Human-centred Design of Self-management Health Systems with and for Older Adults: Challenges and Practical Guidelines

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Abstract: Human-centred design approaches that involve older adults are becoming more and more commonplace in the development of digital systems to support self-management of health and well-being, ultimately contributing to ageing in place. In order to understand and design effective solutions, it is important to involve older adults from the beginning and throughout the iterative development process. However, conducting studies with this target population presents challenges and therefore requires specific adaptations. In this study, we reflect on the different human-centred methods, e.g., focus group discussions, interviews, and user-tests, that were conducted with older adults. In total, 81 participants (aged 65 to 97) were involved in a four-year human-centred design process. On the basis of a thematic analysis, we reflect on the different methodological intricacies encountered and identify four themes: 'a life course marked by grand experiences', 'a discomfort with unknown digital technologies', 'impact of age-related impairments', and 'relatedness as core to research participation'. Finally, insights and practical guidelines are formulated to help future researchers undertake more effective and useful human-centred study designs with older adults.

1 INTRODUCTION

Increasingly, older adults are involved in the design and development of digital systems to manage their health and well-being (Lindsay et al., 2012; Xie et al., 2012; Davidson and Jensen, 2013b; Mehrotra et al., 2016; Volkmann et al., 2016; Sengpiel et al., 2019; Cornet et al., 2020; Czaja et al., 2019). A scoping review[1] of studies with older adults in the ACM Digital Library (Association for Computing Machinery, 2021) revealed 1288 studies, a number that has been increasing exponentially during the last decade. In its slipstream, researchers have directed their attention to the intricacies of involving older adults in the design of interactive technologies, specifically to manage their health (Lindsay et al., 2012; Chaudhry et al., 2016; Sengpiel et al., 2019; Cornet et al., 2020). Most recently, Sengpiel et al. (2019) introduced *HCD+* as 'human-centred design for aging', a specific approach to address how HCD-methods need to be adapted in order to involve older adults as experts of their own age group. Hence, the body of studies on how to adapt an HCD process to older adults is continually growing.

Nevertheless, to date, recommendations and guidelines on including older adults in the design of health systems are still few and fragmented. Most often, research studies focus on the outcomes of HCD methods, e.g., the majority of studies focus first and foremost on the product, i.e., the designed system or service, with the lessons learned on working with older adults as an afterthought to be discussed (Xie et al., 2012; Davidson and Jensen, 2013b; Mehrotra et al., 2016; Volkmann et al., 2016). Notwithstanding the value of such studies, they may be limited in their reflection on the HCD methodology. Moreover, most studies are not specifically geared towards interactive technologies supporting self-management of health, but towards ICT in general.

Self-Management Health Systems (SMHS) have gained increasing interest from researchers; in particular to empower older users and contribute ageing-in-place (Sintonen and Immonen, 2013; Heart and Kalderon, 2013; Peek et al., 2016; Kononova et al., 2019; D'Haeseleer et al., 2019). Yet, SMHS present specific challenges as they may relate to sensitive is-

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sues, and bring a limited biomedical focus on age-related decline (Vines et al., 2015; Nunes et al., 2015).

The aim of this study is to contribute to the growing body of HCD+ in health, by presenting a thematic analysis of methodological observations and reflections on an HCD process of an SMHS, that encompassed all phases (inspiration, ideation, implementation, and evaluation), involving 81 older adults with ages ranging from 65 to 97 (median=83) over a period of four years. In this paper, we present this analysis and provide lessons learned, transformed into practical guidelines, to help future researchers set up more effective and useful study designs for conducting HCD processes with older adults.

2 BACKGROUND AND RELATED WORK

There is an increasing interest in executing HCD processes for and with older adults and health systems in particular. In the paragraphs below, we first discuss the different understandings of human-centered design. Next we present studies on that involved older adults in the design process. We end this section with existing guidelines related to older adults, HCD, and health.

2.1 Involving End-users in the Design Process

Different methodological approaches have been promoted to involve older adults in the design and evaluation of interactive, digital systems, labelled among others as User-Centred Design (UCD), Human-Centred Design (HCD) or Participatory Design (PD). The term UCD was promoted already in Gould and Lewis' (1985) seminal paper on 'Designing for Usability'. In this work, the authors present three pillars for any UCD process: involving users early, using empirical measurement, and conducting an iterative design. In 1999, the ISO standard on HCD was launched, embodying the aforementioned pillars of a UCD process, and further detailing how to involve end-users in the different phases. Moreover, conceptually the ISO-standard also emphasises the *human* rather than the user, thus "putting people before machines" (Cooley, 1996; Brown et al., 2008; ISO, 2019).

In parallel to UCD and HCD processes, also PD grew in importance, originating from the premise that those who ultimately have to use or are affected by the implementation of technology should have a critical role in their design (Muller and Kuhn, 1993). PD is, above all, an ideology that aims for empowerment of end-users, and considers any design process as a dialectic process between the different stakeholders (end-user, designer, project owner, etc.) that serves to unearth conflicting values. Co-design is also frequently used to point to practices where end-users are invited to collaboratively design and prototype (Sanders, 2002). This term is often used interchangeably with PD, although with the term co-design, the emphasis shifts to the actual methods used and less the ideology.

Despite the different origins and delineations, researchers often hold an idiosyncratic interpretation of the methodological approaches, and apply them in a lenient manner. As a consequence, in practice, the boundaries between UCD, HCD, PD, and co-design are fuzzy, yet they are united in the central premise that stakeholders, i.e., here older adults, need to be involved in the design.

2.2 Involving Older Adults in the Design Process

Involving older adults is a recurrent topic in Human-Computer Interaction (HCI), e.g., (Czaja et al., 2019; Lindsay et al., 2012; Xie et al., 2012; Davidson and Jensen, 2013b; Sengpiel et al., 2019; Cornet et al., 2020). Most recently, Sengpiel et al. (2019) introduced HCD+, or 'human-centered design for ageing', a new approach that specifically "considers older adults' requirements and abilities throughout the development process, adapting established HCD-methods to accommodate the participation of older adults as experts for their own age group". The authors applied their HCD+ approach to a project that centred on "Historytelling", including 183 older adults (mean age=66.6, SD=7.5) within different HCD+ activities, i.e., focus group discussions, workshops, interviews, and evaluations. From this, the following guidelines were derived: 'engage with group leaders', 'emphasise reciprocity when recruiting', 'plan for social engagement', 'overestimate the scheduled time', 'accommodate participants' wishes', 'establish (low-technology) fall-backs', and 'use abstract descriptions of technology' (Sengpiel et al., 2019).

Notwithstanding, Sengpiel and colleagues were the first to coin the term HCD+ (Volkmann et al., 2016; Sengpiel et al., 2019), they are not the first to propose frameworks or guidelines on how to include older adults in the design process. Already in 2012, Lindsay et al. (2012) investigated how to engage older adults in PD processes. They identified in particular

four challenges: 'maintaining focus and structure in meetings', 'representing and acting on issues', 'envisioning intangible concepts', and 'designing for non-tasks' (Lindsay et al., 2012). To address these challenges they suggested a new approach (termed OASIS) that highlights the importance of 'stakeholder identification and recruitment', 'the usage of video prompts' to illustrate usage scenarios, followed by 'exploratory meetings' to explore the problem domain, and finally 'low-fidelity prototyping sessions', here to be understood as co-design sessions to generate further requirements.

Two recent systematic literature reviews (Duque et al., 2019; Amaro et al., 2020) further corroborate the growing number of studies on involving older adults in the design process; one on user-centred and participatory design with older adults (Duque et al., 2019), and one on engaging older adults in participatory and intergenerational design teams (Amaro et al., 2020). Their findings echo the same considerations stated above, highlighting the need for a better understanding and proper integration of older adults in UCD and PD in general. Additionally, in their future work, Duque et al. (2019) articulate the need for more research in the domain of health self-medication.

2.3 Human-centred Design of Health Technology

Given the prevalence of studies on older adults and health technology, myriad studies have also applied HCD processes in the domain of self-management of health and well-being by older adults. In this section, we limit ourselves to recent studies of SMHS that provide a detailed account of the process and methodological challenges, followed by recommendations.

The aforementioned OASIS process was also applied in the context of mobile health applications with 18 older adults (Davidson and Jensen, 2013b). Based on their findings, researchers suggested additional considerations. In particular, 'short design sessions', 'allow for socialising among participants', 'encourage active participation' by calling upon specific people, and 'finding a balance between input from researchers and participants' were added during the different workshops.

Chaudhry et al. (2016) conducted a UCD with older adults and caregivers (mean age=66, SD=9.2) to design and evaluate a tablet-application to promote successful ageing called seniorHealth. Focus group discussions, interviews, and pilot studies were conducted. Both methodological and ethical challenges encountered during the design and deployment of the application, e.g., 'difficulties in forming a design', 'high learning curve' for using technology, and the 'need for social support'.

Martin-Hammond et al. (2018) conducted a PD involving 18 older adults (mean age=76, SD=8.25) including seven phases: background survey, app critique, team presentation, current health info management practices, co-design, another team presentation, and a Q&A. Based on their findings, challenges were encountered and strategies were shared: 'enlisting allies in recruitment', 'incorporating a design critique', 'use of common vocabularies', 'accommodating schedules and adapting the protocol', and 'participation in creating tangible artefacts'.

Harrington et al. (2018) used co-design sessions to design fitness apps with 25 older adults (mean age=72.1, SD=4.25). These authors highlight in particular the differences between those familiar with and those new to the technology, resulting in a tension between the need to familiarise a participant with a technology and the importance of not biasing a participant through technology exposure. The authors also found that continued use of the assigned application led to more robust and detailed feedback in design sessions, suggesting that long-term prior use of sample technologies is an important prerequisite to ideating useful features for new health technology.

Finally, a recent study on mobile health applications for older adults with heart failure indicated the importance of tailoring the UCD process to older adults (Cornet et al., 2020). Based on the authors' experiences, 12 practical challenges were enumerated, including, but not limited to, 'managing UCD logistics', 'determining timing and level of stakeholder involvement', 'overcoming designers' assumptions', and 'adapting methods to end-users'. In addition, authors provided suggestions on how to overcome these challenges.

Table 1 summarises the different challenges and recommendations provided by the aforementioned studies. While informative, certain guidelines seem to conflict, e.g., overestimating time (Duh et al., 2016; Sengpiel et al., 2019) versus to keeping sessions short (Davidson and Jensen, 2013a), or providing tangible examples (Lindsay et al., 2012; Martin-Hammond et al., 2018) versus using abstract descriptions of technology (Sengpiel et al., 2019). Moreover, most guidelines were not formulated in the context of SMHS. Finally, not all studies report on the age of the participants that were included, e.g., (Lindsay et al., 2012; Cornet et al., 2020). Others reported findings where mean ages typically varied from 65 to 75 years old (Chaudhry et al., 2016; Harrington et al., 2018; Sengpiel et al., 2019). Therefore, in this research study we set out to perform a rigorous analysis of methodolog-

Table 1: A chronological overview of the studies encountered in the related work section, summarising the research study methodology along with the challenges and guidelines.

Research Study	Participants	Study Design	Challenges & Guidelines
Engaging Older People using Participatory Design (Lindsay et al., 2012)	[not specified]	PD OASIS approach: identification and recruitment of stakeholders, video prompt creation, exploratory meetings, low fidelity prototyping	maintaining focus and structure in meetings (challenge), representing and acting on issues (challenge), envisioning intangible concepts (challenge), designing for non-tasks (challenge), stakeholder identification and recruitment (guideline), the usage of video prompts (guideline), exploratory meetings (guideline), low-fidelity prototyping sessions (guideline)
Participatory Design with Older Adults: An Analysis of Creativity in the Design of Mobile Healthcare Applications (Davidson and Jensen, 2013a)	18 older adults aged 65 to 88 years	OASIS approach: identification and recruitment of stakeholders, video prompt creation, exploratory meetings, low fidelity prototyping	Keep design sessions short: trade-off between design quick and efficiently, and lower novelty score (guideline), allow for informal socialising: informal socialising prior to design sessions (guideline), encourage participation: call on specific people (guideline), balancing researcher and participant input: allow questions but encourage to work together (guideline)
Developing Health Technologies for Older Adults: Methodological and Ethical Considerations (Chaudhry et al., 2016)	40 older adults (M=66, SD=9.2)	UCD with focus group discussions, interviews, and pilot studies	design: limited technology-based suggestions as participants were novices (challenge), learning curve: difficulties on learning using technology (challenge), social support: interpersonal interactions between participants (challenge), knowing the user: busy lives, distracted during training, curious and eager to learn (challenge), sustainability: support network after the study ended (ethical reflection)
Designing Health and Fitness Apps with Older Adults: Examining the Value of Experience-Based Co-Design (Harrington et al., 2018)	25 older adults aged 65 to 80 years (M=72.1, SD=4.25)	co-design in seven sessions and semi-longitudinal deployment	leverage pre-study experience (guideline), facilitate longer-term technology use (guideline), use varied materials and instruments for co-creation engagement (guideline), establish a collaborative and comfortable approach to reviewing brainstormed ideas (guideline), stratify group participants by experience levels (guideline)
Engaging Older Adults in the Participatory Design of Intelligent Health Search Tools (Martin-Hammond et al., 2018)	18 older adults aged 61 to 93 years (M=76, SD=8.25)	PD with background surveys, app critique, team presentation, co-design, and Q&A	enlisting allies in recruitment (guideline), incorporating a design critique (guideline), use of common vocabularies (challenge), accommodating schedules and adapting the protocol (challenge), participation in creating tangible artifacts (challenge)
Considering older adults throughout the development process – The HCD+ approach (Sengpiel et al., 2019)	183 older adults aged 46 to 93 (M=66.6, SD=7.5)	HCD+ with focus group workshops, interviews, evaluations	engage with group leaders (guideline), emphasise reciprocity when recruiting (guideline), plan for social engagement (guideline), overestimate the scheduled time (guideline), accommodate participants' wishes (guideline), establish (low-technology) fall-backs (guideline), use abstract descriptions of technology (guideline)
Untold Stories in User-Centred Design of Mobile Health: Practical Challenges and Strategies Learned From the Design and Evaluation of an App for Older Adults With Heart Failure (Cornet et al., 2020)	older adults aged over 65 (see study design for number of participants), along with clinicians and external UCD experts	UCD including patient interviews (n=24), patient advisory meetings (n=2), clinician advisory board (n=0), individual interviews with 2 cardiologists (n=0), observation of clinical encounters with a patient in the device clinic, usability evaluation (n=4), usability evaluation (n=12), and heuristic evaluation (n=0)	Deciding on number of iterations (challenge), managing UCD logistics (challenge), collaborating as multidisciplinary team (challenge), determining timing and level of stakeholder involvement (challenge), choosing stakeholder representatives (challenge), fostering interactions between stakeholders and designers (challenge), overcoming designers' assumptions (challenge), managing project scope and complexity (challenge), maintaining the innovation equilibrium (challenge), conduction laboratory or in-the-wild usability sessions (challenge), adapting methods to end users (challenge), deciding on the number of concurrent evaluation methods (challenge)

ical observations to yield recommendations for conducting an HCD for SMHS involving older adults, equally including the oldest old (von Humboldt and Leal, 2015).

3 METHOD

In this study, a complete HCD process, i.e., inspiration or analysis of context of use and requirements, ideation of design & prototypes, implementation, and evaluation (Brown et al., 2008), was conducted in an iterative manner over the course of four years, from 2016 to 2020.

3.1 Participants

Participants were healthy older adults, being at least 65 years old, and were still able to live independently at home or in a service flat. In total, 81 participants (30 identified as male, 51 identified as female) with ages ranging from 65 to 97 (median=83), and six moderators and researchers attended at least one of the different HCD activities.

Participants were recruited in Belgium from 2016 to 2020 via local organisations, i.e., InnovAge (InnovAge, 2016), service centres (Zorg Leuven, 2020), and Triamant (Triamant, 2020). In addition, we employed a snowball technique where participants also brought us in contact with family, friends, or neighbours who also wanted to participate.

All studies were approved by either the Medical Ethics Committee (CTC-S60250) or Social and Societal Ethics Committee (G-2019121931).

3.2 Study Design

Figure 1 gives an overview of the different HCD phases and the specific activities that were carried out.

3.2.1 Inspiration

During the inspiration phase, the context of use and requirements were analysed by means of three focus group discussions, semi-structured interviews, and questionnaires.

Focus Group Discussion. Three focus group discussions were organised to discuss the problem domain. Focus group 1 and 2 discussed several topics related to maintaining a healthy lifestyle, ICT use in general, and use of SMHS (activity trackers, health apps, etc). Focus group 3 discussed attitudes towards a high-fidelity prototype in addition to the topics of focus group 1 and 2.

Requirements Specification. Based on these prior focus groups, requirements were enlisted during the analysis specification. Additionally, a persona and a context scenario were created to guide the design. A persona or user model is a "composite user archetype that represent distinct groupings of behaviours, attitudes, aptitudes, goals, and motivations that are observed and identified during the research phase" (Cooper et al., 2007).

Interviews. Upon the evaluation of the final application, semi-structured interviews with participants were organised in order to gain insights into their attitudes and usage of the system. Additionally, a structured interview was carried out to understand older adults attitudes towards motivational designs embedded in SMHS.

3.2.2 Ideation

During the ideation phase, low-fidelity prototypes, high-fidelity prototypes, and an interactive prototype were first designed and discussed with project partners at the university and afterwards with the participants.

Low-Fidelity Prototypes. Low-fidelity prototypes were used to represent concepts and functionalities without risking to lose focus due to distracting visual details. Figure 2 represents a sketch that was made with pencil and paper.

High-Fidelity Prototypes. Next, a high-fidelity prototype was created to represent the look and feel of the application using the digital design toolkit Sketch[2]. An example can be found in figure 3.

Interactive Prototypes. The final prototype was made interactive with Invision prototyping software[3].

3.2.3 Implementation

An online web-application was developed using CodeIgniter web framework[4], a lightweight PHP framework that supports a Model-View-Controller approach. The user interfaces were built with the Bootstrap framework[5] to provide a responsive layout and ensure high-quality interaction through pre-built components and JavaScript plugins. Data was stored in a MySQL database[6]. Figure 4 illustrates the final SMHS application.

[2]Sketch B.V. (2021). The digital design toolkit.
[3]Invision Inc. (2021). Digital product designplatform
[4]EllisLab (2021). CodeIgniter web framework.
[5]MIT. (2021). Bootstrap.
[6]Oracle Corporation. (2021). Mysql.

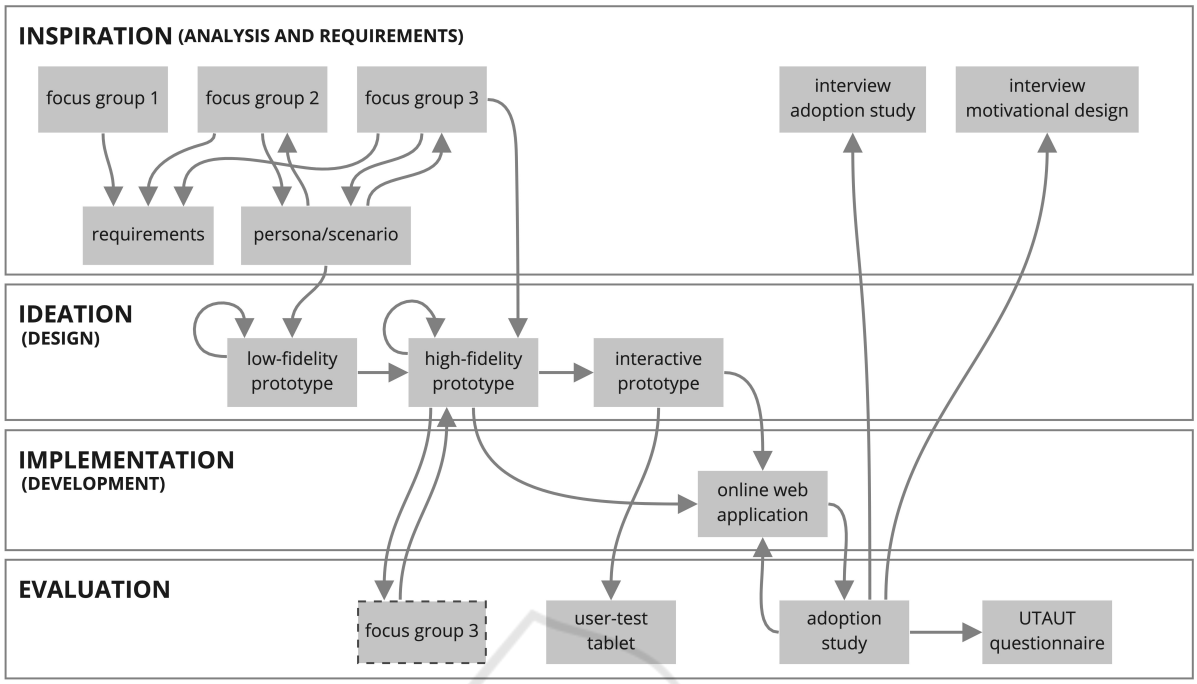

Figure 1: Overview of the different activities that were part of the human-centred design process of self-management health systems with older adults.

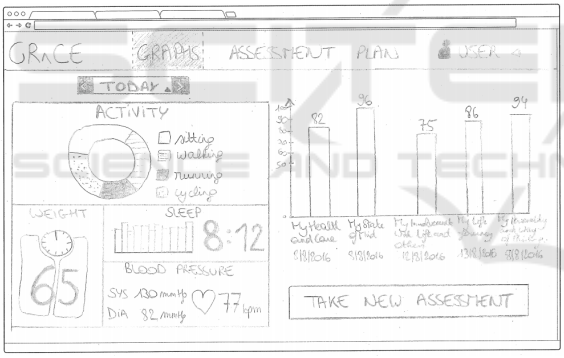

Figure 2: Low-fidelity prototype.

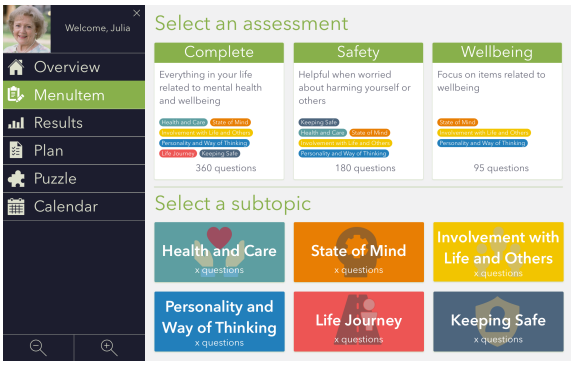

Figure 3: High-fidelity prototype.

3.2.4 Evaluation

The evaluation phase consisted of formative usability testing, summative usability testing, an adoption study, and the Unified Theory of Acceptance and Use of Technologies (UTAUT) questionnaire to poll for acceptance.

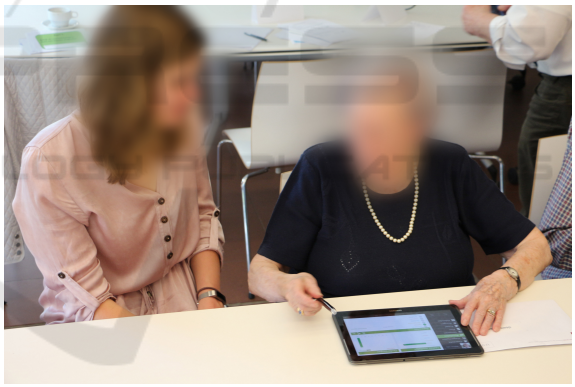

Figure 4: Older adult using the online web-application in tablet mode.

Formative Usability Test. Formative usability tests were carried out using high-fidelity prototypes. Formative usability tests are rapid and more informal user tests; users are given realistic tasks and asked to think aloud while carrying them out. As designers gain insights into the user's mind while interacting with the prototype (Cooper et al., 2007). These tests help to give form to the design.

Adoption Study. Finally, an adoption study was set up. Older adults used the application over the course

of two weeks, in order to investigate the users' actual interactive behaviours through user metrics.

Questionnaires. As the experience of this adoption study shaped their attitudes towards SMHS, a UTAUT questionnaire (De Witte and Van Daele, 2017) was provided to all participants. This UTAUT questionnaire polled for behavioural intention to use the SMHS and in particular investigated perceived ease-of-use, usefulness, social influence, and facilitating conditions.

3.3 Analysis

Noteworthy methodological findings were documented and discussed with the present researchers after every phase. In addition, methodological annotations were made during the analysis of the transcripts which included focus group discussions and interviews. Based on this information related to methodological observations, a thematic analysis (Clarke and Braun, 2014) was conducted. First, all transcripts were studied and nodes were created individually by two researchers (ID and VVA) who went through the entire HCD process. In the second iteration, ID defined patterns and clustered nodes in initial themes which were reviewed by VVA. Afterwards, both ID and VVA discussed findings until an agreement was reached and a thematic map created. Finally, these themes and thematic map were revised by two other researchers (JG and KG), who were also present during at least one phase of the HCD process. This resulted in the final set of themes.

4 RESULTS

Four themes were developed based on the thematic analysis of methodological observations made during the HCD process: 'a life course marked by grand experiences', 'a discomfort with unknown digital technologies', 'impact of age-related impairments', and 'relatedness as core to research participation'.

4.1 A Life Course Marked by Grand Experiences

The first theme addresses the full lives lived by older adults, characterised by joy, but equally misfortune and grief. Shared naturally and unprompted, these life experiences often carried significant emotional weight and permeated all activities of the HCD process. For example, during the introduction round of the focus groups discussion, participants introduced themselves by name and in one breath recounted personal details on dramatic events that occurred during their lifetime.

> *"Eh... What could I say. Yes, I ended up here because my wife got a stroke, four years ago. Four years, well let's say it started in 2009, at Easter [tells story of wife who fell ill, was hospitalized and then moved into a nursing home]. Then they asked me, why do you keep travelling between here and your home to take care of your wife, there is a flat available; and so, since 2013, I reside here."* – man aged 90

Many participants had lost a loved one and shared their sorrow. Others talked about the impact of a chronic or life-threatening disease.

> *"This morning for example, I went to the hospital for a consultation concerning my heart. I have to go every year, and when the results are ready, my GP will give them to me [...]"* – woman aged 81

Naturally, researchers then paused to offer a moment of thought or consolation. As a consequence, sufficient time was needed for welcoming and small talk, e.g., an introductory round during a focus group discussion was estimated to take up 15 minutes, but took up 45 minutes to welcome all nine participants.

In addition, a particular recurring pressing topic was their dire financial situation and related challenges, brought forward by a lack of a proper pension.

> *"They can say 'you have to eat healthy', but what is healthy? Five pieces of fruit a day? You have to buy five pieces of fruit in the store, that is expensive, you know. We will not get there with our pension alone..."* – woman aged 79

> *"These are more serious problems, financial problems for example. Our pension is not sufficient. [conversation on not having sufficient money]"* – woman aged 65

In some participants' opinion, this was a much more pressing problem in their life than the need for an SMHS. This once again impacted the HCD process, as it was difficult for some participants to relate to a technological solution that was perceived as unaffordable.

In sum, their tense personal histories, associated with end of life, were introjected in the different activities of the HCD process and necessitated researchers to adapt by making room for them.

4.2 A Discomfort with Unknown Digital Technologies

The second theme addresses the anxieties and distrust related to the struggle of older adults with current day computing technologies that resurfaced in the discussions and evaluations of SMHS.

The majority of participants in our study had little to no experience with current day ICT technology such as tablets, activity trackers, smartphones, etc. Often, this was voiced as a conscious rejection of these technologies by older adults, propelled by a distrust towards a society that enforces using technology.

> *"I have chosen to spend no, or as little time as possible, on the computer, because otherwise people will become a slave of it."* – woman aged 89

Especially during the focus group discussions, it was noticeable that some participants showed more interest in discussing the health topics addressed by SMHS than the technology itself.

> *"But I thought this session was about other topics too, not just about computers."* – man aged 88
> *"Yes, I thought so too, about nutrition and stuff, what should improve [for a healthy lifestyle]."* – woman aged 65
> *"We have also other problems than [using] computers, huh."* – man aged 88

If they had realised beforehand, they might not have participated.

Similarly, some participants were uncomfortable during the usability evaluations. Some of them had not realised they would be interacting with an online application on a tablet and became somewhat anxious when they heard about having to test an online tool.

> *So I just have to do this [cf. take blood pressure measurements] and then I actually do not have to use [the tablet]?* – woman aged 67

This lack of awareness was initially surprising to researchers as the informed consent did clearly mention the focus on technologies. However, in hindsight, the lack in technological proficiency may equally explain a limited understanding of the different activities that take place as part of an HCD process.

From these observations we understood that underneath many usability issues was the complete lack of a mental model on interactive (tablet-based) applications. The majority of participants did not understand the concepts of touch interactions or logging into a system. For the same reason, formative user evaluations with paper prototypes or screenshots on paper were hard to interpret for some participants. The lack of mental models made it difficult to hypothesise about future usage situations or different kinds of features they would prefer.

Additionally, we encountered a language barrier while testing the application. In Dutch, English terms are common when using digital and networked applications, e.g., account, password, login. However, these mongrel words were not part of participants' vocabulary and therefore not understood.

> *"an account has always been a [bank] account for me. Don't tell me anything else, because I knew an account in banking, but not in here [cf. the application]. And then login..."* – man aged 88

The absolute lack of a mental model also subverted our intention to apply a typical usability testing protocol which recommends starting with a non-obtrusive part, i.e., refraining from guiding users. In contrast, in our HCD process, our participants stressed the importance of receiving help.

> *"I always like them to show me exactly what I have to do."* – woman aged 79

In sum, this theme foregrounds the need to adapt HCD processes to compensate for a lack in experience in using digital technologies to mitigate anxiety and discomfort.

4.3 Impact of Age-related Impairments

This third theme addresses the diverse manifestations of age-related decline, as an interplay of mentally, physically, and emotional effects. During the different research activities of the HCD process, we encountered participants who had a broad range of impairments. These impairments included, but were not limited to, impaired vision, reduced hearing, mobility limitations, and ailments as a consequence of chronic diseases. More often than not, participants had several of these ailments. As a consequence, and perhaps most characteristically, we found our HCD process characterised by a slowness in actions. However, at the same time this was giving way to tranquillity and ample time for reflection.

The age-related impairments necessitated several accommodations. With respect to mobility, it was paramount that studies were organised nearby participants. For one-on-one interviews or user-tests, the researcher went to the participant's home. For focus group discussions or user-tests with multiple participants, a room in a local services centre was reserved. It was ascertained that these rooms were on the ground floor, thus easily accessible for everyone. In addition, for participants who wanted to join a session but had problems reaching the location, transport was provided by one of the researchers who picked up and dropped off participants at home.

In addition, to address visual impairments, we found it essential to provide all documents, i.e., information, informed consents, feedback forms, and increased font size. Furthermore, when testing prototypes, designs were made sufficiently large to make them apprehensible despite visual impairments. As such, screenshots were printed in A3 format by default.

Finally, participants also indicated the importance of talking loud and clear and in isolation. This was particularly demanding in the moderation of focus group discussions. The moderator had to ensure that only one person was talking at the same time, but equally that everyone talked loud enough or repeated arguments when necessary.

Repeating and paraphrasing also helped participants in processing information and mitigated the times that attention fleeted.

> *"What is the actual question, because..."* – man aged 82

This slower processing of information and lesser cognitive load manageable by the participants became particularly prominent when conducting evaluations by means of questionnaires; the shape of the question and the length of the questionnaire presented difficulties. In the scientific validated questionnaires that we used, the same construct was often polled using multiple items. This makes these questionnaires quite long and, in turn, harder for the older participants to sustain attention and complete them in a reliable manner. In addition, negatively formulated questions were found problematic, as we noted that participants often marked the opposite answer of what they intended to answer.

Therefore, it was paramount to orally present questions and verify answers in a structured interview format. It helped when participants could verbally rate their experiences. This also allowed researchers to rectify errors due to negative phrasing.

As a result, there was a need for a slower pace, which also brought a sense of perspective. Participants were often relaxed about these limitations and adopted a mindset that embraced a lifespan perspective on ageing.

> *"Glad we're still alive."* – woman aged 84

Overall, this theme highlights that every activity in the HCD process took more time because of the diverse age-related impairments. This also meant that less 'content' could be dealt with. However, the slower pace also brought along a relaxing atmosphere.

4.4 Relatedness as Core to Research Participation

The final theme addresses the inherent social nature of the HCD process, as a sense of relatedness was a primordial motive for participants to take part in the research. At the same time, this need for relatedness risked obscuring the actual research activities that researchers intended to carry out.

Since it was important to put participants at ease, a familiar and pleasant setting was chosen to conduct all research studies; activities took place at the participant's home or a local service centre familiar to the participants. Moreover, we ensured everyone was welcomed personally and were offered coffee and biscuits to create a setting in which participants would feel comfortable. However, the downside of this informal atmosphere was that the actual research purpose was less clear and perhaps less respected. During focus group discussions, participants often deviated from the subject, and it was not always easy to bring them back to focus on the matter at hand. During interviews, participants seemed unburdened by the researchers' agenda. This unawareness of the situation showed in some participants arriving 25 minutes late and subsequently explaining their entire life story.

At the same time, many participants seemed driven by an altruistic motive to participate in the study .

> *"I am doing this for you, and to support your research study."* – man aged 69

During the different contact moments, it was remarkable that almost all older adults were volunteering or were a volunteer in the past. They all spend quite a lot of their time helping other people. This equally reflected in the research study, as participants often indicated that they wanted to help out on our research.

> *"Pleased I was able to help you; I am glad that it is over, as you are always thinking about it, but I will also miss being able to follow up everything [cf. blood pressure, sleep, activities]."* – woman aged 66

Besides helping out as a volunteer, many older adults equally had other hobbies or activities like babysitting, going for a walk, or petanque. As a consequence, many of them had quite the busy schedule.

> *"For 22 years now, I do not have a job, um, yes, that's it. I'll say it in one sentence: It is wonderful to be retired."* – man aged 82

Remarkably, many older adults endeavoured such a busy schedule to fill their days.

Many activities they tend to do have a social aspect: joining a walking club, going on a group vacation, or being a volunteer. They also emphasised the importance of social interactions. Therefore, we suspect that some older adults participated in these studies primarily to maintain social contact.

> *"contact, social contact is very important. It is for that reason that I am also a volunteer. I'm out of the house for about 70 to 80%, just to forget the grief of my wife who passed away... and that helps a lot. I even play petanque with my grandchildren*

three times a week. Those are all things that take time." – man aged 76

In sum, this last theme indicates that the different research activities were primarily a means for relating to other participants or the researchers for many participants. During the HCD process, there needed to be sufficient room for small talk. As mentioned before, participants found it important to share personal experiences, with conversations often deviating to chitchat. As a consequence, formalities faded and adhering to research protocols was challenging.

5 DISCUSSION

In this study, we investigated the intricacies of involving older adults in the design of SMHS. The different themes confirm the need for adaptation of an HCD process when designing health technologies for the group of older adults including the oldest old.

The first theme identifies that older adults bring a life marked by grand experiences with them that interweave into the diverse HCD experiences. Second, we unearthed a strained relationship with digital technologies, often unknown and unwanted. Third, we found that different age-related impairments manifest in myriad ways, bringing slowness and tranquillity into the HCD activities. Finally, we found that a sense of relatedness was essential to participate in the HCD activities that sometimes complicated the actual research. The four themes highlight the need for tuning the HCD process and brings the specific role of the HCD researcher to the foreground. Below, we discuss this further and relate our findings to prior work.

The Importance of Careful Recruitment and Enlisting of Participants. Given that older adults lack mental models on interactive technologies, it also implied that it is more difficult for them to understand what an HCD study actually entails. According to (Sengpiel et al., 2019; Martin-Hammond et al., 2018; Czaja et al., 2019), it is therefore important to ensure a proper understanding before signing up, which was confirmed in our study. At the same time, this entails the risk of involving only the more tech-savvy participants with a pre-existing interest in health or technology, resulting in a biased sample. Moreover, verbose and lengthy informed consent forms are unlikely to help. It is therefore important to adjust the expectations of both researchers and participants prior to signing up and before each research activity, in order to provide a respectful and useful framework for everyone. The use of video prompts that illustrate the problem space (Lindsay et al., 2012) may support this communication. Pilot testing to identify possible threats or problems can equally help to gain additional insights and optimise the recruitment process (Czaja et al., 2019).

The Challenge of Abstraction in Prototypes. Due to participants often having low mobile device proficiency and lacking a mental model on using technologies, it was found difficult to hypothesise about future innovations. These findings are in line with previous work (Duh et al., 2016; Lindsay et al., 2012),yet contrast with (Sengpiel et al., 2019), who suggested to rather use abstract descriptions of technology.

The Need for Conscientious HCI Researchers. Given the vulnerabilities and personal histories of this older population, there is a need for HCI researchers who are both empathetic and direct. Researchers need sensitivity and integrity, to show respect and give room to dire experiences, yet need to ensure that structured sessions are kept on track and research focus is maintained. Moreover, researchers need to ensure that all participants are involved during the session. When topics fade due to participants trailing off, it is the role of the researcher to redirect them to the study in a clear yet empathetic way.

The importance of making room for small talk and support socialising confirms previous work (Sengpiel et al., 2019; Davidson and Jensen, 2013a; Chaudhry et al., 2016). It is at all costs necessary to avoid that participants get the feeling that they have to pass a (medical or neuropsychological) test; even more than with any other age category, the emphasis should be on 'do not blame the user' (Crumlish and Malone, 2009). The crucial role of the researcher is to balance informal small talk with adequate structure and guidance, which also confirms results from (Xie et al., 2012; Lindsay et al., 2012).

Research from (Davidson and Jensen, 2013a; Sengpiel et al., 2019) therefore indicates that it is important to be flexible and to adapt to the needs of the participants. Moreover, providing a safe environment and additional training could help participants to gain the confidence they need, which confirms the work by (Harrington et al., 2018).

To balance all these conflicting demands, having multiple researchers present in order to provide assistance is not a luxury, but rather mandatory.

5.1 Recommendations

Based on the findings of this study and related work analysed, we end this paper with a set of recommendations to guide a HCD process of SMHS involving older adults, structured according to the different

phases and activities of a HCD process.

5.1.1 General Recommendations

Every research study starts with the recruitment of participants. It is essential to (1) *find a balanced composition of participants with different backgrounds* and (2) *align expectations between participants and researchers*. By (3) *reaching out to local contact points or organisations* a varied sample of participants can be reached, and this can lower their threshold for participation. It is also beneficial to (4) *organise sessions nearby participants*, ideally in their home environment so they do not need to move. However, when organising group sessions, one should (5) *take care of transport* in order to make sure that all interested participants can join.

Given that participants often take part in research studies as a networking event or to help out the researchers, it is important to listen to the participant, (6) *leaving room and time for social interludes*.

5.1.2 Inspiration Phase Recommendations

Interviews and Focus Group Discussions. During conversations, it is important to (7) *talk loud enough*, and (8) *provide a clear structure* in the session. It can help to make things specific and (9) *provide tangible examples*, as it is hard for participants to hypothesise due to their lack of experiences.

Particularly focus group discussions need multiple moderators and researchers, both for providing general and practical assistance. The moderator should make sure to (10) *get everyone on board* and thus (11) *paraphrase regularly what was discussed*, but should also (12) *provide practical assistance* and help participants to write, bring coffee, etc.

Given that there should be room for small talk, but also due to the attention span of older adults, everything proceeds slower. Therefore, it is suggested to (13) *limit the topics* that need to be discussed. A rule of thumb could be to multiply the estimated timing by two. Furthermore, by providing sufficient breaks, participants also have the (14) *possibility to stand up in between*. To ensure that everyone has had enough time to voice their concerns, it could also help to (15) *limit the number of participants to a maximum of 6*.

5.1.3 Ideation Phase Recommendations

Low-Fidelity Prototypes. Although low-fidelity prototypes are interesting to test internally with proxies, it was hard for participants to understand the interactions based on such a prototype. Participants often had little ICT experience, thus lacking a mental model. Therefore, we suggest to (16) *avoid testing paper-prototypes* with older adults.

High-Fidelity/Interactive Prototypes. When presenting information to participants, it was important to avoid English terms and (17) *translate all words into their native language*, even if these terms are official mongrel words.

5.1.4 Evaluation Phase Recommendations

Formative/Summative Usability Test. When conducting user-tests, it is important to start with (18) *reassuring participants that they cannot do anything wrong*. At all cost, it should be (19) *avoided that participants feel that they are tested*, instead of the application. For participants without any ICT experience, it can be hard to understand what to do. Therefore (20) *providing alternatives for participants who have no mental model on using a technology* can help them. Especially for user-tests with multiple participants, it is beneficial to have (21) *one moderator or researcher for every 3 to 4 participants*. These are necessary when participants are stuck or have practical questions.

Adoption Study. Before starting the experiment it is important to (22) *comfort participants* and (23) *try out all features together* so participants can first experiment in a safe environment.

Questionnaires. First of all, it is important to (24) *avoid questionnaires that are too long*, as participants' attention will decrease, resulting in incomplete or incorrectly filled out questionnaires. Furthermore, (25) *avoid negative phrased questions* as these can be harder to interpret. In addition, when possible, (26) *ask questions orally*.

6 LIMITATIONS AND FUTURE WORK

For the participants' recruitment, we aimed for a heterogeneous sample in which we also included the oldest old. However, given that participants chose themselves whether to participate or not, self-selection was inevitable. This could also introduce bias in the findings by favouring those who were cognitively or physically stronger. However, given the transitional quality of ageing (Durick et al., 2013), it is hard to distinguish participants based on only age or ability, as this would simplify the ageing process without having a sound theory (Vines et al., 2015). Moreover, we acknowledge that this research study has come to

life by studying our own practicalities and that it is limited to these experiences on what did or did not work. Therefore, future work is necessary to validate our recommendations.

7 CONCLUSION

In this study, we report findings based on a four-year HCD process conducted with 81 older adults (median age=83). Based on a thematic analysis, four themes emerged: 'a life course marked by grand experiences', 'a discomfort with unknown digital technologies', 'impact of age-related impairments', and 'relatedness as core to research participation'. Moreover, each theme presents insights and guidelines, which are summarised in section 5.1. This study contributes by offering lessons learned in the different phases of an HCD process. Our aim is that these guidelines can help future researchers to undertake more effective and useful study designs.

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