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WHEN CARE IS MOVING IN – PARTICIPATORY APPROACHES TO ELICIT NEEDS AND DESIRES WHEN HEALTHCARE HAS BECOME A NATURAL PART OF YOUR DAILY LIFE

Giana Carli Lorenzini and Johanna Persson

Designing for sustainable care of older people

If we were to describe a person by 2050, she would have gray hair, wrinkles, arthritic hands, diabetes, and high blood pressure. By then, she would be one of the more than 1.5 billion people aged 65 or older (United Nations, 2019). However, she would not be in a hospital bed. Instead, she would most likely be taking many medications at home to keep her health stable and perform her daily activities. At a certain point, she would probably need to get help from assistive technology but sometimes also from a nurse or a home care aide.

This illustrative example reminds us that we are here to live longer supported by extensive developments in healthcare that allow many treatments for chronic conditions to be taken at home. The shift from hospital settings to home settings brings independence in the process of care, but it also puts additional responsibility in the hands of patients and their informal caregivers (Genet et al., 2011). Society must be prepared to support a healthy and active life of older people, while simultaneously being able to meet changed disease patterns including comorbidity, polypharmacy and increased needs for long-term home care (Nordic Council of Ministers, 2014). In this context, participatory approaches are of relevance to understand how users interact with healthcare artifacts at home, and how users can be involved in decisions that impact directly on their processes of care.

This chapter builds on experiences from two empirical cases, where qualitative participatory data collection and validation methods were used regarding the design of home care products used by older people. Based on the cases, we present learnings, methodological challenges, and recommendations when involving users in participatory research in home care.

Participatory approaches in design research

Participatory Design has its origins in Scandinavia, in response to “the transformation of workplaces driven by the introduction of computers” in the early 1970s (Ehn et al., 1987; Simonsen & Robertson, 2013). The core idea was that those impacted by a certain technology should actively participate in their design. Participatory Design challenges an expert-led perspective, where designers “instinctively design for their own capabilities and skills” (Keates & Clarkson, 2003), and users are often excluded from the design process or excluded from the use of the design solutions – to genuine participation, where users collaborate as partners in co-creating (Sanders & Stappers, 2008). Participatory Design also stems from the civil rights movements in the 1960s (Arnstein, 1969; Sanoff, 2000), the aim being to empower citizens guided by democratic practices where power relations are equalized, giving voice to those who are affected by the design solutions and by working with users in real context (Kensing & Greenbaum, 2013).

Participatory Design in design research comprises some participatory approaches in which a toolbox of methods can be implemented to activate and engage users (Ehn, 1993). The design researcher takes the role of facilitator, leading users in their expressions of creativity and self-expression (Sanders & Stappers, 2008), as well as advancing theory and methods for participatory approaches to design. This role differs from the traditional role of “translator” when a design researcher merely translates insights from users to professional designers.

Levels and modes of user participation

Overall, different levels of participation take place at different stages of the design process and imply using distinct methods. Scholars seem to agree that user participation at earlier stages of the design process creates opportunities for genuine participation when users are then invited to actively elaborate on their experiences and co-create having designers as facilitators (design *by users*). As users are involved in later phases, their participation tends to take a consultative role, where solutions previously created by designers are then presented and commented upon, and design is made *with users*. Finally, participation can be limited to designing *for users*, when users act as informants, i.e., a source of data to designers, with limited say on how products are designed (Damodaran, 1996; Kaulio, 1998).

The different levels of participation also imply a selection of different forms through which users actively or passively participate (Vines et al., 2013). In that sense, users can simultaneously become the producers and consumers of content through different media – e.g., through digital platforms where they can upload videos and photos, or just comment on content posted by others. This can also be done in an analog way, through co-creation workshops, bodystorming, or prototype testing, for example. Using multiple forms of participation can potentially enrich the participatory process, at the same time it lets users take a reflective role.

Participatory approaches in home care research

Participatory approaches have been called for from many fronts in home care but are rather recent, with scarce empirical studies. Research conducted with users and their interaction with healthcare products often have users displaced from home, with testing of products in

laboratory settings that either simplify or exclude the complexity of the home environment. Home care is a collaborative care context with patients, caregivers, and family members often working closely together (Christensen & Grönvall, 2011). Home care requires much equipment and material, which tends to make parts of the home hospital-like. It is a challenge to create good working conditions and high safety for all parties, without losing the character of the home. Therefore, it is important that participatory approaches used in the home care setting include this highly collaborative perspective, capturing the characteristics of the home care setting.

Differently than for other commercial products where users are invited to participate and co-create when a marketing opportunity is foreseen, for home care products participatory approaches are ultimately meant to empower users (e.g., family members, healthcare personnel) in their processes of care. When participatory approaches move into the home, there are further challenges due to the diversity of people's home environments as compared to the hospital or nursing home. Additionally, it has been shown that the motivation for older adults to participate might be to break routines, differentiate themselves from other seniors, or hope contributing to improve care (Frennert & Östlund, 2016). This is in line with Grönvall and Kyng (2013), who point to the divergent interests of participatory design of home-based (technology-assisted) treatment among older people.

Case 1: Participation in design research about medications and their packaging

In the processes of self-care at home, patients and carers often face a daily use of multiple medications, which come packed in different types of containers. Medication packaging is known to be designed with emphasis on its protective function but with a lack of consideration of user needs (de la Fuente & Bix, 2011). Surprisingly, research in this field has focused on investigations of interaction that exists between people (especially older people) and packaging in situations where participants are displaced from their home environment (Lorenzini & Hellström, 2017) and where study participants have a minimal role in reflecting about their experiences with their treatment and how medication packaging takes part on it.

Considering that, the case described here was designed to actively involve older people in the data collection and validation about their day-to-day experiences of using multiple medications and medication packaging. The case presented reflects about the participatory approach of completing a solicited diary with photo elicitation through the perspective of the diarists (i.e., older people).

Solicited diaries and photography to elicit participation at home

Solicited diaries are, in nature, different from personal diaries: they are meant to fill a purpose and they bring strong awareness about the presence of another reader (e.g., the researcher) (Elliott, 1997). Through a note-taking process, participants report in writing their experiences with life events, products, and daily routines with the intention of allowing the researcher to read and take part in the interpretation of it. Solicited diaries follow the pace of the diarists, giving them time to reflect about feelings and experiences lived in an environment where the researcher is not present to make inferences. Solicited diaries

have been used for decades in healthcare research as a useful methodological approach to uncover otherwise trivial or difficult to capture experiences (Milligan et al., 2005), especially in relation to “symptom identification and management, use of health services, and responses to medical and nursing interventions” (Burman, 1995, p. 151). Solicited diaries allow a participatory approach to home care.

A classical approach is to intercalate the solicited diary with interviews in what is known as the *diary interview method* (Zimmerman & Wieder, 1977). The interviews become a meeting place where power relationships become balanced, having the solicited diary as a common ground for discussion. As highlighted by Rosner et al. (1992, p. 263), interviews with older people about their health conditions are often seen “as a social visit, an unhurried opportunity to talk about themselves to an interested listener”, taking on “the feeling of conversation”. Lately, researchers have started to increment the use of a solicited diary, adding other resources for data collection through participants, such as photography. Taking photos elicits significant moments for the diarists, creating an opportunity for them to build on their narrative of daily events, and inviting the researcher to become acquainted with the life of the diarist (Kantrowitz-Gordon & Vandermause, 2016).

Method

Data was collected with older people through the diary interview method. Invitations were made in community facilities for social gathering and through a patient education center. People who were 65 years of age or older at the time of the study, using three or more different medications daily, and interested in reporting their routines and experiences with their medication packaging were invited to participate. Participants could also indicate other people to be contacted.

Fifteen people (ten females, five males), mean age 76.2 years (range=65-88 years) enrolled in the study as participants, i.e. diarists. Two-thirds of them had to take up to seven different medications daily, whereas one-third had up to 15 medications for everyday use. For most of them, medication had been part of their lives for many years, with 12 participants reporting the use of at least one medicine for a chronic condition for over a decade (e.g., high blood pressure, diabetes). Other medications were added to their treatment over the years (Lorenzini et al., 2022).

First, one interview was carried out with each diarist by one researcher, either at the home of the participant or at the university facilities. This initial interview was an opportunity for the researcher to know about the context of living of each diarist, their history of using medications, and the daily routines for taking them. At the end of this interview, the diarist received: one instant photo camera to take pictures of the medication and their routines; one step-by-step manual with instructions about how to operate the instant photo camera; a glue stick; a copy of the signed consent form; and a diary. The diarist could ask questions and try to use the instant camera before starting to complete the diary on their own.

For seven consecutive days, each participant filled out the diary. The diary had one cover page and seven double-sided A4 sheets. In each sheet, there was a space to paste the photo of the day, followed by a description (*I took this picture because...; when I see this picture I feel...; this picture reminds me of...*). There were general questions about general well-being and self-care routines (e.g., *What did I do today to take care of my health; How was my experience today with my medication packaging?*).



Figure 14.1 On the left: storage of medications at home. On the center: variety of medication packaging used. On the right: routines for the intake of medication.

Within three weeks of diary completion, a follow-up interview was booked. In this interview, the same researcher sat down individually with each diarist to reflect about the entries made in the diary, but also to talk about the overall process of completing the diary, the intentions and reasonings with each photo taken, and the notes associated with it. The participant could explain the photo and the general memories of that day. All the interviews were audio recorded and transcribed verbatim.

Reflecting about the use of medications and their packaging design

Diarists, in general, wrote the diary and took the pictures without problems (Figure 14.1). The solicited diaries were filled with idiosyncrasies of the daily living of entirely different people, who shared the situation of being old and in need of managing multiple medications for chronic conditions (Lorenzini et al., 2022). Many diaries had a very objective approach to the task, with photos of medication and packaging followed by descriptive notes. For those, short sentences or a single word seemed to be enough to respond to the prompted questions. Nevertheless, other diarists preferred to write very detailed answers and tidily hand-written notes. They were committed to the task of completing the diary and making the most in their contribution to the research process.

More than just describing the routines built around their medication management, diarists reflected about inherent facts related to the use of multiple medications, for instance, when taking photos and commenting about the waste generated by the plastics used in the packages, how taking the medication impacted in their lives, and how they perceived home care (Lorenzini et al., 2022). Common aspects of the narratives in the diaries allowed the researcher to identify the frustration with medication packaging, e.g., packaging that was difficult to open or packaging that made the removal of the medication complicated or time-consuming (Figure 14.2).

A few diarists had a creative approach to the process of completing the diary, deviating from the main task by taking photos of other ordinary facts of their lives and commenting about this in the follow-up interview. One example was a diarist that pasted a photo of her training shoes. She explained she did not manage to exercise because of the side effects of her medication. Later in the week, she added another picture, this time of a bicycle, commenting she was finally able to ride her bike again. In the follow-up interview, she explained that it was important for her to be able to exercise after having



Figure 14.2 On the left: a package difficult to open. On the center: multiple blister packages, indicating the time spent to remove the medication from their packaging. On the right: tools used to open the medication packaging.

a stroke, and to feel active in her daily life. Similarly, another diarist added photos that were not related to medication but to her life in general – flowers at her home, which were given to her in celebration of her birthday, the image of a bus referring to a trip with friends, a picture of students to symbolize her work at the university. For her, these were pleasant moments that seemed more important to register amid the use of many medications.

Revisiting the process of writing a solicited diary

The process of revisiting the diaries together with participants was an enriching process, where diarists could describe orally about their choices of what to depict or comment on the diary, adding information to it. Together, diarists and researchers could spend time talking about the overall experience of completing a solicited diary and contributing actively to research about self-care and the management of multiple medications and their packaging. Differently than in other data collection processes, the blank diary pages with question prompts and the camera gave autonomy to the diarists to depict their own narratives in the diary. Despite that, it was clear from their comments in the final interview that there was an invisible presence of the researcher, which led those diarists to ask, for instance, *What do they want with this answer?; What is important here?*

By answering the question *How do you feel today?*, diarists were instigated to reflect about their feelings in regard to their health, but also about stressful experiences in their healthcare that, otherwise, would not be acknowledged. In this process, some diarists put themselves in a perspective in relation to other patients, showing empathy with other older people living with chronic conditions, who also needed to manage several medications a day.

When asked about the process of writing the diary, it became evident that filling a diary with the same prompt questions became monotonous as time passed by, with an evident loss of interest as life mostly went along as usual. By the end of the week, it was not uncommon to see diarists were out of ideas about what to write, as one diarist mentioned:

It went well for three days, then I thought ‘aff, should I do that again?’, It was because I’d grown tired of the repetition. Doing the same thing every day. The diary asks how I am and so on, and if nothing dramatic happens, you [the researcher] just get ‘no, okay, well’ [...]

[extracted from Lorenzini and Olsson (2021)]

Regarding this, another diarist commented that completing the diary was *nice and easy* as he just *had ideas and suggestions for seven days*, probably indicating he had planned his diary ahead according to the timeframe the researchers gave him. Likewise, another diarist said: *It was only a week, so really nothing at all. If it had been three months, one could complain about it.*

Case 2: Participatory design of equipment for home care – a home for one and a workplace for the other

The aim of the study presented in this case was to develop solutions which combine ergonomics and aesthetic aspects to improve home care both for the resident and the care personnel. This case looks at the participatory methods performed throughout the three phases of the design process: (1) exploring the home environment, (2) generating product prototypes that support home care, and (3) developing and evaluating these prototypes. Emphasis is put on the methods that have served to make the process participatory both for residents and care workers.

Safe care and a home-like feeling

A home environment represents personal values and lifestyle and contributes to a sense of security. The atmosphere associated with one’s home is important to an older person (Gillsjo et al., 2011). Research on how the introduction of home care and the design of artifacts for this purpose affect the older person’s sense of being at home is sparse. A few studies investigate design for achieving a home-like feeling in nursing homes (de Veer & Kerkstra, 2001; Vihma, 2013), pointing to the importance of finding a good balance between the common spaces and the resident’s private space, to help the residents to feel as at home as possible despite being in a nursing home. For care personnel, the home becomes their workspace and many studies point to a number of work-related risks in the home care setting (Carneiro et al., 2017; Hignett et al., 2016). The needs of the two user groups in home care patients and residents on one hand, and home care personnel on the other hand – may hence be contradictory. Ergonomic equipment and adjustments of the home is necessary to deliver safe care and support a sustainable work environment. On the other hand, all equipment needed for home care may transform parts of the home into a hospital and cause stigma for the resident.

Method

The study was divided into three phases, each one involving activities together with the different user groups: (1) exploring the home environment with a focus on the home care situation, (2) innovating and designing product prototypes to support home care, (3) developing

and evaluating the prototypes. Phase 1 explored the home environment in homes where a resident received home care and potential improvement areas were identified. This phase consisted of interviews and observations. Eight contextual interviews were conducted with home care patients in their homes. Five interviews were also held with care personnel (three nurses, one doctor, and one biomedical engineer). Finally, 11 observation sessions with home care personnel were carried out. The observations were full-day sessions, where one person from the home care team was followed throughout their workday. The observations were carried out in the form of shadowing (Czarniawska, 2014), which means that the researcher, as a “shadow”, observes in the background, without disturbing or influencing the person being observed.

In Phase 2, students from product development, product engineering, and design education were engaged to generate new product ideas for the home care setting. The ideas should be functional but also focus on preserving the home-like feeling. In the students’ own design process, they had to involve users, for instance, through design workshops with older people. In the third and final phase, the most promising ideas from Phase 2 were further developed into functioning physical prototypes. To check the validity of the proposed products, they were evaluated through interviews, workshops, an exhibition, and actual usage in the home.

Perspectives of home care from two user groups

Phase 1 served as an entrance into the private sphere of people living with home care, allowing them to display their living space and how their care situation was entangled in their home and social life, and what they liked and disliked about the situation. Following home care personnel around provided an opportunity to see an even bigger variation of homes, how care was organized in these different settings, how relatives acted, but – most importantly – that the home is first and foremost a home, and not customized for the care situation. The observed home environments looked very different depending on how large the living space was, how the home was furnished, and how much care material was needed.

A hospital or a nursing home has spaces adapted to the activities that are to be performed, whereas a home can never be adapted in the same way. A threshold between two rooms may suddenly be a hindrance for the patient to move around, a risk for falling, and a work environment problem for home care personnel. The home may be adjusted to some extent for certain equipment. Ramps may be used to overcome the worst threshold problems; lift support at the bedside or sofa and a walker are aids that increase the patient’s ability to move around. There are also a number of other aids of various sizes to support either the patient or the personnel. In several of the homes, spaces were crowded, and boxes with different disposable materials were often stacked in different places. The combination of supporting equipment and disposable material for providing proper care was not optimal since there was seldom space to use the equipment without certain modifications in behavior. Figure 14.3 exemplifies what the environments with home care looked like.

Being able to access the home environment together with different user groups, i.e., both with patients, other family members, and care personnel, was necessary to understand the different perspectives, and sometimes contradicting needs, that are unique for this specific context. It was furthermore valuable to meet the various user groups one at a time (or at least separate the care personnel from the patient and family) to be able to speak about



Figure 14.3 An example of how the home environment might look like when home care has moved in.

the care situation without filters. Care personnel might have a good relationship with the patient but still, be able to point out issues in the patient's home that they know would be sensitive to mention in front of the patient. Likewise, the patient might have many ideas about how their care situation could be supported in ways that are beyond the scope of what the care personnel can do. For the patient, it was also about power structures since speaking their mind towards the municipality, which they are dependent on for receiving good care, might feel awkward. Having someone neutral facilitating the process was hence advantageous.

Participatory design of product ideas

The product ideas that were generated in Phase 2 – a total of approximately 150 ideas in different stages of development – were generated with various levels of participation. On the lowest level of participation, knowledge about the users generated in the first phase served as a source of data for the designers to create product ideas. From a participatory perspective, this can only be considered to be an informative level (Damodaran, 1996) since design is only informed by data about the users, while the users were not actually co-creating the product ideas.



Figure 14.4 Design workshop with older users.

The majority of the student design processes reached a consultative level of participation, where user groups were consulted throughout different steps of the process (Damodaran, 1996). This was, for example, achieved by showing sketches or prototypes to users and discussing them together. One example of an activity that reached even further on the participatory design scale and approached the co-creating level where users take on the role of designers (Damodaran, 1996), was a workshop in which older persons were invited to interact with sketches or physical mock-ups of the product ideas (Figure 14.4), in order to develop the ideas further.

A few product ideas were built as physical prototypes that were close in functionality to a final product. These were: a storage furniture that can modulate to different needs, a tray table, a stool, a leg support, and a wearable light. These product ideas were evaluated at the end of the project and two of the methods – testing in the home and holding an exhibition – will be described and discussed here.

The storage furniture was built in two copies and placed in the homes of two different patients and used for a few weeks (Figure 14.5). After this time the residents were interviewed and personnel that had worked in these homes gave feedback on the product. Both user groups were hence able to be active in the evaluation of this product. As pointed out by Damodaran (1996), in these later phases of the design process, user participation is more on a consultative level since the design cannot be changed as easily but merely



Figure 14.5 The prototype of the storage furniture tested in the home environment.

commented upon. On the other hand, the residents were able to actively elaborate on the product and provide ideas that would feed directly into the next iteration of the product.

Testing in the actual home environment is a desirable method but it must be done with the highest consideration. No hazards to the care situation, or to the people in the home, can risk to be introduced. The storage furniture was considered useful for all patients and all home environments and was not considered to induce any additional risks. It basically just collects all material in one place and offers a clean and ergonomic work surface.

To get a practitioner perspective, an exhibition with prototypes was created. All home care personnel could visit the exhibition and see, feel, test, and provide feedback on the product ideas. Although the personnel were not asked to think from a patient perspective, it often happened that they did just that, or at least from the perspective of working in a person's home. This group of people is used to create solutions for their work situation departing from the needs and desires of the patient and the patient's home. So, it is quite natural for them to include this perspective in their way of thinking, and, in this way, the personnel served as proxies to the patients and the homes.

Learnings, methodological challenges, and recommendations for participatory approaches of home care products in older people's lives

Both cases brought a series of fruitful learnings that presented us with advantages of involving older people and healthcare personnel in participatory approaches of design research that can, ultimately, lead to the design of better home care products.

In Case 1, participation was activated in the data collection process, where participants became diarists, narrating their experiences with multiple medications and their packaging embedded in their self-care routines. Many diarists were interested in advocating for a change in medication packaging design. They wanted to share their knowledge about living with chronic conditions, as well as they shared empathy with other older people dealing with similar issues. The knowledge generated and the active participation of diarists gave rise to the unmet needs, often not evident by other traditional research approaches in this field.

We learned that it is important participants find purposefulness in their participation in design research to keep the engagement throughout the process, especially when the researcher is not there. In Case 1, this was done through communication and open dialogue from the early start. Simply giving the diary with instructions to participants would probably not be enough, which stresses the importance of using a combined method to increase the participation level. Through the interviews, researcher and diarists became familiar with one another; while through the diary completion, diarists were given time to frame their thoughts, take photographs, and write about them. This process gave ownership to diarists of the data collection process, which differed consistently from what would have happened if the researcher had taken all the photos. Through their photos, diarists showed different angles of living with multiple medications to take, and the role packaging played in their experiences with chronic diseases and treatment. More than this, by reflecting about the photos and notes, diarists allowed the researcher to enter their reality, seen through their eyes. It is known, for instance, that medication packaging can be difficult to open by shaky hands that have lost strength. However, it is less known that an older woman needs to buy several household tools to open different sorts of containers or that managing medication routines makes sense when built into other daily life routines.

In Case 2, participation was created in the exploration of the home environment where home care was performed, followed by the generation and evaluation of ideas for new product design. The contextual interviews with elderly care recipients gave a rich and descriptive view of the situation with home care and – in combination with the observations performed together with home care personnel – the home care situation was observed and understood in its actual context. Since the home is a private sphere, and the patients might be in a vulnerable state, it is not always possible to access the home or involve older patients in design and research. Relatives, home care personnel, or other persons with vast knowledge about the home care setting might then serve as proxies in the design process. In Case 2, we were able to access the home environment together with the different user groups, older people/residents as well as care personnel, which was crucial for understanding the various and sometimes contradicting needs. However, doing observations with home care personnel did highlight the perspective of this user group rather than the patients, which one must keep in mind.

The participatory approaches in Case 2 involved a lot of sketches, models, and other visualizations of the product ideas. Working with such design material is useful to direct the discussion toward the artifacts and the environment rather than the people in it, which was noticeable both when testing prototypes in the home and with personnel in the exhibition.

Table 14.1 Summary of key learnings, methodological challenges, and recommendations

<i>Summary of key learnings</i>	<i>Methodological challenges identified</i>	<i>Recommendations to tackle methodological challenges</i>
Participants actively involved in the data collection and validation process became responsible for their own narrative through multiple sources (e.g., personal notes, photography) and could present the data from their perspective.	<ul style="list-style-type: none"> - Extensive, in-depth qualitative data that are complex to analyze. - Loss of focus on the main task and deviation can compromise data collection. 	<ul style="list-style-type: none"> - Concise coding scheme. - Consultation with participants during different phases of the data collection process. - Consultation with research peers throughout the coding process. - Clear instructions. - Explain how their participation contributes to the research. - Pre-formatted tools and prompt questions to avoid deviation.
Older people are capable of using technical gadgets to collect data and can learn from participatory approaches to design research.	<ul style="list-style-type: none"> - Technical disturbances can compromise data collection. - Technical limitations can annoy participants and demotivate them. 	<ul style="list-style-type: none"> - Conduct a pilot study. - Use intuitive gadgets. - Provide demonstrations and instructions. - Establish contact while data collection is ongoing.
Participants may represent different user groups and highlight different challenges or needs.	<ul style="list-style-type: none"> - User groups with possibly contradicting needs participate. - Home care personnel may represent both their own perspective, the care recipient's perspective, or a relative's perspective when expressing challenges or needs. 	<ul style="list-style-type: none"> - Analyze the results through the lens of the user group's perspective and be extra attentive to who's needs the personnel express. - Let participants from one user group have an opinion on ideas emanating from other user groups.
The home is a private sphere and doing participatory design research there, with potentially vulnerable people, is not always possible.	<ul style="list-style-type: none"> - Those who can participate only represent a subset of those receiving home care. 	<ul style="list-style-type: none"> - Home care personnel or relatives may serve as proxies for the real users. - Make sure that the proxy person is asked to answer on behalf of their own perspective as well as the patient's or the home's perspective.
Evaluating design prototypes in the home environment increases the chances of active participation and relevant feedback.	<ul style="list-style-type: none"> - The prototypes that are being evaluated must not impose any risks in the care process. - If high-fidelity prototypes are used, it must be clear to all users that they are prototypes and not completed products. 	<ul style="list-style-type: none"> - Only prototypes that do not impose any risks may be tested, ethical considerations must be taken and information about what is being tested and the state of the prototype must be clearly communicated.

Adapted from Lorenzini and Olsson (2021).

The design material, whether being simple cardboard mock-ups or high-fidelity prototypes, enables the stakeholders to make their own experiences and knowledge more explicit, which encourages the participants to take a more active role in the design process (Ehn, 1993).

In parallel with the learnings from the two cases, methodological challenges arose. In Table 14.1, we present a series of methodological challenges found along the way and make recommendations to respond to those challenges. These recommendations might be useful to other academics and practitioners using participatory approaches to design research with older people and home care personnel.

Finally, it is important to acknowledge that, even though it is recommended to let users also participate in the definition of the research process, for instance, by defining methods, tools, and techniques used (Vines et al., 2013), both of our projects did not reach that far. Our efforts were focused on later stages, where users were given voice to express themselves. Their participation happened at a consultative level (Damodaran, 1996).

Doing participatory research in the home care setting is challenging mainly due to the privacy of the home and the vulnerability of the person receiving home care. The effects of home care on the home environment are an insufficiently studied field of research that will need more attention due to the increasing amount of older people living with complex care needs in the home. It is furthermore a challenging environment for providing care, which means that both the residents, including care recipients and their relatives, and care personnel should be made active participants in the continuous development of home care. We are strong advocates of participatory approaches that allow older people to reflect upon their own capabilities and needs in their daily care situation to design healthcare products that fit with real user needs and that promote good health and well-being.

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