirements from user research, it is not only desirability that must be accounted for, viability and feasibility also need to be considered. Again, the people with dementia usually do not have a direct voice in the prioritising of requirements, unlike the business partners and developers. This might result in the requirements being aimed more towards project and product viability, effectiveness and feasibility. Moreover, when designing new technologies, it is quite challenging to invite people with dementia onto the project in the early stages. Although we have learned from our systematic literature review that people with dementia can be part of the generative phase in the development process, from our experiences in FreeWalker and eWare,

requirements are more easily drawn from the perspectives of informal and formal carers. Even though this shortcut affects outcomes later in the process such as the need for redesigning technology to better match the needs of people with dementia. Overall, it remains challenging to strike a balance between desirable, feasible and viable designs for supportive technologies. A clear vision, at the start of the project, of how the project partners want to involve people with dementia and an action-based process evaluation might overcome the temptation to choose the quickest way. Moreover, sharing honest reflections of designers and researchers within the field on the process and the used materials and methods is highly valuable to strengthen the ways we undertake to co-design with people living with dementia, such as at the Dementia Lab conference (Rens Brankaert & Ijsselsteijn, 2019)

#### 5.4.1 What does co-design mean in developing supportive technologies?

In this chapter we took a closer look at the different disciplines and challenges involved in the development of supportive technologies for people with dementia. The methods and materials that various disciplines are acquainted with influence the role that people with dementia can play in the development of technology. Merely involving people in evaluating ideas, concepts and prototypes does not create the equal partnership that is required for a genuine co-design process, as described in the beginning of this chapter. More knowledge should be shared on how designers use the creative capacity of people with dementia and actively involve them in the pre-design and generative phases of technology development. The collaboration between partners in the development of supportive technologies can be quite challenging, due to different backgrounds and cultures. Our examples show that the level of involvement of people with dementia in the pre-design and generative phases of supportive technology development can, despite the growing interest in the field, still be improved. Furthermore, more attention is needed in how people with dementia appraise their involvement and how this can be guided toward their desired role by means of appropriate research and design methods.

Future research should therefore continue to focus on and describe how research methods and materials could be shaped, chosen and applied. This does not need to interfere with the explorative nature of design activities in the pre-design and generative phases, for example by writing detailed method stories of these design activities with different people with dementia (Hendriks et al., 2015). In line with person-centered dementia care (Brooker & Latham, 2015), the research methods and materials should consider users' changing individual strengths and vulnerabilities, and give people with dementia their desired role in the development of supportive technology. Only when people with dementia have the right sense of control designers, developers and researchers will gain the necessary empathic understanding to create meaningful and suitable technology. This is beautifully described by one of the participants in the development of the DecideGuide by Span and colleagues (Span et al., 2017):

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

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