

Next Steps for User Integration in ICT for Aging Well

Alina Huldtgren¹^a, Holger Klapperich¹^b and Cordula Endter²

¹CoDe4Health, Media Department, University of Applied Sciences Düsseldorf, Germany

²Faculty of Social Sciences, University of Applied Sciences Zittau/Görlitz, Germany

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Abstract: In the last decade user-centered and participatory design have become central approaches for the design of technology in the context of ageing well. They promise a better fit of system requirements to user needs and, eventually, a higher user acceptance of the end-product. In Germany funding programs explicitly ask for the integration of users and user studies in real life contexts. They also started to fund accompanying research on how technical projects implement user-centered methods. Given our own experience and research on user-centered design from both an inside perspective as designers and developers as well as an outside perspective as ethnographic researchers, we examine the current practice of user integration critically in this paper and provide a list of crucial aspects including reflexivity, reciprocity, and empowerment that should be the focus of the research on user-centered approaches for ICT design in healthcare in the coming years.

1 INTRODUCTION

10 years ago the first author started doing research in Information and Communication Technologies (ICT) for ageing. Coming from a Scandinavian user-centered design (UCD) background, coupled with a strong personal motivation for creating a better, more independent life for older adults through technology, she was highly motivated to start on her first European Ambient Assisted Living (AAL) project using UCD. Later, she met the last author of this paper trained in ethnography, who was interested in how UCD unfolded in AAL projects. Now, 10 years later it is time for a shared reflection and roadmap to further research in this field.

10 years ago, we still observed a strong technology push in the field of AAL and ICT for ageing. It was postulated that technological advances in the areas of ICT, robotics, sensors, AR, and VR offered high potential to solve challenges related to the ageing population, support people in living longer at their own homes and mitigate the lack of caregivers. A plethora of systems was developed, but few were accepted by potential users. User-centered approaches were around but not yet commonly employed. This changed in the last decade. A stronger

positive attitude towards the early integration of users in the design and development process arose and by now funding programs often dictate the use of user-centered, or participatory design (PD). Participation of people from the target audience of the envisioned system should increase the fit between system requirements and user needs to ensure that the outcome is useful and usable by these people. Subsequently, user acceptance should be increased. Participation of so-called users is currently happening in diverse ways in ongoing research projects. They are labelled UCD (Norman & Draper, 1986), co-design or co-creation (Sanders & Stappers, 2008), some following the original Scandinavian approach to PD (Schuler & Namioka, 1993). Many approaches are described in the literature as user-centred or participatory. However, the definition of these terms and the accompanying research activities are diverse with various degrees of participation ranging from selective moments of involvement, e.g. through interviews during the requirements analyses, to co-creative involvement throughout the projects, e.g. through regular focus groups or user workshops, iterative ideation sessions and prototype testing.

While it has been proven (see e.g. Bertelsmann Stiftung, 2018) that a continuous user participation can be beneficial to the acceptance of eHealth

^a <https://orcid.org/0000-0002-0542-8626>

^b <https://orcid.org/0000-0002-0321-6187>

applications, a systematic analysis of the levels of participation, their effects on the people involved and their value towards the project outcomes is missing. Compagna and Kohlbacher (2015) emphasize that user integration functions mainly as a guarantee for receiving project funding. In how far people are successfully integrated is rarely evaluated or discussed. Neither is there much discussion on what successful integration means, how it could be measured and for whom it is beneficial. However, as we argue, it is especially important for the area of health and wellbeing to analyze and reflect on the forms and methods of user participation and their added value, since the results have direct impact on the health and life quality of the involved stakeholders. While the scope of this paper is neither a systematic analysis of methods nor success criteria of user integration, we rather provide experiences from our own research and pose several themes and accompanying research questions that are meaningful to consider in future research in the field of UCD of ICT for ageing well.

2 METHODS OF USER INTEGRATION

There is a range of methodologies and methods to integrate people into technology development processes. While we present UCD, PD and Co-Design separately in the following, it must be pointed out that research practice moves along a continuum of participation reaching from a focus on user needs being elicited to fully shared control of design decisions being made. To understand the viewpoints of the approaches and the tensions and overlaps between them, a historic view of their origin would be necessary, which is, however, outside the scope of this paper. In projects, we often see combinations of methods from these approaches and sometimes projects label their approach with a specific approach even though its original values are not embedded.

2.1 UCD

UCD is probably the most widely used umbrella term when it comes to IT development that involves people from the target audience, denoted as ‘users’, at certain points in the design process (e.g. requirements analysis or prototype testing). The term goes back to Don Norman’s (1986) work in the 1980s – who worked at the intersection of psychology and computer science to develop design principles for

user interface design that adapts to the user’s cognitive and physical abilities. Throughout the last decade funding programs on assistive technologies for seniors have set on UCD as the main approach to enable user participation in the design and development of ICT (Fischer et al. 2020; Merkel and Kucharski 2019; Ogonowski et al. 2018). One of the main objectives for using UCD in this context was to overcome the lack of market success of early AAL systems, which derived merely from a technology push, and did not serve the needs of the envisioned users (Fachinger 2018; Greenhalgh et al. 2016).

2.2 Participatory Design

Participatory Design (PD) is another approach that is cited more often in the context of integrating seniors into the design of AAL and eHealth systems. The approach has its origin in the Scandinavian tradition of Cooperative Design that aimed at empowering later users and other stakeholders of ICT through giving them more control and possibilities to influence the design process (Kaptelinin und Bannon, 2012). PD dates back to the 1970s when the digitalization of the workplace started. There was a strong demand by labor unions of a broad, societal participation of workers and emancipatory citizen engagement. Bringing together workers and managers in what was originally called cooperative design to envision a digitalized workplace together was unique. PD followed humanistic and democratic values. Nowadays, PD is mainly seen as an approach to involve future users in the design process of technology (Bødker et al., 1988; Greenbaum und Kyng, 1991; Muller und Kuhn, 1993; Schuler und Namioka, 1993).

Mackay et al. (2000) point out that the current practice of user participation in gerontechnology has little in common with the humanistic, democratic and utopian ideal of PD. Rather, users are considered as a “good thing” (2000, 738) because their participation would lead to an improvement of the technical artefact (Endter, 2021).

2.3 Co-design & Co-creation

Co-creation involves diverse stakeholders in a creative process leading to shared innovation. Co-Design is a specific implementation of co-creation focused on designing technology. As described by Sanders and Stappers (2008) the difference to UCD in its traditional form, is that PD or co-design do not see the user only as a source of information, but as an active designer. Co-Design can be seen as newer

implementations of PD without the focus on democratic and humanistic values, but with a stronger focus on creative activities mediated by a range of hands-on methods for designing prototypes. Ideally, participants identify with the envisioned tool, evaluate developments continuously, influence design, decide on functionality or even develop parts of the system themselves (Lieberman et al., 2006).

3 EXPERIENCES AND CHALLENGES

As argued by critical gerontologists, UCD fails to involve older people adequately (Lassen et al. 2015; Merkel and Kucharski 2019; Peine and Neven 2019). Main critique points include that participation is used to legitimize technological development or to foster market success through matching user requirements and systems (Endter 2016; Neven 2010; Peine et al. 2014). In addition, socially deprived or educationally disadvantaged older people are often left out of participatory processes (Biniok et al. 2016), (Künemund and Tanschus 2013; Compagna 2012).

When funding programs dictate the integration of users, developers are faced with involving people that they often know little of. Nevertheless, they must choose the right methods to let them participate while making sure that the project is not jeopardized. From our own experience, we know that balancing project objectives and the integration of people into the process is not easy. Next, we will describe insightful experiences from selected research projects as well as overarching challenges before we discuss our proposed theoretical themes for future research.

3.1 Care@Home Project

Care@Home (Fitriani et al., 2013) was an EU AAL-funded project that focused on the development of a smart TV platform for seniors allowing them to access services of daily living (from a doctor's call to grocery shopping to live stream church service). The project based on assumptions that older adults 1) are or may become less mobile and 2) are used to operating TV sets. Thus, the envisioned TV service platform seemed like an ideal technical solution to allow seniors to age in their own homes. We engaged in a UCD process. We involved seniors for the first time when we had paper versions of the UI ready and, later, when hi-fidelity prototypes required usability testing. The first author of this paper led the tests in both phases. Reflecting the first sessions, which were

carried out at the homes of the older people, who were recruited through a partnering senior organization, we realized that the test group was biased in terms of technology affinity and competence. Several of them had taken part in previous studies and had acquired technologies like smartphones, tablets, and even smart TVs. They were generally positive towards technology. In addition, since the sessions were at people's own homes – a conscious choice to mitigate barriers – we experienced that some test participants were acting as hosts, being explicitly polite. In our perception this, however, stopped people from giving the critical feedback that would have been helpful at the early project phase. Although we explicitly asked for critique, the configuration of host-guest situation hindered them. In addition, we had a young student with us who had hand-drawn the interfaces – also a conscious choice to avoid making it look like we had programmed the UIs already. During an interview an older participant asked whether the student had drawn them herself, and then exclaimed how impressed she was that the student drew so well. A nice compliment, but when asked about feedback to different designs she simply liked them all and called them “beautiful”. While we could be happy as technology developers that people like the UI design, another situation during the prototype testing showed the pitfalls of involving people to “confirm” the usability of the design. This time the running system was set up in a community center to avoid the host-guest situation but to still allow for a familiar environment. A usability test was set-up with several tasks test participants had to execute by themselves, using the prototype and concurrent think-aloud. This time we made sure to recruit a mixed group of older adults with various level of technology knowledge. We were happy to see that even the 70+ woman in the wheelchair – a seemingly perfect match to our target group – could navigate the UI. Such a result would be communicated in a paper as a success of the system design, had it not been for the post-test interview when we asked whether she would use the system. She told us that she did not need such a system and suggested that her 90+ mother could. She agreed that she was immobile but doing everything through the TV was clearly not what she intended to do. While not being representative, this nevertheless shows that even highly usable systems could be designed far from the lived world of the target audience.

3.2 Nutzerwelten Project

Nutzerwelten (English: User Worlds) was a project at University of Applied Sciences Düsseldorf that

followed a participatory approach by engaging stakeholders, i.e. care givers, people with dementia, social workers, relatives, before having a clear idea of what to develop (Huldtgren et al., 2017). The set goal at the project start was to support people with dementia to communicate with caregivers and relatives mediated by digital media. We took our time to get familiar with the target audience, their lived world and communication patterns. In the project we developed several technology probes based on our gained insights, early field visits and conversations with stakeholders. One such probe was a tangible world map (Huldtgren, 2015) that was interactive and showed the places where a person with dementia had lived, as well as an audio line with recorded stories from the person about the place. While we understood the map as a means for a person with dementia to keep memories while the disease progresses, but also to give caregivers conversation triggers, in an interview with the person the following situation unfolded.

“What are you going to do with the map? Will it be in an exhibition?” Mrs. Smith asks. My colleague is surprised and says that our intention was to improve the map and maybe give it to her, but Mrs. Smith likes her idea of making the map and her stories publicly available. “It could be interesting to other people to hear my stories,” she says. Later in the conversation Mrs. Smith suggests that we could also give the map to her GP, who seems to be dear to her, after she passed away. “Then he can remember my stories.” she says – her eyes filling with tears.”

Clearly, the map had a very different purpose for her than what we understood. This shows that we need the deeper engagement with the participants to fully understand their needs and motivations to participate beyond the goals of our projects.

3.3 MemoPlay Project

MemoPlay was a German state-funded technology development project which ran from 2012 until 2014 to develop an interactive online platform with the goal to enable older people suffering Mild Cognitive Impairment (MCI) to train their cognitive abilities by conducting the memory training. It was intended for individual use at home without the need for assistance from care givers or medical staff. In the UCD people aged 60+ were involved as interview partners or test users during the requirements analysis, the formative and summative evaluation of the prototype.

The last author of this paper conducted ethnographic fieldwork from March to November 2014 in this project. She accompanied project

members in their UCD process, conducted interviews and participated as a participant observer in test sessions with seniors in the laboratory and at their homes. In the following we provide only a short excerpt from a usability test session, for the detailed account, see (Endter, 2020).

“[The researcher conducting the test] repeatedly emphasises how important it is that older people are involved in the development of technology that they will later use, hence why it is so important that the participants are here today and have agreed to participate in the study. She also appeals to their individual ambition and sense of responsibility when she describes the user test. No questions are asked during her presentation, everyone is listening carefully. Some take notes, but most of them follow [the researcher’s] explanations and wait and see how things will unfold. In the further course of the test, they also only react when asked, they keep quiet, they complete the questionnaires without asking questions and they agree to the tests [the researchers] are doing with them, even if some mention later in a subordinate clause that they felt uncomfortable in the test situation they had to undergo during their visit. They want to appear competent and informed and, as if their participation would be put to the test, they want to prove themselves as suitable candidates.” (ibid, p.104)

In an analysis of the observed usability test we found an asymmetrical relationship between the researchers conducting the usability test and the older test participants. The way the researchers conducted the study guaranteed that the participants behaved like test users, developed a high level of compliance with the procedures and ensured that the evaluation was carried out successfully. The hierarchy between testers and participants ensured that the uncertainty introduced by the participation of older people is brought under control, thereby serving the goals of the project rather than accounting for the motivations and feelings of the older participants. This is in contrast with recent approaches to genuine participation, which includes that the participants are involved “as themselves” instead of being forced into a role (Østergaard et al., 2018).

3.4 General Challenges

The provided excerpts only reveal a glimpse of our experiences. However, they point to some interesting insights. Researchers configure people as users in the UCD studies. People are invited into the process that fit the age group, and ideally match the defined user

characteristics. They are involved at certain points in the process, typically as interview partners during requirements analysis, or as test persons to evaluate prototypes of various fidelities. Rarely are they asked beforehand whether they intent to actually become users of the system or about their motivations to take place in the first place. Nevertheless, we still call it ‘user testing’ and talk about ‘users’ in publications. Both the Care@Home and the Nutzerwelten example showed that not all participants considered themselves users. In fact, we often heard that people enjoy “helping science” or “feeling needed” as motivations for becoming participants. This points to a consideration that participation can take other forms than being users, e.g. taking part as design partners or consultants (see 4.1.1).

An accompanying problem is that seniors or people with dementia are often seen as a homogenous group with certain skills, lifestyles or motivations. In projects with people with dementia focus is often symptom-based and little research tries to see the people as full individuals (see Wallace et al., 2013 for a notable exception). This may not always be possible as it may counteract the project goals. To be honest, allowing real needs, feelings and motivations to surface may result in requirements that do not match the original project idea anymore. However, in the way funding is organized, the goals and envisioned system must be started clearly in proposals. There is little room for changing direction during the project. Thus, as we saw in MemoPlay, user testing is mostly configured in a way that people are involved to confirm the system’s usefulness. Hierarchies between researchers and participants ensure the compliance and keep uncertainties under control.

Another important issue lies with recruiting. There is a selection bias towards people who are generally interested and active, higher educated with good income and more technology savvy as we e.g., saw in the Care@Home project. While a more heterogenous group should be involved it is challenging to reach people who do not volunteer. In addition, projects could benefit from an involvement of a broader stakeholder range, not only direct users. Limited resources make this difficult. Nevertheless, a first step would be to make the biases more visible in publications, reflect on the implications of excluding groups (e.g. precarious elderlies, older migrants) and think of ways to motivate people to volunteer.

4 THEMES FOR FUTURE RESEARCH

4.1 Reflective Participation Practice

To address the critiques from gerontologists (Lassen et al. 2015; Merkel and Kucharski 2019) and the challenges identified above, researchers in the field of ICT for ageing well need to engage in a more reflective participation practice. By reflective practice we refer to reflecting on (1) our own role as ‘researcher participants’ configuring the design and development process, (2) the selection of ‘user participants’, (3) their motivations and attitudes towards the system, and (4) the effect of participation on the project outcomes. In the following we will discuss the aspect of configuring users in detail and provide a novel view on participation as matters of care (Puig de la Bellacasa, 2011).

4.1.1 Configuring Users and Participation

As the MemoPlay example showed, researchers conducting user studies in UCD configure older people as users. In a deeper analysis of the design case Endter (2020) describes how the researchers conducting the usability test employ powerful practices to configure the older adults as users in four ways, i.e., spatially, affectively, discursively, and materially. The way the seating is arranged in the room, the materials researchers give people and the ways they present the participants’ involvement (e.g., in this case appealing to the people’s competence and compliance) establishes a hierarchy and the presented case left the participants in a rather passive position, not acting ‘as themselves’ or ‘with themselves’, which are preconditions to genuine participation (see Østergaard, 2018). In the Care@Home case, we saw a different scenario unfolding when we interviewed people in their own homes, an environment we had little control over. As it happened, we suddenly found ourselves in a host-guest relationship, in which participants were maybe too polite to criticize our designs.

15 years ago, Redström (2006) pointed out that there is a predominant interest in fitting people to technologies within the field of HCI – although at that point the discipline had already moved away from the notion of users as mere cognitive information processors and acknowledged their richness in terms of motivations, feelings, and culture. Indeed, employing words like ‘users’, ‘user testing’ implicates that we do focus on how people can become users of the things we present to them.

Vines et al (2013) have taken up Redström's argument as a starting point and discussed several important aspects around how we configure not only users but participation. They consider a reflection on the forms of participation, and initiators and beneficiaries of the participation as well as sharing control as central issues. Besides, they call for reflection on how participation can unfold, e.g., people can and already do participate in ways that are "witting, unwitting, spectator-like, as a reflexive commentator or as creator" (p.433) and argue for more transparency on these engagements, and on who benefits from it. We believe this is especially true in the case of ICT for ageing well, since we often design for vulnerable people, and the benefits of including these should be made clear. In addition, opening up to moving beyond involving people as users only, but also seeing them as commentators, or design partners and letting them transition between roles throughout the project will allow more genuine participation.

Furthermore, as Endter (2020) put it „user participation is less a manifestation of the participation process of older people than of the powerful practices of establishing controllable users. If UCD should lead to an involvement of older users, it must become a matter of care for those responsible for the user involvement.” (p. 109) What this means, is explained in the following section.

4.1.2 Participation as a Matter of Care

As described, older people are integrated into the design of assistive technologies in a process mostly initiated and configured by researchers or developers. The images taken for granted about old age as a time of decline, loss and vulnerability and assistive technologies as generally being helpful for people in such a state, however, is problematic. To reflect and consider alternative configurations of participation, we propose, in accordance with (Endter, 2020), to think of UCD as matters of care. The concept was introduced by Puig de la Bellacasa (2011), who expanded Latour's conception of technology as matters of concern by an affective dimension. "Caring in this sense is understood [...] as a reflexive practice that asks how the project members involved in the constitution of the technical artefact evaluate their actions of user involvement and to what extent they see themselves as responsible for the involvement of older people as users in the design of the technology." (Endter, 2020, p.99) Part of this reflexive practice is also questioning the general notion of user participation as being a good thing. To understand what can be considered as good care, we

turn to Tronto (1993). She conceptualized good care as characterized by attentiveness, responsibility, competence, and reciprocity. These aspects are required and fulfilled by caregivers to recognize the needs of others and to serve them, thereby building a mutual relationship between caregivers and people being cared for. Tronto's criteria can function as a "heuristic for examining the extent to which user-centred design actually empowers users to participate in the design process and fosters a fit between technology and user needs" (Endter, 2020, p. 99).

4.2 Empowering People to Participate

Older people need to be empowered to participate to create a mutual relationship between researcher and participant. As we have seen UCD tends to involve people at specific points in the process (e.g., to gather requirements, user test). However, if we want to reach a point where participants can benefit as well, and control is truly shared between researchers and participants, a move towards a long-term engagement with citizens in the target group and employing more democratic, participatory methods is needed. Early PD (Greenbaum & Kyng, 1991) provided such methods, as the focus was on democratic values and destabilizing power structures in times when workers and unions were faced with the introduction of new technology in the workplace. "[PD] emphasized the importance of providing these workers and union officials the knowledge and skills about the potential of computational systems so that their views would be better articulated when bargaining with management." (Vines et al, 2013, p.430) Thus, the focus of involving people should not be on how to get the information developers require out of them to design the system they have in mind, but to empower people with an understanding of the technologies that enables them to vocalize their concerns and needs as well as actively take decisions in the development of digital systems. We must be aware, that empowerment entails that informed participants and truly shared control may lead to a rejection of the envisioned designs and to large changes or at least uncertainties in the projects. Ideally, funding programs allow researchers to react on this. One way to deal with changing requirements is to employ an action research approach, e.g. the community-based participatory research approach by Kang et al. (2020).

In addition, approaches to participation, such as Co-Design and Co-Creation (Sanders & Stappers, 2008) may focus less on the emancipatory values, but nevertheless they provide many creative tools to engage with people in user workshops. This is one

step to provide people with boundary objects (i.e., objects that bridge between social worlds, in this case between designers and citizens, e.g., a model of a scenario) to understand the design space and communicate. Nevertheless, we argue that there is a need for developing participatory methods that focus more on advanced user interface technologies such as AR, VR, or mixed reality as well as AI-based systems. Especially given the older target audiences, who are commonly less in touch with such advanced user interfaces, need to be given space to experience and grasp the technologies – besides the specific system that is being developed in a particular project.

4.3 Reciprocity

Reciprocity refers to the human activity of mutual exchange. It was mentioned above as one of the four requirements for good care, and it is also a core value in PD (Bødker & Iversen, 2002). We pose that empowerment of citizens to take part is a key requirement for reciprocity. According to Dreessen et al.'s (2020) reciprocity is a mutual exchange that can either lead to a direct gain for the participants or can be characterized by acts with the interest of the other in mind regardless of direct gains. A reciprocal relationship can be open, closed, or dynamic over time. In their analysis of their own community-based participatory projects they describe a lack of felt reciprocity and provide four handles to foster reciprocity, e.g., the designers' competence of being embedded in the community of the participants, or their willingness to become engaged in the community in the long run. As we see, supporting reciprocity requires a deeper understanding of the people we envision as users, which in turn needs long-term engagement with these people in their own settings. Open questions revolve around 'How can ICT researchers manage this involvement and the resulting complexity?' 'How can projects be initiated and closed within these mutual relationships of researchers and citizens?' In addition, the strategies provided by Dreessen et al. focus merely on the researchers. However, 'What are the needs of developers and the responsibilities of participants to enable and foster mutual relationships?' These are the questions we would like to pose for future research regarding reciprocity.

5 CONCLUSIONS

In this paper we have presented our reflection of user-centered design in the AAL/eHealth setting. Starting

from our own experiences to insights from the literature we have critically looked at challenges of including people as future users and given central research themes to be investigated in the future. First, we advocate more reflection and transparency on our own roles and practices on how we configure participation, on how participation can unfold and on who benefits, and second, we call for new methods to give people, in particular older adults, an understanding of new technologies, and third, we provided a theoretical frame for understanding participation as a matter of care, focusing among other aspects on the competence of the participants and reciprocity. We hope others find this work inspirational for their research agendas.

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