Together we do not forget: co-designing with people living with dementia towards a design for social inclusion

Citation for published version (APA):

Document license:
CC BY-NC

Document status and date:
Published: 07/06/2017

Document Version:
Accepted manuscript including changes made at the peer-review stage

Please check the document version of this publication:
• A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher’s website.
• The final author version and the galley proof are versions of the publication after peer review.
• The final published version features the final layout of the paper including the volume, issue and page numbers.

Link to publication

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the “Taverne” license above, please follow below link for the End User Agreement:
www.tue.nl/taverne

Take down policy
If you believe that this document breaches copyright please contact us at:
openaccess@tue.nl
providing details and we will investigate your claim.

Download date: 05. Jun. 2022
Together we do not forget: Co-designing with people living with dementia towards a design for social inclusion

Wintermans, M.C.*; Brankaert, R.G.A. and Lu, Y.

University of Technology Eindhoven, The Netherlands
*Corresponding author e-mail: m.c.wintermans@tue.nl
Doi: 93

Dementia is increasingly becoming a societal challenge worldwide. In order to address the needs of people living with dementia through design, it is important to develop products and services in collaboration with them. For this study, a co-design approach was used to involve people with dementia throughout the design process. With them we aim to find a solution for social inclusion. This resulted in ‘Stay Tuned!’ , an easy-to-use messaging radio for people with dementia, that allowed them to stay up to date with the lives of their loved ones. In this study, we used a mixed method approach including a group session, probes and an in-context evaluation. With this study, we contribute on how to involve cognitively impaired participants in co-design processes.

keywords: co-design; probes; in-context; participatory design.

Introduction
Dementia remains one of the greatest global societal challenges facing our generation. The number of people living with dementia worldwide today is estimated at 47 million. By 2050 this number is projected to increase to more than 131 million. Most of our current healthcare systems are unresponsive to the needs of people with dementia and their families (Prince, Comas-Herrera, Knapp, Guerchet & Karagiannidou, 2016) and therefore we have to find alternative ways, such as design, to support people living with dementia. Dementia is a syndrome caused by a number of progressive illnesses. On a cognitive level persons with dementia (from mild to moderate) mostly suffer from a deterioration of
memory, difficulties in language and communication, the inability to perform purposeful movements and/or orientation in time and place (Hendriks, Truyen & Duval, 2013). The most common types of dementia are Alzheimer’s disease, vascular dementia, dementia with lewy bodies and frontotemporal dementia (Wortmann, 2015). Characteristics of Alzheimer's disease are impaired memory, apathy and depression (Wortmann, 2015). Vascular dementia is similar to Alzheimer's disease, but the memory is less affected, while the mood fluctuations are more prominent (Wortmann, 2015). In dementia with lewy bodies there is a fluctuation in cognitive ability and parkinsonism (Wortmann, 2015). Frontotemporal dementia includes personality and mood changes, disinhibition and language difficulties (Wortmann, 2015).

The progression of the dementia syndrome can be described by the Clinical Dementia Rating or CDR (Morris, 1993). This rating consists of five stages, namely: 0 - no signs of dementia, 0.5 - very mild signs, 1 - mild dementia, 2 - moderate dementia and 3 - severe dementia.

Dementia is most often seen in older adults, and currently there is no cure available. Therefore, new solutions are needed to keep people living with dementia at home to remain the quality of life they had.

Kujala (2003) found the following benefits of participant involvement within ICT systems design: higher quality of system requirements, higher system quality, a better fit between the system and participant's needs and improved satisfaction of participants. However, there are three reasons to be careful in relying on participant involvement in co-design processes: 1) participants may not be aware of their needs; 2) they may not be able to articulate their needs; and 3) they may not be willing to speak about their needs with a researcher (Kleef, Trijp & Luning, 2005). Therefore, it is important to trigger these needs of the participants. Thus, for co-design efforts to be effective (to deliver the intended benefits) it is important to select appropriate methods and ways of working, and to apply them appropriately (Steen, Manschot & De Koning, 2011).

In the area of technology design for people with dementia there is an evident need for more participant involvement (Topo, 2009). There are several examples in which people living with dementia are involved in design-driven processes (Lindsay et al., 2012; Wallace et al., 2013). However, these examples focus on the inquiry method rather than the design results themselves. Understanding the daily context of people with dementia in the development of new technologies is essential to cater to their, often complex, needs. As such there will be a better fit between the participants' needs and the resulting design (Kujala, 2003). However, the traditional participatory design methods are not fully appropriate for people with dementia, since these methods make inherent assumptions about for example people's cognitive abilities (Lindsay et al., 2012). On top of that, the opinion of people with dementia is often replaced by proxies, such as a partner. Although proxies do, in fact, often have a good understanding of the person with an impairment, they also project their own norms and values in the co-design process (Hendriks, Slegers & Duysburgh, 2015).

Therefore, it is important to voice the individual traits and personal perspectives of the people with dementia by themselves in the design process, rather than being a unified category (Kontos & Maurits, 2013). This is in line with emerging trends in person-centered care for people with dementia (Clarke, Hanson & Ross, 2015), which focus on a personal
approach towards caring to ensure a higher quality of life. Therefore, we want to find out about people's individual needs and translate these to a final design.

Literature suggests that participants should be involved equally to the designer in a co-design process (Hendriks et al., 2015). However, to frame the design scope and move the design process forward a designer is needed to take the lead and synthesise the results. Therefore, we apply this in a combined manner, where participants act as equals in the individual sessions but not over the entire process. By doing so, and not just acting as a facilitator (Sanders & Stappers, 2008), we prevent ourselves from losing valuable insights the designer might contribute in this creative process (Mitchell, Ross, May, Sims & Parker, 2016).

To conclude, our research question for this paper is as follows: How can we involve people with dementia in co-design as part of the design process? With this we aim to contribute to the body of work on how to involve difficult target groups, and making their voice heard, using co-design methods in different stages of the design process. Additionally, in the case presented, a new design is explored as a potential intervention to enhance social communication and engagement between people with dementia and their surrounding social network.

**Method**

We used a mixed method approach through collaboration with people with dementia and their surrounding social network. During these iterations, the users and their social context were involved in different ways to push the design forward and develop it further by every step.

**Design process**

The iterative co-design process applied in this study is inspired by the “Human-Centered Design process” (HCD), which pertains to people being the focal point of the design and the design process (Brown & Katz, 2011). The HCD process begins by examining the needs, dreams and behaviours of the people we want to affect with our solutions. And then builds further on these to come up with a design proposal to address them. The process consists of three iterative phases (Figure 1):

1. Collecting stories by conducting field research (Hear)
2. Translating stories into frameworks, opportunities, solutions and prototypes, while regularly shifting between concrete and abstract (Create)
3. Testing the design in real-life context (Deliver)
Different phases including the participants
In this section, we will elaborate upon the three different phases in the iterative design process. Participants in this process were selected by professional caregivers of a mental health care institute (GGzE). This institute checked whether they were capable to start participating in this study and regularly checked whether they maintained in good condition by attending our meetings. From all the participants, two participants should be highlighted because they were involved in the whole process. We will name these participant A and B.

Participant A was a 72 years old male with Alzheimer’s and was in stage 2 of dementia (CDR scale). The partner of participant A supported him during his conversation with for example specific dates or locations when he was telling a story.

Participant B was a 77 years old male with lewy body disease, but only showed mild cognitive signs of dementia. His intention to join this project was to become aware of the innovative products which are created, in case he needs those in the future. Also, he believed it is important to contribute to help others. In contrast with participant A his partner did not contribute to this project, because he did not want to burden her. As these two scenarios show, dealing with the impairments of dementia can be handled differently.

Phase I: Collecting Stories with Field Research (Hear)
The aim of this phase is to involve and connect with people with dementia, focusing on their personal situation and experiences rather than starting from a general perception on dementia derived from the literature (Kontos & Martin, 2013). For this we aim to gather stories from couples living with dementia. These stories allow for insight in the participant’s background to inform and inspire the design (Kankainen, Vaajakallio, Kantola & Mattelmki, 2012). In the literature, it is stated that participants should be seen as
experts. However, they must be given the appropriate tools for expressing themselves (Sanders and Stappers 2008) such as for example design probes.

During these meetings probes were used as a tool to start a dialogue rather than a one-way interview. Probes originated as a method to non-invasively gather in situ insights about personal experiences of participants to open up the design space (Gaver, Boucher, Pennington & Walker, 2004).

The first phase consisted of two parts, namely 1) a co-design session with 15 participants at GGzE to gain an understanding of living with dementia and reflect upon a concept and 2) a design probe session at home to learn about individual needs and preferences.

First, during the co-design session about half of the participants where people with dementia, and the other were caregivers or close family members of people with dementia, to make them feel comfortable and trigger storytelling (Figure 1, phase 1: Co-design at GGzE). The focus of the design space was selected before this meeting, and was social inclusion for people with dementia. The cases of dementia varied between 0.5 and 2.0 on the CDR scale.

Second, during the personal session at home, two people with dementia who still lived independently at home with a caregiver, participated in the study. For this session at home we developed three different design probes inspired by Wallace and colleagues (Wallace et al., 2013) (Figure 2 and 3): ‘the family necklace’ (A) to understand the relationships in the participant’s social network, ‘the present’ (B) to learn who they value most by asking “who would you like to thank?” and ‘the sound jar’ (C) to gain insight in their daily activities both in the past and present by asking “Which song or sound would you like to put in a jar and when opening it, hear it?”.

Figure 2, 3  The design probes ‘the family necklace’ (A), ‘the present’ (B) and ‘the sound jar’ (C).

Phase II: Translating Stories into Opportunities (Create)
The aim of the second phase was to translate the stories gathered in phase I, in values and key design decisions to inform the design process. Based on the gathered insights an aesthetic model was created (see results, Figure 4). This model was discussed with the participants at home to formulate a perspective in context (Koskinen, Zimmerman, Binder, Redstrom & Wensveen, 2013). In this session, we reflected on a correct translation of the insights from phase I with the participants and allowed them to contribute to the design as well.

Phase III: Testing the design in real-life context (Deliver)
The insights from phase II were translated into a final design. Following this, we used this third phase to evaluate and reflect upon the final design in their real-life context. In the development of assistive technology for people with dementia there is a shortage of evaluations in context of new technological concepts (Bharucha et al., 2009). By evaluating
a design in context, we improve the ecological validity of the research outcome (Koskinen, Zimmerman, Binder, Redstrom & Wensveen, 2013). Therefore, we have developed a working prototype of our final design and evaluated this for 10 days at the homes of participant A and B.

The number of participants increased to 12 in total, since their surrounding social network was asked to contribute to the design intervention. For participant A, the family members that were involved in the test were mostly children (one daughter (47)) and grand-children (two boys (19, 23) and two girls (22, 24). For participant B, the friends that were involved in the test where mostly people from a similar age as the person with dementia (two male sports friends (65, 75), male neighbour (62) and a female friend (54)).

In order to further improve co-design practices in service design, there is a need for methods or tools to monitor and evaluate whether the intended benefits are actually realized (Steen, Manschot & De Koning, 2011). Thus, for this evaluation in-context we used three input methods.

First, to gather personal reflections, we asked the participant for daily written input through some questions about the concept. In this way, we could learn about their opinion about the prototype and how it integrated in their daily lives. Second, we logged how often the design was used by automatically sending this data to the email of the designer. And third, we send a questionnaire to the social network of the participants. These results were analysed in a qualitative way and used to formulate a conclusion on the design proposal.

Result and analysis
We gathered results based on the design process consisting of three phases.

Phase I: Collecting Stories with Field Research (Hear)
In the design process, it was decided to start with a concrete direction to address the need of social inclusion and communication (Moyle et al., 2014). To address this, we chose the design of a classic radio because this is a familiar object for elderly. Additionally, people with dementia are still able to understand the interaction paradigm and can use it. Finally, the function of a radio is reminiscent of social interaction and sound. This radio was used as a tool for brainstorming together during the co-design session and the probe session at home. Because we already had a direction the participants may have experienced the brainstorming easier, since they could imagine this particular idea as a part of their own daily lives, instead of coming up with an idea from scratch.

During the co-design session at the GGZÉ participants shared their opinion about the concept of receiving messages through a radio. The participants stated that it would be very important to them to have a familiar interface, because learning something new is often challenging.

In this session three messages were played to provide the participants with a concrete example to reflect upon and show the variety of the type of messages: 1) someone making an appointment to pick the participant up, 2) someone saying she got his driver license, 3) someone who played a part of the concert she was visiting.

The response of the participants was that making appointments through a radio were not the type of messages they would like to get from a radio: "I would be afraid to miss an
“appointment”. However, sound recordings of for example the sea or a music band, were considered valuable: "I would love to hear my granddaughter who plays piano".

Moreover, participants came up with features they would appreciate in the radio such as: clear notifications of a new message, being able to replay a message and receiving a notification as a sender of a voice recording when the message is being listened to by the person with dementia. Most importantly, the radio should not play the messages automatically, because people may not be aware of where the sound comes from and this could result in people getting anxious.

During the probe session at home we understood more about living with dementia and the methods being used. A confronting example with ‘the family necklace’ (A) was that the person with dementia took the necklace in his hands and started filling in the blank portraits out loud: "Grandson, granddaughter, daughter, son-in-law and people from daycare." After a while his partner suggested she may also be part of the group of important people. The approach and patience of the informal caregiver became clear immediately. Also, this scenario showed that we have to interpret the results from these probes, as the partner was clearly important. Since that moment, we tried to empathize with the people with dementia as much as possible and especially did not fill in the blanks, but let them give the answer.

From these meetings at people’s homes with the probes we could draw three conclusions:

1. Through using probes to get a personal perspective we concluded that the target group for the design proposal was bigger than only the close family members. Other people - like neighbours and friends - play an important role in their social network as well.
2. The probes method was experienced pleasantly by the participants. This was especially the case for the compliment box (B), because it evoked enthusiasm to tell their story.
3. The participants liked the empathic approach of the designer. They did not only have to fill in a questionnaire, but through probes a personal conversation was created in which they felt at ease.

Concerning the design, insights were gathered in the importance of the social network for the people with dementia. This motivated us to continue in this design direction.

Understanding people’s current situation was important to be able to connect with their needs. We analysed this from a positive point of view by their hobbies, dreams and social connections, rather than their disabilities. People are not just the sum of their acquired impairments (Lindsay et al., 2012). Many of the researchers and designers in the workshops indicated that they prefer to choose and adapt co-design techniques based on their participants’ abilities (i.e. their strengths and skills) rather than their disabilities (Hendriks, Slegers & Duysburgh, 2015). Especially the probing study catered for this and generated input that would not have been found via general inquiry methods like for example a questionnaire (Gaver, Boucher, Pennington & Walker, 2004).

**Phase II: Translating Stories into Opportunities (Create)**

In the second phase, we designed an aesthetic model, based on the information gathered in phase I. This model is a non-functional design proposal, to discuss the concept and appearance with the participants (Figure 4). We found for our communication device that it is important that it is a familiar shape and interaction. This is important because seniors
can relate to it and are able to use it (Brankaert, 2016). Thereby we found that the design should be simple to use and involve the entire social network (see phase I).

The final concept we developed is called “Stay Tuned!” This is a radio with an old familiar shape, but with modern technology inside. Loved ones can record audio messages and send these through WhatsApp (an app used on smartphones to send messages to each other), to the “Stay tuned!” radio. Elderly people can play these messages easily by rotating the knob to a picture (Figure 4). The other knob was used to adjust the volume of the message. With this design people with dementia can stay up to date of the activities their loved ones do. This contributes to the feeling of independence and involvement of the person with dementia.

Figure 4 Stay Tuned! is a radio with modern technology integrated in an old familiar shape.

This aesthetic model was discussed in an informal evaluation with two participants at their homes. This discussion was structured to cover the following three aspects: 1) simplicity 2) perspective and 3) usability.

1. Simplicity: keep the product both simple to use, logical and focusing on one function only. For example, “I appreciate it that I can only receive messages from loved ones, and not advertisements or unclear other notifications like on my phone. This is also the reason why I would choose not to integrate the functionality of a normal radio, but only messages.” (Participant A, person with dementia). Moreover, participants suggested to add other functionalities to the design as well such as an alarm or music. However, this would make the interaction more complex, and the designer had to take charge of this part.

2. Perspective of participants: “It could motivate people to relax since they hear a familiar voice.” (Participant B, person with dementia) and “The radio does not look stereotypical, instead it looks just normal.” (Participant A, partner)

For our participants, the aesthetics of the radio fit well in their houses. We frequently asked the participants to have critical feedback on the concept and aesthetics of the radio. However, they strongly suggested to make no changes on its appearance at all. They felt comfortable with the shape, colour and materials
of the radio (Figure 4). On top of that, they did not feel like it was a stereotypical product for a disabled person. Instead, they explained several loved ones in their social network recently bought a retro product like for example a radio.

3. Usability: “I would like to see whether the radio is turned on.” (Participant B, person with dementia) and “I would not appreciate a new interaction, just stick to the old radio.” (Participant A, person with dementia). Furthermore, as the current design is rather too symmetrical, implying the two rotating buttons which are identical. It is suggested for the next design to make them obviously different to represent their function.

Phase III: Testing the Design in Real-life Context (Deliver)
In this phase, we translated the refinements and participant’s feedback to improve the “Stay Tuned!” message radio, and got to our final design. To evaluate this design, we put a fully functional prototype in the home context of our participants for 10 days, which communicated via WhatsApp to a Raspberry Pi.

When a message was received on the radio, a blinking light at the specific picture of the person who send the message, shows who send a voice recording. When the elderly person listened to the message, a confirmation was automatically sent to the sender of the message. We performed this evaluation in the home context rather than in a lab setting (Figure 5) to see how the concept would be integrated in their daily lives.

Figure 5  The fully functional prototype in the home context of the participant

Personal reflections
From the daily written input of the participants can be concluded that the feeling in general was positive about “Stay Tuned!”, for example “We listened together. I did this to see his reaction. It gave me a warm feeling.” (Participant A, partner) and “Our granddaughter loves it if she is allowed by her mom to tell grandpa something through the radio.” (Participant A, partner) and “I would prefer push buttons instead of a rotating knob, to select which message to play.” (Participant B, person with dementia). It was interesting to see the different outcomes of the two participants again, since participant A focused on the social value, while participant B focused mostly on the functions of the prototype.

We found that both participants said they listened to the messages together with their partner which means it not only contributed to family communication, but also proposes a meaningful activity for the couple. This differs from their previous situation, because in both cases the partner was the translator of the messages of family and friends, towards
the person with dementia. With our design, people with dementia hear the first story directly, rather than communicated by someone else. It gave him a feeling of being in control and an increase of contact moments with the family was measured.

The logged data
The logged data showed that early in the in-context evaluation both participants kept the radio on nearly the whole day, while later on this amount decreased to occasionally turning it on through the day. In addition, testing the design in real-life context resulted in finding out unexpected scenarios, like a broken internet connection in the house of participant B.

Questionnaire to the surrounding social network
The goal of this in-context evaluation was to explore the effect and use in general of the “Stay Tuned!” concept. Because it concerns an innovation for one’s social network, we asked this network to become a part of the evaluation as well.

The family members of participant A send about 3 messages a day (accumulated) to the radio and the couple listened about 5 times every day. The friends of participant B send about 1 message a day (accumulated) to the radio and he listened about 3 times every day.

As we found in the personal reflections, the intention of participating differed in the two cases. On the one hand the surrounding social network of participant A stated they liked to do it and that they were aware that their parents would really appreciate receiving a message from them: “I just wanted to let them know I was thinking about them or to let my daughter sing a song.” On the other hand, the surrounding social network of participant B stated they participated because they were asked to participate in this research: “I promised to do so in this test phase”.

Furthermore, one granddaughter, one daughter (Participant A) and a friend (Participant B) explained they found it annoying to receive a confirmation every time the participant listened to a message. They would suggest to only send this confirmation once, because they do think it is important and comforting to know the message is received.

At last, a participant could also imagine this radio to work in an elderly home: "When I see how much my grandfather enjoys the radio, it is just amazing to see this. I talked to a friend who works in an elderly home and we both agreed that it would be very useful in an elderly home as well. Just because there are people who do not have family close by. It could even be recorded by the nurses. In this case people with dementia think they are in the centre of the attention, they are being included." (Participant A, granddaughter)

Discussion
Our research question for this paper was as follows: How can we involve people with dementia in co-design as part of the design process? With this we aim to contribute to the body of work on how to involve difficult target groups, and making their voice heard, using co-design methods in different stages of the design process.

This paper presents four activities where people with dementia and their surrounding social network were involved in a design process (Figure 6). These were the following: 1) a group session to trigger storytelling, 2) design probes at home to learn about individual needs, 3) the first prototype - focused on aesthetics - to discuss at home and 4) the second prototype, to experience at home.
Thereby, we want to elaborate upon the role of the designer in these activities and the progress of the probes over time to understand the user and their context. Additionally, we aimed for these activities to contribute to the overall design challenge.

Figure 6  The four activities of the design process with the involved participants

We believe the difference in co-designing with people with dementia in comparison to other user groups, lies in the role of the stakeholders in each of the activities. When designing with people who do not have an impairment, everyone has an equal opportunity to express themselves in such co-design sessions. However, traditional Human-Centered Design activities often ask users to describe previous usage scenarios or imagine future ones, which is a challenging activity for people with dementia (Dawe, 2007). Therefore, facilitating them to voice their opinion was more challenging and one of the main contributions of this article. We found that tools such as reminiscence, a personal approach and a trusty relationship, were important as a motivation to let these people express their opinion and perspective.

The four different probes used in the design process enabled for different kinds of input by the participants. For instance, in the first activity (Figure 6), the group session, the main contributor was the informal caregiver, while the designer was the facilitator. In the second and third activity, the main speaker was the person with dementia, while the designer took the lead in what topics to reflect upon to steer the design process further. In the fourth activity, the involvement of the informal caregivers (IC) and the person with dementia (PwD) within the technology probe, the radio, was equal. However, the designer did not have an active role during the use of the radio, but only in the reflection session with the participants after they used the radio for 10 days.

Reflecting on the steps taken in this order, starting the co-design process in a group setting made people feel comfortable sharing daily experiences with each other. This introductory meeting is a nice moment to get to know each other, before the home visits starts. A strong participant-researcher relationship is important when working with people with dementia (Suijkerbuijk, Brankaert, de Kort, Snaphaan & den Ouden, 2015). However, we could in future processes limit the first group meeting to an introduction, rather than a brainstorm. In this way, the individual needs can be better expressed in a personal setting at home by the people with dementia. After the individual sessions, it may be relevant to organize another group session to consolidate the input so far, to make sure everyone’s voice is being heard and people are on the same page.
Balancing the participant’s input
As a designer, you have to balance between collecting input from the participant and keeping a holistic view on how their input contributes to the overall goal of designing a product. An example of this study is that multiple participants separately have interesting ideas, but if you would merge these ideas into one design, it would not be a simple or fitting design anymore. To give an example, one family member wanted the functionality of recording a message. However, this would make the interaction more complex and confusing, because it is different from its original meaning. The radio could work as a trigger to make a phone call, rather than having the functionality itself. Also, as was mentioned by Steen et al. (2011) it is important that the people involved in co-design identify the desired goals of the project and align these. For example, informal caregivers found it valuable to add a medicine alarm in the radio, while people with dementia did not want to include care functionalities, but only positive features related to family and friends. This is a good example of how stories of participants are reflected in the design, or are deliberately chosen to be left out. Therefore, the designer selects, based on existing knowledge of the literature, needs and values of the participants to be included in the design.

How to get to know the participant
Concerning the probe evaluations at home, we found that probes were open enough to answer directly by the participants. In addition, it shifted the focus towards existing important relationships and values of the people with dementia. As these probes were very open-ended questions, we tried to connect with their most important memories and dreams. It is suggested to invest time and attention to people’s personal situation and believes, to be able to create a match between them and the design proposal (Kujala, 2003).

The aim was to make the process of getting to know each other comfortable and inviting. Though one of the participants asked what his background information implied for the design process, which might illustrate a participant’s feeling of being outside their comfort-zone. Yet, after explaining the importance of understanding them and their context on a personal level for design it became clearer. Therefore, it is important to be transparent about the design and research goals when working with fragile users and check continuously if these are still simple and understandable. Furthermore, it is important to share unfinished sketches and shapes in the beginning of the design process with the participants. As these are still unfinished people dare to give their opinion about the sketches and shapes. Later in the process, as the design becomes more detailed, people can imagine it as a real product in their own house if the prototype is close to a real product. We recommend in future research to keep this format of openness in the beginning of the design process and work closer to reality in the later stages when evaluating a concept.

We found in co-design processes with individuals with dementia, that it is important to not only involve the participant as subjects of study, but truly listen to their stories, needs and opinion, as also suggested by Hendriks and colleagues (2015). In addition, their perspective allows for valuable feedback on how you translate their input into a design proposal (being acknowledged and valued as stakeholders in the process). Therefore, we
can confirm that it is important to keep them motivated to participate in the entire process, as mentioned by Lindsay et al. (2012).

**The evaluation tool**
In care the clinical and medical needs are often prioritised over personal and social needs. Even though we know the positive effect of social activity and personal well-being on the mental health of older adults (Renehan et al., 2012). Often, researchers focus too much on the illness, rather than the person. Therefore, we propose to involve participants frequently by a face-to-face meeting, as well as their surrounding social network. However, compared to the meetings with the people with dementia, the amount and detail of information gathered through questionnaires from the surrounding social network was limited in our study. Therefore, we propose for more explorative and qualitative involvement of them as well, which might result in even stronger design results in the future.

**Further development of the probes**
The designer did not have a very active role in the evaluation of the technology study at home, in this activity the informal caregivers were taking the researcher’s role to gather and stimulate response from people with dementia. Therefore, we believe it is essential to create probes which express characteristics of openness and incompleteness, which allow the participants to contribute to the design (Brankaert & den Ouden, 2017). In this way, we try to stimulate a feeling of security that there is no specific answer expected on the design, but telling any story which is important to them is relevant for us to gain insights in their values to further develop the design.

In this study, we explored a number of probes and applied them as part of a design process. However, to develop this approach into a method it is recommended to increase the number of participants and the focus on analysing the probes as a method. In this way, a variety of probes used in our study can be investigated further concerning the amount and quality of the output.

**Limitations**
Over the course of the design process some limitations were found. This co-design process started involving elderly people from the moment there was a clear scope defined, namely social inclusion addressed by an audio concept. Starting with a concrete example was experienced as efficient and also supported the participants in reflecting on something concrete. However, defining the scope together with the participants could also have been meaningful, by for example targeting a hidden need generated in the first group session. The challenge would be to find the right tools for people with dementia to design from scratch, but probes could definitely be one of these tools.

Additionally, another limitation of this design can be found in the look and feel of the radio. We selected a radio design inspired by the 50’s, however, this should adapt to the current generation of elderly continuously. Therefore, we would recommend making the product modular, with for example changing covers.

Collaborating with a low number of users, enabled us to dive deeper into the details of their background. However, having such a low number of participants does not reflect the population well. So, it would be interesting to investigate the difference between a personal design and a more general design when designing for people with dementia. In
our case the personal approach was important and it would be difficult and time-consuming to extend this design process to a bigger target group. However, by developing concepts that are platform-based or adaptive both needs can be served. These topics therefore remain to be addressed in further research.

References


*Neurology, 43*(11), 2412-2414.

Moyle, W., Jones, C., Cooke, M., O'Dwyer, S., Sung, B., & Drummond, S. (2014). Connecting the 
person with dementia and family: a feasibility study of a telepresence robot. *BMC Geriatrics, 14*, 
7.


Renehan, E., Dow, B., Lin, X., Blackberry, I., Haapala, I., Gaffy, E., Cyarto, E. (NARI); and Brasher, K., 

4*(1), 5-18.


Seeing the first-person perspective in dementia: a qualitative personal evaluation game to 
evaluate assistive technology for people affected by dementia in the home context. *Interacting 
With Computers, 27*(1), 47-59.


Topo, P. (2009). *Technology studies to meet the needs of people with dementia and their caregivers 

inquiry into personhood in dementia. *Proceedings of the SIGCHI Conference on Human Factors in 


Dementia, 11*(7), P837.
About the Authors:

**Marjolein Wintermans MSc.**, currently a PhD candidate in design for ageing, focuses on co-designing with senior citizens to design personal solutions which fit individual needs.

**Dr. Rens Brankaert**, Assistant professor in active & healthy ageing, has a special interest in chronic diseases such as dementia. He focuses on embedding the design skill and perspective in the Living Lab approach to support health innovation.

**Dr. Yuan Lu**, Associate professor in designing for healthy and active ageing, is interested in exploring the use of probes to create motivational strategies for behaviour change and support design decisions with multi-stakeholders.