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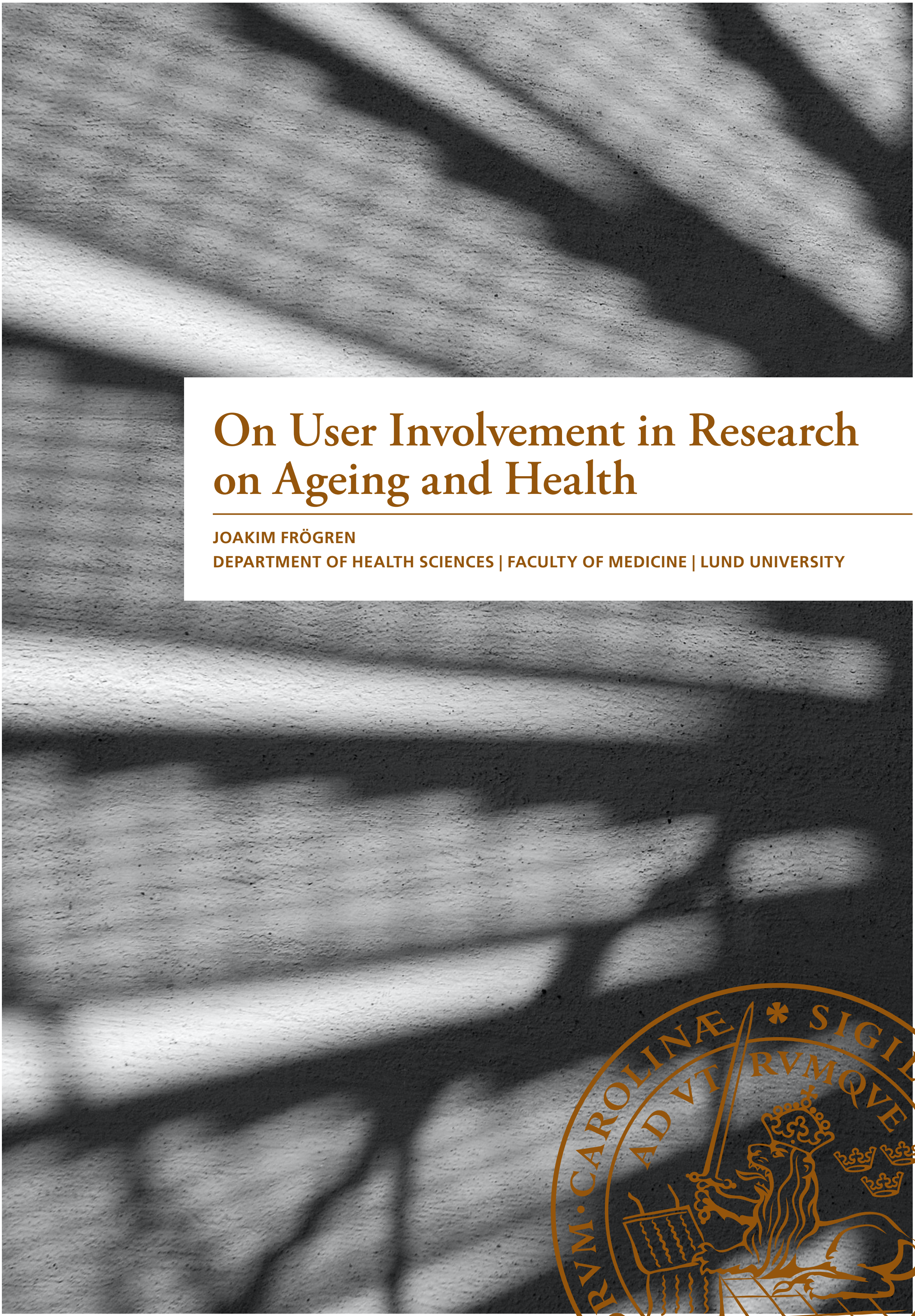

On User Involvement in Research on Ageing and Health

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DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

On User Involvement in Research on Ageing and Health

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DOCTORAL DISSERTATION

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Abstract

The aim of this thesis was to explore the perceptions of, prerequisites for and benefits of user involvement among older people, persons with functional impairments and other user groups important to the research area. By using an adapted conceptual tool to categorize the various user involvement studies comprising the thesis, the aim was also to reflect on the importance of study design for the outcomes of the user involvement, and thus to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health.

The PhD thesis consists of four empirical studies that are linked to four different research projects. Two of the studies constituted research about user involvement and had a quantitative design, whilst two studies consisted of research with user involvement and were qualitative in their design.

Study I consisted of a study with user involvement and aimed to test and evaluate an mHealth application for older people with mild cognitive impairment (MCI) and their informal carers prior to its launch in a large-scale randomized controlled trial. The user satisfaction evaluation was conducted via a structured interview in a clinical environment with user representatives for both user groups (N=38). Study II comprised the second study with user involvement and focused on a research circle where researchers (N=3) and user group representatives (N=12) with an interest and experience of issues related to housing and health in Sweden during three sessions (3 x 3h) strived to untangle the complex issue of accessible housing provision in Sweden.

Study III (N=881) was a quantitative study about user involvement and consisted of a survey study (online/paper/phone) directed at older people in the general population and aimed to explore their awareness of and attitudes to user involvement in research. The second quantitative study (Study IV; N=147) was directed at older people from senior citizens organisations and people with functional impairments from disability associations. The study was linked to the Citizen Science (CS) initiative on housing accessibility and aimed to evaluate the benefits of this project in terms of changed attitudes and acquired skills among its users. The evaluation consisted of two online questionnaires that participants were asked to complete prior to (pre-Q) and directly after (post-Q) the CS initiative.

To address the overall aim of the thesis, a categorization matrix was used to analyse the thesis findings, which was largely based on a conceptual tool (Jönson et al. 2021) containing four considerations of user involvement (Why?; Who?; When?; How much?) developed within a Swedish research program dedicated to the study of user involvement in research on ageing and health. The analysis indicated a connection between willingness to be involved in research and higher levels of formal education among users; that mobile digital literacy is an important prerequisite for older people and people with disabilities to be involved in research involving mobile technology. The main benefits of user involvement in research as perceived by older people and other user groups were that it could lead to new insights into complex problems. However, it was found that user involvement does not always necessarily lead to benefits and there are indications that this has to do with the depth of involvement.

Thus, conducting research with user involvement requires sensitivity towards the prerequisites of different user groups and insights into what possible benefits it is reasonable to expect from the user involvement. The adapted conceptual tool and the categorization made from it within this thesis, constitutes an attempt to systematically value user involvement. Namely, to what extent it has the potential to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health.

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MADE IN SWEDEN

In loving memory of my father,
Roland Frögren (1952 – 2020)

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Svensk populärvetenskaplig sammanfattning

Brukarinvolvering i forskning syftar på att personer eller grupper – här benämnda *brukare* – som är intresserade av och/eller har nytta av forskning (men som själva inte är forskare), involverar sig i forskning. Brukare är representanter för olika grupper och betraktas ofta som experter utifrån den egna livssituationen och de egna levnadsvillkoren. Inom forskning om åldrande och hälsa utgör följande kategorier eller grupper exempel på olika slags brukare: äldre personer ur den allmänt åldrande befolkningen; sköra personer med specifika egenskaper och behov; informella vårdgivare; hälso- och sjukvårdspersonal; socialtjänstpersonal; yrkesverksamma inom olika branscher; myndighetsföreträdare samt representanter för olika intresseorganisationer.

Involvering betyder i detta sammanhang att forskningen bedrivs *tillsammans med* snarare än *för* brukarna. Exempel på brukarinvolvering i forskning är agera rådgivare i en styrgrupp för ett forskningsprojekt, vara med och ta fram eller kommentera forskningsmaterial eller vara med och samla in data.

Kritik mot brukare

I ett svenskt sammanhang går ordet ’brukare’ tillbaka till 1980-talet i diskussioner inom den offentliga sektorn. Till en början användes ordet brukare för alla slags offentliga tjänster såsom barnomsorg, skola och sjukvård. Vid slutet av 90-talet blev begreppet vanligt att använda inom socialtjänsten. Det förekommer samtidigt en stark kritik mot ordet ’brukare’. Av många anses det förminskande, inte minst för att det är så närbesläktat med ordet ’missbrukare’. Till exempel är flera seniorföreningar motståndare till begreppet. Samtidigt är ordet etablerat och det har varit svårt att enas kring ett ord, och frågan är om det ens är lämpligt.

Varför brukarmedverkan?

Brukarinvolvering i forskning har sina rötter i en rad olika forskningstraditioner, men bedrivs idag bland annat utifrån motiv som har att göra med att dels belysa och stärka utsatta gruppers situation. Ett annat skäl för att bedriva forskning med brukarinvolvering är utifrån en förvissning om att det utgör ett sätt att bättre kunna förstå, förklara och förbättra tillvaron för människor jämfört med om forskning inom detta område enbart bedrivs på ett traditionellt sätt.

Inom forskning inom åldrande och hälsa som utgör forskningsområdet för denna avhandling utgör en gemensam problembild att den åldrande befolkningen inom många länder, däribland Sverige, innefattar många utmaningar som är av en komplex natur. I takt med att allt fler människor lever allt längre, och tack vare medicinska landvinningar, så lever allt fler människor med olika typer av såväl fysiska som kognitiva funktionsnedsättningar, till följd av till exempel stroke eller demens. Det ökande antalet människor som lever med fysiska funktionshinder ställer till exempel högre krav på den fysiska miljön, däribland bostäderna, för att möjliggöra ett aktivt och hälsosamt liv även för dessa personer. Detta är ett exempel på ett komplext problem och en situation som forskare inom åldrande och hälsa har ambitionen att förstå, förklara och förbättra.

Krav på brukarinvolvering i forskning

I forskning som på olika sätt försöker ta sig an komplexa problem av det slag som nämnts ovan utgör brukarinvolvering idag ett vanligt inslag. Det utgör ofta till och med ett krav för att överhuvudtaget få forskningsmedel för att kunna bedriva forskning inom området. Att det sätts upp som ett kriterium för att få forskningsmedel görs utifrån en förvissning om att involverandet av brukare utgör en förutsättning för att kunna förstå, förklara och på sikt förbättra den rådande situationen.

Forskning med brukarinvolvering och viktiga frågor

Den forskning som bedrivs med involvering av brukare idag lägger oftast inte så stor vikt vid att redovisa och utvärdera själva involverandet. Det är i stället den frågeställning som ligger till grund för involverandet av brukare som oftast utgör fokus. Själva involverandet i sig och hur det gick omnämns oftast inte mer än att det beskrivs vilka som deltog och hur det gick till.

Det föreligger risker med att forskning bedrivs med brukarinvolvering på sätt där det inte förekommer så mycket reflektion kring själva involverandet. En risk med det är att det i studier med brukarinvolvering är så att vissa grupper inte får eller ges möjlighet att komma till tals i dessa sammanhang.

Om det är så att vissa kategorier äldre personer systematiskt inte ges möjlighet att göra sina röster hörda innebär det inte bara att de själva som individer och som grupp riskerar att känna sig uteständga. Det innebär också att det som forskningen har som ambition att försöka förstå, förklara eller förbättra inte inkluderar dessa grupper. Det vill säga att de förutsättningar de har, de erfarenheter de bär på och den kunskap de besitter inkluderas inte i det som utgör resultatet av forskningen.

Här är det rimligt att människor åtminstone ges chansen att medvetandegöras om möjligheten att involvera sig i forskning. Hur stor kännedomen är hos äldre personer i Sverige om möjligheten att involvera sig i forskning på det här sättet är dock inte känt. Kring detta finns med andra ord ett behov av forskning.

Inom forskning om åldrande och hälsa är äldre personer en viktig brukarkategori. Men när de gäller hur de ser på att involveras i forskning har det inte gjort så många studier. De flesta studier med detta fokus är, eller bygger på, små kvalitativa studier. I en svensk kontext har det inte gjorts någon kvantitativ studie av detta slag alls. Här finns alltså ett tydligt behov av kvantitativ forskning som kan ta reda på hur äldre personer i Sverige ser på att involvera sig i forskning. Det är intressant att ta reda på eftersom det ju också ger en indikation på vilka undergrupper av äldre som sannolikt involverar sig i forskning och vilka som inte gör det.

För att fortsätta resonemanget kan det också vara så att vissa människor inte ser så stor vinning själva i att involvera sig i forskning på det här sättet. Inte för egen del och inte heller för att man ser det som att forskningen kommer att göra så stor skillnad genom involvering. När det gäller vad brukare själva får ut av att involvera sig finns också här en brist på kunskap.

Forskningsprogrammet UserAge

Den här avhandlingen är skriven inom forskningsprogrammet UserAge. Det är ett forskningsprogram med ett fokus just på brukarinvolvering och i synnerhet på metoder och modeller som kan öka effekten av brukarmedverkan. Forskningen inom UserAge bedrivs vid Lunds universitet, Göteborgs universitet, Högskolan Kristianstad och Linnéuniversitetet. Inom forskningsprogrammet samarbetar vi med representanter för pensionärsorganisationer, anhörigvårdare och sköra äldre personer. Aktörer inom offentlig och privat sektor är också engagerade. Personal inom vård och omsorg samt bostads- och fastighetssektorn bidrar också i forskningsprogrammet.

…och tankeverktyget SAPO som utvecklats där

Genom forskningen inom UserAge har det tagit fram en modell, eller tankeverktyg, för att utforma och utvärdera forskning med brukarinvolvering. Verktyget bygger på centrala frågor som ofta förekommer inom forskningen om och med brukarmedverkan. Frågorna är:

- Varför ska brukarinvolvering ske (syfte)
- Vilka ska involveras (aktör),
- Inom vilka delar av forskningsprocessen ska involveringen ske? (processen),
- Vilket inflytande ska brukaren eller brukarna ha över forskningen? (omfattning)?

Med hjälp av tankeverktyget är det tänkt att både forskare och olika kategorier av brukare kan föra mer systematiska och kritiskt värderande resonemang om forskning med brukarinvolvering. Det kan i sin tur leda till effektivare arbetsformer och att den kunskap som forskningen leder fram till får bättre spridning och därigenom kan förbättra tillvaron för den åldrande befolkningen.

Övergripande syfte med avhandlingen

Det övergripande syftet med avhandlingen var att öka kunskapen om brukarinvolvering inom forskning om åldrande och hälsa genom att utforska: uppfattningarna om, förutsättningarna för och nyttan av brukarinvolvering bland äldre personer och andra för forskningsområdet viktiga brukargrupper. Genom att anpassa och utvärdera ett tankeverktyg för att utforma och värdering av forskning med brukarinvolvering, syftade avhandlingen också till att bidra till utvecklingen av generaliserbar kunskap och kumulativ kunskap inom forskning om åldrande och hälsa.

Studier i avhandlingen

I Studie I var syftet att testa och utvärdera en mobil hälsoapplikation riktad till äldre personer med lindrig kognitiv funktionsnedsättning och deras informella vårdgivare före att kunna använda den i en fullskalig randomiserad kontrollerad studie. Syftet var också att erhålla kunskaper om hur

I Studie II var syftet att få en djupare förståelse för vilka faktorer som är viktiga för beslutsfattande som rör hur man ska kunna möjliggöra fler tillgängliga bostäder för den åldrande befolkningen i Sverige

I Studie III var syftet att undersöka hur väl äldre personer ur den allmänna befolkningen kände till brukarinvolvering i forskning om åldrande och hälsa, och vilka attityder de hade till den

I Studie IV var syftet att studera vad som utmärkte de äldre personer och personer med funktionshinder som deltog i ett medborgarforskningsinitiativ om boendetillgänglighet och om deras deltagande resulterade i några attityd-förändringar eller andra förtjänster

Slutsatser

Resultaten från de fyra avhandlingsstudierna visade dels att det verkar finnas ett samband mellan intresset för att som brukare engagera i forskning och högre utbildning. I studie III, där äldre personer som var 60 år eller äldre ingick framkom att högre utbildning var en viktig faktor för att både känna till och engagera sig i forskning.

Resultaten från Studie I och Studie II visade vidare att mobil digital läskunnighet verkar vara en förutsättning för äldre och personer med funktionsnedsättning när det gäller möjligheten att engagera sig i forskning som involverar mobilteknologi.

De främsta fördelarna med att engagera sig i forskning som uppfattas av äldre och andra brukargrupper var att det kunde leda till nya insikter om komplexa problem.

Detta visade sig i Studie II där olika brukargruppsrepresentanter med intresse och erfarenhet av frågor som rör boende och hälsa deltog. Men resultaten visade också att brukarinvolvering inte alltid leder till förtjänster. Av studie IV framkom att engagemanget i medborgarforskningen inte resulterade i några större attitydförändringar eller några förvärvade färdigheter. Resultaten tyder därför också på att det krävs en lyhördhet hos forskaren/arna för olika brukargruppers förutsättningar att engagera sig i forskning, liksom insikter i vilka möjliga fördelar det är rimligt att förvänta sig av brukarinvolvering.

Slutligen utgör tankeverktyget (Jönson et al. 2021) och den kategorisering som gjorts utifrån det inom denna avhandling, ett försök att systematiskt värdera brukarinvolvering och i vilken utsträckning den har potential att bidra till utvecklingen av generaliserbar kunskap och kumulativ kunskap inom forskning om åldrande och hälsa.

List of publications

This thesis is based on the following papers:

I. Quintana, M., Anderberg, P., Sanmartin Berglund, J., **Frögren, J**., Cano, N., Cellek, S., Zhang, J. & Garolera, M. (2020). Feasibility-usability study of a tablet app adapted specifically for persons with cognitive impairment — SMART4MD (Support Monitoring And Reminder Technology for Mild Dementia). *International Journal of Environmental Research and Public Health, 17*(18), 6816. http://dx.doi.org/10.3390/ijerph17186816.

II. Jonsson, O., **Frögren, J**., Haak, M., Slaug, B., & Iwarsson, S. (2021). Understanding the wicked problem of providing accessible housing for the ageing population in Sweden. *International Journal of Environmental Research and Public Health, 18*(3), 1169. http://dx.doi.org/10.3390/ijerph18031169.

III. **Frögren, J**., Schmidt, S. M., Kylén, M., Jonsson, O., Slaug, B., & Iwarsson, S. (2022). Awareness of and attitudes towards public involvement in research on ageing and health among older people in Sweden. *PLoS One 17*(6):0269993. http://dx.doi.org/10.1371/journal.pone.0269993.

IV. **Frögren, J**., Granbom, M., Jonsson, O., Bergman, M. Iwarsson, S. Characteristics and attitudinal changes of senior citizens and persons with functional impairments involved in citizen science. (Revised after peer review and re-submitted)

Author contributions

The authors' contributions to the four studies included in the thesis are listed in Table 1.

Table 1. The contributions of the authors to the four studies included in this thesis

Contribution	Study I	Study II	Study III	Study IV
Conceptualisation	MQ, PA, JSB, JF, MG.	OJ, JF, MH, SI.	JF, SMS, MK, OJ, BS, SI.	JF, MGB, OJ, SI.
Data curation	MQ, JF	OJ, JF, MH.	SMS.	JF
Formal analysis	JZ.	OJ, JF.	JF, SMS.	JF, MGB, SI.
Funding acquisition	SC	SI	SI	SI
Investigation:	MQ, NC, MG.	OJ, JF.	JF, SMS	JF
Methodology:	MQ, PA, JSB, JF, MG.	OJ, MH, SI.	JF, SMS, OJ, SI.	JF, MGB, SI.
Project administration:	SC	OJ	SMS, MK, OJ.	MGB, OJ, MB.
Resources:	MQ, NC, MG.	SI	SI	SI
Supervision	-	OJ, SI.	OJ, SI.	OJ, SI.
Validation:	MQ, JF, NC.	OJ, JF, MH, SI.	JF, MK, OJ, BS, SI.	MGB, OJ, SI
Visualisation	-	-	JF, OJ.	-
Writing – original draft preparation:	MQ, PA, JSB, JF, NC, SC, JZ, MG.	OJ, JF, MH.	JF, OJ.	JF
Writing – review and editing:	MQ, PA, JSB, NC, SC, JZ.	OJ, JF, MH, SI.	JF, SMS, MK, OJ, BS, SI.	JF, MGB, OJ, MB, SI.

BS = Björn Slaug**; JF = Joakim Frögren**; JSB = Johan Sanmartin Berglund; JZ = Jufen Zhang; MB = Martin Bergman; MG = Maite Garolera; MGB = Marianne Granbom; MH = Maria Haak; MK = Maya Kylén; MQ = Maria Quintana; NC = Neus Cano; OJ = Oskar Jonsson; PA = Peter Anderberg; SC = Selim Cellek; SI = Susanne Iwarsson; SMS = Steven M. Schmidt.

Abstract

The aim of this thesis was to explore the perceptions of, prerequisites for and benefits of user involvement among older people, persons with functional impairments and other user groups important to the research area. By using an adapted conceptual tool to categorize the various user involvement studies comprising the thesis, the aim was also to reflect on the importance of study design for the outcomes of the user involvement, and thus to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health.

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and people with disabilities to be involved in research involving mobile technology. The main benefits of user involvement in research as perceived by older people and other user groups were that it could lead to new insights into complex problems. However, it was found that user involvement does not always necessarily lead to benefits and there are indications that this has to do with the depth of involvement.

Thus, conducting research with user involvement requires sensitivity towards the prerequisites of different user groups and insights into what possible benefits it is reasonable to expect from the user involvement. The adapted conceptual tool and the categorization made from it within this thesis, constitutes an attempt to systematically value user involvement. Namely, to what extent it has the potential to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health.

Abbreviations

CEPPP	Centre of Excellence for Partnership with Patients and the Public
mHealth	mobile health
NIHR	National Institute for Health Research
RCT	Randomized Controlled Trial
UserAge	a research program where researchers from Lund University, University of Gothenburg, Kristianstad University and Linnaeus University together investigate different perspectives on user involvement.
PPI	Patient and Public Involvement
PAR	Participatory Action Research

Definitions

Informal carer = A person who provides care to a relative or near friend often unpaid and on a regular basis outside of a formal or legal framework

Mobile digital device = Smartphone or tablet

Mobile digital literacy = The ability to handle digital devices such as smartphones and tablets

Non-academic actor = A person or stakeholder who is not primarily concerned with research

Public involvement = A concept that, similarly to user involvement, denotes research carried out ‘with’ or ‘by’ one or several user groups rather than ‘to’ or ‘for’. However, the fundamental difference is that the research with public involvement mainly includes people within the general population.

Transdisciplinary research = Research that is rooted in a belief that different kinds of knowledge from both inside and outside academia are required to make complex social problems comprehensible

User = A non-academic actor who is interested in and/or benefits from research

User involvement = The involvement in the research process by non-academic actors who are interested in and/or benefit from research.

Introduction

User involvement in research refers to the involvement in the research process by non-academic actors who are interested in and/or benefit from research. Users are representatives of various groups and are often viewed as experts with regards to their own situation and conditions (Ross et al., 2014). Within research on ageing and health, examples of various user groups include: older people within the general population; older persons with physical and/or cognitive impairments; informal carers; healthcare professionals; social services staff; industry professionals; public agency representatives and non-governmental/ interest organisation representatives (Kylberg et al., 2018; Iwarsson et al., 2019).

User involvement in research differs from regular study participation in that it is research carried out ‘with’ or ‘by’ one or several user groups rather than ‘to’ or ‘for’ them (Fudge et al., 2007). Examples of user involvement in research are: acting as advisors in a steering group for a research project, being involved in collecting data, or being involved in communicating the research results.

User involvement in research is rooted in democratic aspirations to empower or to ensure that people whom the research affects, directly or indirectly, should have the right to influence how it is conducted. Here, Sherry Arnstein's 'Ladder of citizen participation' (Table 2) has been influential in the academic thinking regarding user involvement. It was created in 1969 to assess citizen involvement in urban-planning processes in the United States (Arnstein, 1969), but has been extensively used in other contexts (Slotterback and Lauria, 2019). Arnstein’s ladder is about citizens', especially vulnerable groups', participation in decision-making and describes eight steps. The top six steps refer to degrees of participation from symbolic influence via information to civic power and control, while the two the bottom steps are non-participation (manipulation and therapy respectively), where citizens are not given influence over the decision-making process, but rather are expected to adapt to a prevailing situation.

Table 2. Sherry Arnsteins ‘Ladder of citizen participation’ (1969).

8	Citizen control	Citizen control
7	Delegation	
6	Partnership	
5	Placation	Tokenism
4	Consultation	
3	Informing	
2	Therapy	Nonparticipation
1	Manipulation	

Within an ageing and health research context, health and social service user groups’ struggle for better health and social care has been influential for the progress towards more inclusive research (Jackson, 2020). In several cases, this movement has led to the creation of state-sanctioned frameworks or research platforms such as the Canadian CEPPP (Centre of Excellence for Partnership with Patients and the Public) and British NIHR (National Institute for Health Research), the latter with the goal of “conducting leading-edge research focused on the needs of patients and the public” (NHR, 2019, p. 2). These frameworks and research platforms have had a strong influence on the discourse in research related to user involvement in above all medicine and the health sciences and have established the concepts of Patient and Public Involvement (PPI) and public involvement as commonly employed terms. In research conducted within PPI, there is a strong focus on the operationalization of involvement, i.e. on how to go about, for example, distributing power between researchers and patients when conducting research together, and how to develop models to measure it (Jönson et al., 2021). Arnstein's ladder is often the starting point for these models. Public involvement, it is a concept that, similarily to user involvement, denotes research carried out ‘with’ or ‘by’ one or several user groups rather than ‘to’ or ‘for’. However, the fundamental difference is that the research with public involvement mainly includes people within the general population.

Participatory Action Research (PAR) is derived from another research tradition than that of PPI. and consists of action research that aims to improve the situation of vulnerable groups. It is common for researchers to take the side of the vulnerable person/s in PAR (Blair & Minkler, 2009). The concept of transdisciplinary research can also be seen to constitute another form of user involvement. Here, “trans” stands for a crossing of the boundaries between research and actors in the surrounding society and between different forms of knowledge. These actors can be individuals, representatives of groups or other stakeholders who are seen as affected by the research in question. Transdisciplinary research is rooted in a belief that different kinds of knowledge from both inside and outside academia are required to make complex social problems comprehensible (Pohl, 2011). There are differences in origin and emphasis within the various traditions. PAR research has its background in power analyses, while other approaches are in many cases more neutral towards power. However, there are some exceptions as highlighted by Greenhalgh et al., (2019) who argued that some PPI models focus on power relations in much the same way as PAR research.

A research tradition that is growing in popularity and is often aimed at a wider public is Citizen Science (CS). CS is used as an umbrella concept for research collaboration involving the public to address real-world problems using participatory approaches (Bonney et al., 2016). Within this traditon a distinction is often made between contributory and co-creating CS. While contributory CS is researcher-initiated, co-creating citizen science usually derives from a grassroots movement with members of the public (often constituting a community) involved in most or all of the process (Wiggins and Wilbanks, 2019).

Moreover, within the public sector, the concept of user originates from a desire to connote a more active choice to health and social service usage, as a contrast to concepts implying a more passive role such as care recipients (Hultqvist & Salonen, 2016). This occurred as part of a development in the manufacturing industry moving away from mass production to the development of products and services that were to a greater extent based on the intended users' interests and needs.

Today, it is common that user involvement in research is conducted based on motives that have to do with giving voice to various groups considered in need of strengthening their situation (James and Buffel, 2022; Kylen et al., 2022). Another frequent rationale for research with user involvement is an assurance that it is a necessary approach in order to untangle many of today's societal challenges and issues (Kalinauskaite et al., 2021; Iwarsson et al., 2019).

User involvement is primarily conducted within applied research, where the results should be possible to apply in a practical context (Bickman & Rog, 2008). Applied research contrasts with basic research, which is focused on advancing knowledge "per se" asopposed to how the knowledge can be applied (Bickman & Rog, 2008). The motives for involving users in research are strongly linked to the aims of the research. In applied research in ageing and health, which is the research area for this thesis, the overarching questions today are about trying to understand, explain and improve the lives of different groups of people with a focus on the ageing population.

A common theoretical point of departure within applied research on ageing and health is that the ageing population in a large part of the world, including Sweden, poses many challenges that are of a complex nature (Christensen et al., 2009; Tsuchiya-Ito et al., 2019). That people today, largely thanks to medical achievements, can live longer with chronic diseases that involve physical and/or cognitive impairments is in itself something that is viewed as highly gratifying and positive. Nevertheless, at the same time it also means that increased demands are placed on society in various areas as a result of the demographic ageing trends (van der Wel, 2019).

The growing number of people living longer with physical disabilities places increased demands on the physical environment, including housing Namely, to ensure affordable, accessible housing which in turn can help facilitate an active and healthy life for people ageing with a range of physical disabilities (Slaug et al., 2020). In the Swedish housing stock, there is a high incidence of physical environmental barriers and substantial accessibility problems for older people living with functional limitations (Granbom et al., 2016; Petersson et al., 2008). Meanwhile, accessibility measures on existing housing are costly and also risk causing rents to rise and subsequently forcing more people into homelessness (Sendi, 2014; Lind, 2017). This is an example of a complex problem and situation that researchers in applied ageing and health research have the ambition to understand, explain and improve. At the research centre Centre for Ageing and Supportive Environments (CASE), based at Lund University, to which the author of this thesis is associated, there is a strong research focus on the issue of physical accessibility in housing. It is also an important reason why, in addition to older people, persons with various types of impairments are important user groups in the research conducted at the centre[1].

With advanced old age there is an increased risk of developing dementia (Doblhammer et al., 2013) even though more recent studies have highlighted that the incidence rates have declined by 13% per calendar decade consistently across studies (see for example, Wolters et al., 2020). Neverthess, cognitive difficulties in old age represent a societal challenge as governments need to be able to offer people ageing with a variety of disabilities a dignified life with access to good quality long term care (Higgs & Gilleard, 2017). Within applied research in ageing and health, this constitutes another example of a complex problem and situation that researchers have the ambition to understand, explain and improve.

In research that, in various ways, tries to untangle and solve complex problems of the kind mentioned above, user involvement is increasingly a common element (Hultqvist et al., 2021; Jönson et al., 2021). Further, it is also increasingly a requirement for receiving external research funding within research fields such as health, working life and welfare, for example (Hultqvist et al., 2021). That it is set up as a criterion for receiving research funding is based on an assurance that the involvement of users is a prerequisite for being able to understand, explain and eventually improve the current situation for the specified target group/s in question.

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[1] At CASE there is also has a User Board linked to its operational activities that has been running for more than 10 years approximately. It consists of older people and representatives of relevant organisations, such as senior citizens' associations and other non-governmental/interest associations. Representatives from authorities and companies can also be included, as well as professionals in sectors such as health care and community planning. The User Board contributes with ideas, opinions and research questions to various projects.

There are also indications that the involvement of older people within research has positive outcomes. In a recent systematic review examining the outcomes of older people's involvement in research (James and Buffel, 2022), such involvement was found to lead to an improved understanding of the problems experienced by older people themselves. It was also found to lead to more inclusive and responsive policies and services, opportunities for the users to develop new skills and to give voice to marginalized groups of older people.

Research that aims to tackle problems in different ways through user involvement is, however, partly based on different types of research questions, some of which are more focused on simply understanding and trying to explain (Fischer et al., 2020) whilst others are more focused on developing, testing and evaluating a potential solution (Bischof & Jarke, 2021).

Depending on the aim/s of the specific research in question, researchers within ageing and health include users in different ways. This can be done, for example, by inviting intended users to be involved in the actual design process of a potential technical solution via which older people with presumed incipient dementia (mild cognitive impairment, Jessen et al., 2014). and their informal carers may access support, which in turn can ultimately help to improve their everyday quality of life. It can also be to invite non-academic actors, such as representatives from civil society with an interest in and knowledge about housing accessibility to meetings during which the complex problem of providing accessible housing in Sweden can be discussed. Alternatively, it can consist of inviting older people from the general population to find out which physical environmental barriers exist in Swedish homes and how common these are by using an application on their smartphones or tablets. All three of these are examples of how various groups of users were included in research studies that this thesis covers.

However, it is relatively common for research which includes users (in various ways) during the research process does not often place much emphasis on reporting and evaluating the actual involvement (Staniszewska et al., 2011; James & Buffel, 2022). Rather, most studies tend to focus mainly on the outcomes rather than describing and evaluating the user involvement in detail. A study by Staniszewska (2011) indicated that in health research concerning the involvement of user groups consisting of patients or members of the public many scientific articles lacked clarity, transparency and completeness in how the authors actually conducted the research. There are several risks with research being conducted with the involvement of users in ways where there is not much reflection on the actual involvement itself. One important risk goes back to one of the common motives for conducting research involving users, namely giving voice to various groups considered in need of strengthening their situation. If researchers are not conscious of what characterizes the users who they involve and how representative they are for the user group they intend to represent, there is a risk that certain subgroups of users are frequently excluded. If a skewed recruitment of users systematically occurs, it is a clear indication that certain groups do not get, or are not given, the opportunity to get involved in such research (Kylberg, Haak & Iwarsson, 2018; Malm, 2021).

In the systematic review examining the outcomes of older people's involvement in research, James and Buffel (2022) have highlighted the risk of older people's involvement in research to "further empower those who already have considerable social capital while adding to the exclusion of more marginalized groups" (p. 21). This concern is based on James and Buffel's (2022) analysis that the involvement of older people in research tends not always to be representative of the older population at large and that the potentially systematic lack of the voices of marginalized individuals and groups may result in allocating them even less space and power.

A study by Poli et al. (2021) indicated that there is a selective exclusion of study participants in eHealth trials of people who are older, have poorer health, belong to lower socio-economic groups and are less used to using digital technology. However, the knowledge is scarce concerning to what extent such selective exclusion also occurs in research with user involvement due to the low emphasis on reporting and evaluating the involvement as previously outlined above (Staniszewska et al., 2011; James & Buffel, 2022).

However, a counterargument to describe the absence of certain user groups as "excluded" may be that it could rather be a lack of interest or willingness to be involved among certain user groups. The problem with this assumption however is that the non-involvement or exclusion of certain user groups might in fact be due to a lack of awareness of the opportunity to become involved in research. Thus, it is important for researchers to be able to adequately inform potential participants about the possibility of getting involved in research. In a Swedish context, knowledge about the extent to which older people are aware of the possibility of getting involved in research, or how willing they are to get involved is lacking and there is thus a need for more research in this area (Kylén et al., 2020).

Moreover, it may also be the case that some user groups do not regard the involvement in research as sufficiently beneficial for being worth the effort. The study by James and Buffel (2022) indicated that in this area, there is also a need for further research since the benefits for the users when involved in research are often ignored, assumed or subject to speculation and seldom analyzed systematically (Kasperowski and Brounéus, 2016; Wehn et al., 2021).

In research on ageing and health, older people are an important user group. However, when it comes to how a range of older people perceive user involvement in research, larger quantitative studies are lacking since most studies with this focus are, or are based on, small qualitative studies (Kylén et al., 2020). In a Swedish context, there has not previously been any larger quantitative study conducted of this kind (Kylén et al., 2020). It can be argued that such a study would help to give an indication of which subgroups of older people are less likely to get involved and why.

If it is the case that certain groups of older people are not systematically given the opportunity to make their voices heard, not only does it mean that they may feel excluded,it also means that what the research aims to try to understand, explain or improve will not include these groups. This means that the conditions these groups of older peoples possess, the experiences they carry and the knowledge they possess risks not being included in what constitutes the results of the research.

For researchers, research results consitute knowledge, and in applied research, Nowotny (2003) has convincingly argued that it is important that researchers strive to ensure that the knowledge produced is not only applicable but also "socially robust". This means that it can be applied not only in the research environment but also outside; in the social, real context where it is intended to be used. If one or more important perspectives are missing, there is a risk that the abilities, experiences, and knowledge they represent are not included in, for example, the description of the problem that is made (unless there are other representatives who can clearly describe and account for these experiences and that knowledge). If, based on that description of the problem, various proposals for solutions are then developed, there is a risk that when these "solutions" are put into use, they do not work in the social contexts where they are intended to be used, partly because in the solutions there is lacking one or more important perspectives. Van De Ven and Johnson (2006) also highlighted that different perspectives on a problematic situation increases the likelihood that the research will address the multifaceted nature and complexity of the problem under investigation.

When conducting research in ageing and health it can be argued to be important to consider older people as a collective because of the issue of ageism that exists within society (Levy & Macdonald, 2018; Walker, 2007). Thus, in this line of thinking, older people in general are. viewed as in need of strengthening their position in society due to the adverse effects of ageism and the marginalization of older people in today’s society (Chang et al., 2020; Burnes et al., 2019), which was made evident during and in the aftermaths of the COVID-19 pandemic (Fraser et al., 2019). All of which points to a need for increased power and empowerment for older people as a collective (Walker, 2007). At the same time, it can be seen to be important as a researcher in ageing and health to strive to gain a more thorough and nuanced understanding of the different needs and attitudes of this major segment of the population which is far from homogeneous (Nguyen et al., 2021) and exhibits largeat differences in experience, needs, preferences and resources for example.

This thesis and the studies included in it has a focus on older people's involvement in research. The older people included in the various studies are partly in different age ranges and some are recruited from the general population whilst others are recruited through interest associations of which they are members. In one of the studies, older people with mild cognitive impairment are involved. In addition to older people, this thesis also includes informal carers (of older people with mild cognitive impairment). Regarding informal carers' involvement in research on ageing and health, a quantitative study by Malm (2021), suggest that informal carers have a strong interest and willingness to involve in research. Among the study's informal carer respondents (n=147), a majority (83%, n=121) were interested in research, and 32% (n=47) had previously been involved in research, assuming the role of a user.

However, in addition to whom gets involved in research, it is also important to consider when in the research process the users are involved. James and Buffel's (2022) review examined which stages older people usually are involved. Involvement in the design of surveys, recruitment, data collection and knowledge dissemination were stages where involvement was established and occurred frequently. What was unusual according to these authors was involvement in the planning of research projects and in the scientific reporting – that is, when research results are written up in the form of articles and reports.

Within the framework of the research program UserAge, of which the author of this thesis was affiliated, Jönson et al. (2021) developed a conceptual tool, SAPO, for designing and evaluating research with user involvement. The tool is based on a type of meta-analysis where Jönson et al. (2021) identified central issues addressed in the internationally established traditions studied. In all traditions, these questions deal with why user involvement should take place (aim), who should be involved (actor/s), within which parts of the research process the involvement should be seen (process), as well as the level of involvement and influence (scope). With the help of the tool, it is intended that both researchers and different groups of users can conduct more systematic and critically evaluative reasoning about research with user involvement. This, in turn, can hopefully lead to more efficient working methods and utilization of results from the multifaceted research area concerning the ageing population.

Thesis Context

UserAge

This thesis is one of five PhD student projects in UserAge. UserAge was a six-year research program financed by the Swedish Research Council for Health, Working Life and Welfare (Forte 2016-07090) during the period 2017–2022. One aim of the research program was to increase knowledge about research conducted with representatives of non-academic actors, who have an interest in or potential use for the results from the research produced (Iwarsson et al., 2019). Within the research program, these actors were referred to as “knowledge users” or simply “users,” and the effort to involve the users in research was referred to as “user involvement” (Iwarsson et al., 2019). Categories of users involved in UserAge were: a) frail older people in residential care facilities, b) family members who provide care to older people (informal carers), c) professionals in the health care sector and d) representatives of key actors in the housing sector. The research program aimed to conduct studies both with and about the involvement of all these categories of users.

UserAge was led by Professor Susanne Iwarsson and engaged about twenty researchers from the University of Gothenburg, Lund University, Linnaeus University and Kristianstad University. In addition, representatives of the broader group "older people" were involved throughout the project (e.g. in work meetings, seminars, retreats and other research activities).

UserAge was organized through nodes at the four universities, each with different but complementary foci. Through a panel study that included informal carers and researchers, the awareness of and attitudes towards involvement in research among older people, informal carers and researchers were investigated. In addition, the program team developed models for the analysis and implementation of research conducted with the involvement of various categories of users.

Rationale

User involvement in research refers to the involvement in the research process by non-academic actors who are interested in and/or benefit from research. Users are representatives of various groups and are often viewed as experts with regards to their own situation and conditions.

Within ageing and health research, examples of various categories or groups of users are older people in the general ageing population; vulnerable people with specific characteristics and needs; informal carers; staff who provide health care or social services; industry professionals; policymakers; public agency representatives, and interest organization representatives. User involvement in research differs from regular study participation in that it is research carried out 'with' or 'by' one or several categories of users rather than 'to,' 'about' or 'for' them. This could be, for example, acting as an advisor in a steering group for a research project, being involved in developing or commenting on research material, or being involved in collecting data.

User involvement in research has enabled researchers to develop more respect for users and form stronger contacts with the groups of users with whom they conduct research. Within research on ageing and health, user involvement has been found to improve the understanding of the problems experienced by older people, to create more inclusive and responsive policies and services, and to create opportunities for users to develop new skills.

However, circumstances that may make it difficult to involve users in the research process include poor health, time constraints and challenges associated with travelling from home to various activities. Moreover, there is a lack of knowledge about the interests, conditions, needs and preferences of different categories of users in relation to involvement in research. Furthermore, the gains from user involvement such as the acquisition of skills or changed attitudes, are often ignored, assumed to occur or subject to speculation and are seldom analyzed systematically. There are indications that the lack of representativeness is problematic, although it is unclear to what extent, as most of the studies conducted are small and qualitative in design. There is a knowledge gap regarding the importance of the study design for the diverse categories of users with whom researchers strive to engage.

A recent effort with an ambition to advance knowledge on user involvement in research on ageing and health is a conceptual tool developed within the UserAge program - the research program within which this thesis is written. The conceptual tool aims to facilitate the design and evaluation of user involvement in research.

Aims

The overall aim of this thesis was to further the understanding of user involvement in research on ageing and health by exploring the perceptions of, prerequisites for and benefits of user involvement among older people, persons with functional impairments and other user groups important to the research area. By using an adapted conceptual tool to categorize the various user involvement of the thesis, the aim was also to reflect on the importance of study design for the outcomes of the user involvement, and thus to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health.

Specific aims

The four studies that make up this thesis each had specific aims based on their respective project context as follows:

I. To evaluate the design of an intervention in the form of a mobile health application directed to older people with mild cognitive impairment and informal caregivers prior to utilization in a full-scale randomized controlled trial; to contribute knowledge to future studies based on the user feedback and lessons learned in the study.

II. To gain a more in-depth understanding of variables deemed to be important for decision-making about the provision of accessible housing for the ageing population in Sweden.

III. To investigate the awareness of and attitudes towards public involvement in research on ageing and health among older people in Sweden.

IV. To investigate characteristics and attitudinal changes of older people and persons with functional impairments in a citizen science initiative on housing accessibility.

Methods

Project contexts for Studies I-IV

Study I was carried out as part of the project SMART4MD, which was a six-year (2015-2021) Horizon 2020 project (ID no. 643399) in the form of a randomized controlled trial (RCT) performed at four centers in three European countries: Spain, Sweden and Belgium (Anderberg et al., 2019). The target of the RCT was to recruit 1,200 dyads comprised of persons with a diagnosed neurocognitive disorder or an undiagnosed subjective memory problem or cognitive impairment (in the project referred to as persons with mild cognitive impairment) (n = 600) and their informal caregivers (n = 600). The dyads were split into an intervention group and a control group. The objective of the project was to investigate the effects of a customized mobile health (mHealth) application on the self-reported quality of life (Logsdon, 2002) of the intervention group dyads. The mHealth application was installed on tablets provided by the project. Tablets were loaned to the intervention group dyads during the course of the project. The mHealth application was developed specifically for the RCT through a user-centered design process involving representatives of the target group. Healthbit, a micro-sized mHealth enterprise specialized in mHealth which is based in the UK, was responsible for the software development of the mHealth application. Study I was based on a report, which was a work package delivery in the SMART4MD project. The goal of this work package was to investigate, through a small-scale feasibility-usability study (n = 20 dyads), whether the designed intervention was sufficiently feasible and the mHealth application sufficiently usable to launch the full-scale RCT. The study was conducted in parallell in two countries: in Sweden by the Blekinge Institute of Technology (Swedish initials—BTH) in Karlskrona (Blekinge), and in Spain by the Consorci Sanitari de Terrassa (CST) in Terrassa (Barcelona). The purpose of conducting the feasibility study in two countries was to examine whether any linguistic and/or cultural differences had an impact on the perception of the mHealth application.

Study II was carried out as part of the three-year project Decision Support System for Improved Accessibility in Multi-family Housing (FORMAS grant no. 2017-01508). The project had the overarching aim to develop, test, and evaluate a new decision support system (DSS) for improved accessibility in multi-family housing. The idea behind the new DSS was that, at its core, it should contain a database with valid information about environmental barriers, and housing accessibility, and the skills of the persons using the database (Jonsson et al., 2021). The idea was that the DSS would facilitate decision-making and collaboration among the professionals involved in health care and social services, planning, and housing provision, as well as citizens who are representing present or future residents of multi-family housing. A research team, a public housing company and a software development company were responsible for the design and implementation of the project.

Study III was conducted as part of the Panel Study on User Involvement in Research on Ageing and Health (onwards referred to as the Panel Study). It is an empirical project of the UserAge program that aims to determine the awareness of and attitudes toward user involvement in research on ageing and health among different categories of users (people aged 60 years and older, informal carers, and professionals in health care and architecture) and researchers over time (Kylén et al., 2020). The panel study was designed as a survey with a data collection period from autumn 2019 to spring 2020 (baseline) and a first follow-up in 2022. The panel study includes surveys aimed at different categories of users and with data collection occurred across multiple study waves.

Study IV was conducted as part of the four-year (2019-2022) project Socially Sustainable Housing Policies for People Ageing with Disability: Producing a Knowledge Base Supporting Participation and Active Citizenship (onwards referred to as Sustain@home) (Forte grant no. 2018-01793). The project had the overarching aim to generate new knowledge on challenges and opportunities in housing for older people, in particular for those ageing with disabilities, thereby contributing to research-based and socially sustainable housing policies that support participation and active citizenship. Sustain@home consisted of four studies, whereof the Housing Experiment (HX) was one. HX was a large-scale citizen science initiative in the area of housing accessibility, with older adults and people with disabilities as the main target groups. The aim of the HX was to engage people across Sweden to assess environmental barriers in the ordinary housing stock, using a mobile application developed for this purpose (Granbom et al., 2023, forthcoming) and to perform analyses using the public database on the HX website based on the collected data. The idea was that the users could use the collected data as support for further discussions about accessibility with, for example, policymakers and with the wider society. HX was implemented in a collaboration between the association Public & Science and researchers at CASE, involving the three largest Swedish senior citizens associations (approximately 695,000 members in total) as well as the micro-sized software enterprise miThings.

Overview of the studies comprising the thesis

Although the focus of the thesis as a whole was *on* user involvement in research on ageing and health, not all of the studies included in this thesis shared this focus (Table 3); Two studies comprised research *with* user involvement (Study I & II), and two studies constituted research *about* user involvement (Study III & IV). Research *with* user involvement here refers to that one or several categories of users have been involved in the research process. Research *about* user involvement here means that the focus of the research has primarily been to gain knowledge about one or more categories of users' perceptions of or benefits of user involvement.

Table 3. Overview of the studies of the thesis

	Study I	**Study II**	**Study III**	**Study IV**
Focus	Research *with* user involvement	Research *with* user involvement	Research *about* user involvement	Research *about* user involvement
Users/ Study participants	People older than 55 years with mild cognitive imparement (n = 19) and their informal caregivers (n = 19) in Sweden and Spain (N = 38).	Persons representing various groups of users[1] with an interest and experience of issues related to housing and health in Sweden (N = 12).	People aged 60 years or older in Sweden (N = 881).	Older people and persons with functional impairments in Sweden (N = 147).
Data collection/ Generating the analysis material[2]	Usability testing	Research circle	Survey, three alternative administration modes	Online questionnaires before and after the completion of Housing Experiment
Data analysis/ Analysing the generated material[2]	User satisfaction evaluation, descriptive statistics	Deductive content analysis	Desciptive statistical analysis, logistic regression	Descriptive statistical analysis, paired-sample sign test

[1] The users were representatives from Public housing companies (n=3), Municipal building administration (n=2), National senior citizens' organization (n=1), Municipal health care administration (n=2), Private service provider within the assistive device sector (n=1), Private architecture and engineering consultancy (n=1), National public authority (National Board of Health and Welfare) (n=1), Business developer (n=1).

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[2] Since, the concept of 'Data collection' did not fit with regards to the users' involvement in Study II, the term 'Generating the analysis material' was employed instead. Following this logic the 'Data analysis' stage was renamed to 'Analysing the generated material'.

In Study I the user groups involved were people older than 55 years with mild cognitive impairment and their informal caregivers in Sweden and Spain. They were involved in the usability testing of a tablet application (the mHealth application SMART4MD) aimed to support people with mild cognitive impairment in their everyday life.

In Study II, the individuals involved were persons representing various categories of users[1] with an interest and experience of issues related to housing and health in Sweden. They were involved in a series of meetings – with a set-up based on the *Research Circle* methodology – to discuss and approach an understanding of the problem of providing accessible housing to the ageing population in Sweden.

Since the two studies in the thesis about user involvement (Study III & IV) were quantitative studies, the people who took part in the study were not refered to as users but as study participants. In Study III, the study participants were people aged 60 years or older in Sweden, and their participation consisted of responding to a survey in one out of three modes: online, on paper, or by telephone. In Study IV, the study participants were older people and persons with functional impairments in Sweden. They participated in the study by responding to two separate questionnaires that were available online. While Study III investigated the study participants' awareness of and attitudes towards being actively involved in research on ageing and health in general terms, Study IV aimed to investigate the study participants' views on involving in one specific project: The Citizen Science initiative the *Housing Experiment*.

After this overall description of the four studies, here follows a more detailed account of each of them in turn.

Study I

Focus

This study constitutes research *with* user involvement.

Users

The recruitment of users took place partly in different ways at the two sites where the study was conducted in parallel.

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[1] The users were representatives from Public housing companies (n=3), Municipal building administration (n=2), National senior citizens' organization (n=1), Municipal health care administration (n=2), Private service provider within the assistive device sector (n=1), Private architecture and engineering consultancy (n=1), National public authority (National Board of Health and Welfare) (n=1), Business developer (n=1).

In Sweden, people who had previously shown an interest in the study after hearing about it through one or several local channels (meetings, posters, radio, mailings) were contacted. A pre-screening interview was conducted via telephone with the potential users. The pre-screening interview consisted of questions relating to the eligibility criteria for the project and focused on age, type of dwelling, the presence of an informal caregiver, and self-rated memory. The pre-screening was a way to roughly sort potential users before the actual screening. The screening was conducted in a clinical environment where, among other things, cognitive ability and the degree of depression were assessed through valid instruments to ensure that the eligibility criteria were met. For a complete account of the screening procedure and the eligibility criteria, see Appendix 1. In Spain, potential users were identified by reviewing patient databases linked to one primary care center and one hospital associated with CST. Potential users were then contacted via telephone and asked if they were interested in participating in the study. The patient databases used in Spain contained information on the age and cognitive ability of the patients, and thus the telephone calls were primarily made to identify individual interest in participating. In Sweden, the situation was quite different. There, it was known that there was interest in participating, but there was uncertainty as to whether potential users had cognitive impairment or had reached the target age.

All the potential users who met the pre-screening criteria were sent information about the study. They were then given a period of reflection to consider whether they wished to participate. The selected user-carer dyads who consented to participation then moved on to the screening procedure and, if they fulfilled all the eligibility criteria, to the feasibility-usability study. For a more detailed description of the screening procedure, see Appendix 1.

The users who consented to participation consisted of 19 user-carer dyads, which consisted of one individual with with mild cognitive impairment (n = 19) and his/her informal caregiver (n = 19). The motive for also including informal caregivers as users was because they were considered necessary to provide support when using the app. That informal caregivers constitute an important category of users with good conditions to be involved in research is something that is indicated by previous research (Malm, 2021).

Table 4 provides the characteristics of the users in the study. Worth noting is that users with mild cognitive impairment in Spain had substantially less experience handling mobile digital devices, such as smartphones and tablets, than users in Sweden.

Table 4. Characteristics of the users and participants in Studies I-IV

	Study I (N = 38[1])					**Study II (N =12)**	**Study III (N = 881)**	**Study IV (N =147)**	
	BTH: PwMCI[2] (n=9)	**BTH: IC[3] (n=9)**	**CST: PwMCI[2] (n=10)**	**CST: IC[3] (n=10)**	**Total (N=38[1])**			**FSP (n = 100)**	**PSP (n = 47)**
Sex, % men	67	55	50	70	61	58	47	44	37
Mean age (years)	77	68	80	64	72	N/A	72	73	75
Average MMSE[4]	25.2	N/A	23.4	N/A	N/A	N/A	N/A	N/A	N/A
Experience with MDD[5]	56% had used MDD[5] almost every day last 3 months	-	70% had never used an MDD[5]	-	N/A	N/A	N/A	99% had downloaded apps before; 51% had downloaded app last week.	85% had downloaded apps before; 28% downloaded app last week.

[1] Total number of individuals = 38. This corresponds to 19 user-carer dyads. Each dyad contained one person with mild cognitive impairment and one informal carer. Study I included 9 dyads at BTH (Sweden) and 10 dyads at CST (Spain)

2PwMCI = Persons with mild cognitive impairment 3Informal caregivers 4Mini-Mental State (Folstein et al., 1975)

5Mobile digital devices = smartphones or tablets

Data collection

The study setup contained two stages. The first stage was an initial usability testing session (Nielsen, 1993) using the mHealth application on a tablet in a clinical environment. This was followed by a four-week test period in the user-carer dyads' home environments ending with a user satisfaction evaluation conducted through a structured interview in a clinical environment. This setup was inspired by a previous study (Sheehan & Lucero, 2015) where it was considered a suitable method to combine the validation of changes (based on earlier iterations of user feedback) with an assessment of specific features. The assessment method used for usability testing was a task analysis (Dumas & Redish, 1999), where the persons with mild cognitive impairments and informal caregivers performed several predefined tasks individually. To ensure valuable feedback is collected using this method, it is recommended that each task is performed by a minimum of five users (Goodman et al., 2012), and the testing was designed accordingly. For a more detailed description of the task analysis, see Appendix 2.

During the four-week test period, the user-carer dyads were offered the opportunity to receive a weekly call from the research team, which all users agreed to. The purpose of the weekly call was to determine whether the user-carer dyads needed assistance with the tablet or the mHealth application. All contacts with the users during the test period were logged and all questions and problems they reported were registered. A user satisfaction evaluation was scheduled in the clinical environment at the end of the test period. It was based on the most significant quality attributes for general user satisfaction among users of similar health information technology (Eivazzadeh et al., 2016) and on principles that provide the foundation for web accessibility according to WCAG 2.0 conformance requirements (Web Accessibility Initiative, 2019).

The user satisfaction evaluation was conducted through a structured interview with the person with mild cognitive impairment and informal caregiver separately. Here, they were asked to rate the extent to which they agreed with five statements each representing a quality aspect (Table 5). The response alternatives were: 1 = Strongly disagree; 2 = Disagree.; 3 = Neither agree nor disagree; 4 = Agree; 5 = Strongly agree. Based on a user's response to all five statements, a sum score was calculated, with a range of 5-25. In connection with the structured interview, all perceived difficulties and areas of improvement reported by the users were registered.

Table 5. The quality aspects included in the user satisfaction evaluation and the corresponding statesments used for assessments

Quality aspect[1]	Statement
Accessibility	I find the application easily accessible.
Safety and Trustability	I feel that I can trust the application and that it is safe to use.
Perceivability	I find it easy to understand how to operate the application.
Understandability	I am able to understand all the information presented in the application.
Empowerment	I feel that the application gave me a better control over my daily situation.

[1]Based on quality attributes from Eivazzadeh et al., (2016) and principles from Web Accessibility Initiative (2019).

Data analysis

The user satisfaction evaluation was analyzed as follows (ref?): if a person had a minimum total score of 60% (15 out of 25) or more, he/she was considered to be satisfied with the mHealth application. According to the standard operating protocol for SMART4MD, the feasibility study was to be considered successfull if at least 15 of the 20 user-carer dyads (75%) were satisfied with use of the mHealth application.

Throughout the course of the feasibility-usability study, the most relevant issues regarding feasibility and usability described by the user-carer dyads were continuously registered and summarized. Descriptive statistics were used to summarize the data. This information was then provided to the developers of the mHealth application to improve the usability. It was also used as a complement to the results from the user satisfaction evaluation in order to summarize the user feedback and the lessons learned in the study.

Study II

Focus

Research *with* user involvement.

Users

Study II included 12 participants, who represented various user groups with an interest in, and experience of issues related to housing and health (see Appendix 3 for more details). Recruitment was based on purposive sampling (Patton, 2015) via two channels: (1) A list of persons who had previously shown interest in participating in research at CASE; (2) persons who were encountered during the planning and start-up of the project. Homogeneity was reached as all users had an interest in, and experience of issues related to housing and health. Heterogeneity was attained using professional position, organization, and sex as selection criteria.

Generating the analysis material

The part of the project that forms the basis of this study was a research circle with three sessions, which involved three researchers and twelve users. The research circle methodology is a joint educational and exploratory group setting, promoting active collaboration and mutual learning opportunities on equal terms between user groups and researchers (Härnsten, 1994; Haak et al., 2015; Löfqvist et al., 2018). In a research circle the aim is to reach consensus at the end of the discussions and, for example, agree upon a list of items or a product or service that can be used or applied in the existing organization(s), or developed further in forthcoming steps (Löfqvist et al., 2018).

The research circle was planned and structured around the initial aim of Study II; an aim that was later revised. The initial aim of the study was to gain an understanding of the opportunities and challenges potential users of the DSS observed in relation to the development, implementation, and commercialization of the new system. This study aim was later revised to: To gain an understanding of crucial variables in decision-making related to providing accessible housing to the ageing population in Sweden.

The researchers hosted the first and third sessions, which were held in conference rooms at the university. By a joint decision, a public housing company hosted the second session. In the first session, the theme concerned how problems addressed by the new DSS were currently solved. The theme of the second session concerned the potential outcomes and practical applications of the new DSS. The theme of the third session concerned the identification of potential customer segments and the development of a draft business plan for the new DSS. Two of the researchers assumed the role of moderators in the research circle sessions. The author of this thesis participated in the third session by taking notes. The data for Study II consisted of transcribed audio recordings from three research circle sessions, which were scheduled for three hours each.

Analysing the generated material

The audio recordings from the research circle sessions were transcribed by the author of this thesis. A deductive manifest content analysis was applied as described by Elo and Kyngäs (2008), focusing on the ten characteristic attributes of wicked problems (Rittel & Webber, 1973). Wicked problems have been defined as "a class of social system problems considered to be ill-formulated, where information is confusing, and where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing" (Churchman, 1967, p. 141). In 1973, Rittel and Webber formulated ten characteristic attributes of wicked problems (Appendix 4) that were used as a focus of analysis. In addition, Brown et al. (2019) developed a conceptual five-dimension framework (Appendix 5), which was used as a grid to sort or extract crucial variables for decision-making in relation to the provision of accessible housing. The generated material was reviewed for such crucial variables, coded in emerging categories, and sorted into the five dimensions. The emerging findings were validated repeatedly through communication between all authors, as well as through input from interdisciplinary research seminars.

Study III

Focus

Research *about* user involvement.

Participants

The panel study aimed to collect a sample representative of the total population of people 60 years or older residing in Sweden. Based on population data from Statistics Sweden (SCB, 2022), approximately 2.66 million (53% women) people aged 60 years and older were residing in Sweden at the time of the study. Using a confidence level of 95% and a margin of error of 4, a total sample size of 1,200 was estimated to be representative (Cochran, 1977) of the targeted population. Based on previous experience (Ryan et al., 2016) and a pilot study, the expected response rate was estimated to 50–60%. Hence, for the number of respondents to meet the requirements for size and power, the questionnaire should be sent out to 3,427 individuals, and this number was thus randomly selected from the National Population Register.

The survey questionnaire was constructed based on existing literature and input from researchers in the UserAge program. Next, a user forum consisting of eight persons aged 70 to 84 years and three researchers was formed (Kylén, et al., forthcoming). During three sessions, the user forum refined the survey for readability and time/length to complete. The user representatives involved were familiar with both the research conducted at CASE and the terminology employed in the discourse on user involvement in research on ageing and health. The discussions that arose between researchers and user representatives concerned the following methodological questions: a) age range of target group; b) scales for instruments; c) scope of the survey; d) format of the survey (email, letter, telephone interview, etc.). The discussions included linguistical questions such as using an appropriate vocabulary for the survey and information letter sent to potential respondents. The work largely consisted of achieving a balance between clarity and a reasonable workload for the target group versus the scientific demands for consistency and the aim to cover all relevant aspects of the phenomenon under study.

A professional survey company was commissioned for the practical implementation of the survey, which opened in late August 2019 and closed in November 2019. Potential respondents received an invitation letter by mail including instructions on how to complete the survey online, on paper, or by telephone. About two weeks later, those who did not complete the survey online were contacted by phone by the survey company and reminded about the three options to complete the survey. To assess the quality of data collection, one researcher listened in on 5% of all telephone interviews. After 10% of the surveys had been answered, a quality check of the data that had been collected so far was carried out by the survey company.

In total, 881 persons completed the survey (26% response rate): 41% (n = 361) online, 32% (n = 282) on paper and 27% (n = 238) via telephone. The respondents were 60–97 years old with a mean age of 72.2 (SD = 7.30) years. The sex distribution in the sample was 52.9% (n = 462) women and 47.1% (n = 412) men. In terms of education, 24.2% (n = 210) reported elementary school as their highest level of education, 17.9% (n = 155) upper secondary school, 23.2% (n = 201) college less than three years and 34.8% (n = 302) college three years or more.

Data collection

Study III was based on baseline survey data targeting the population aged 60 years and older in Sweden. The survey included 27 questions divided into the following sections: Awareness of and previous experience of public involvement in research (Q1-4); Attitudes towards public involvement in research (Q5); Interest in research and willingness to be actively involved in research (Q6-8); Facilitators and barriers for public involvement in research (Q9-13); Demographic questions (Q14-22); Self-rated health and frailty (Q23-27). For a detailed description of the questions, see Appendix 6. The quantitative data for Study III consisted of 881 completed survey questionnaires.

Data analysis

Univariate analyses were applied to describe the sample in terms of demographics and to provide descriptions of the respondents' awareness of attitudes towards, and willingness to participate in research. Bivariate analyses were applied to test how awareness and previous experience of public involvement in research related to various respondent characteristics. The chi-square test ($\chi 2$) was used in relation to variables that had a nominal scale, and the Mann Whitney test was used for variables that had either a continuous or an ordinal scale.

Next, an initial logistic regression model was set up to investigate how various independent variables related to willingness to be actively involved in research on ageing and health (dependent variable). Before the model was set up, multicollinearity between the independent variables was checked using Pearson correlation coefficient.

Study IV

Focus

Research *about* user involvement.

Participants

The study participants in Study IV consisted of older people (≥ 65 years) who were members of senior citizens' organizations, and persons with functional impairments who were members of disability organizations. The reason why the latter group was also included here was because there are points of contact between the groups at least in certain areas since high age is associated with an increased prevalence of functional impairments (Brown et al., 2017). There are common questions of interest even if the research in these areas is to some extent conducted in parallel and constitutes separate research areas: Ageing research and disability research, which is a research area focusing on the study of people who, regardless of age, have functional impairments and how they can be supported (Joss et al., 2016). The study participants constituted the respondents to a survey containing two online questionnaires to be answered before (pre-Q) and after (post-Q) participation in the Citizen Science (CS) initiative Housing Experiment (HX).

The pre-Q and post-Q were constructed based on existing literature and then drafted and revised in several rounds by the research team, including input from three older persons (not among the study participants). These individuals were recruited through snowballing from the network of the author of this thesis. During a two-week period, the three older persons individually provided feedback on the questionnaires and on the information letter that was to be sent out to potential participants. The input and suggested changes from the three persons were then discussed among the researchers before the final versions were developed.

The study participants were recruited using two methods. The first was through an email invitation sent to members of local branches of senior citizen associations and interest groups for persons with functional impairments in southern Sweden, (selected through convenience sampling). Attempts were made within the CS initiative as a whole and in this study to also seek interest from these groups as well because they were considered to be groups with the potential to have a strong interest in these issues. Out of 14 associations and interest groups contacted, 11 agreed to participate by distributing information about the study by email to their members. Approximately 2,500 potential participants received an email. Participants were also recruited via the support function (by email, telephone, and Facebook) of HX, by informing people who made contact of the possibility of participating in the study.

In total, 147 persons completed the pre-Q (~6% response rate) and 115 persons completed the post-Q (~5% response rate) (Figure 1). The study participants were divided into two groups: “full study participants” and “partial study participants.” The term “full study participants” was used for those who confirmed their involvement in the HX in the post-Q (n = 100). “Partial study participants” was used for those who filled out the pre-Q but did not take part in the HX and/or did not respond to the post-Q (n = 47).

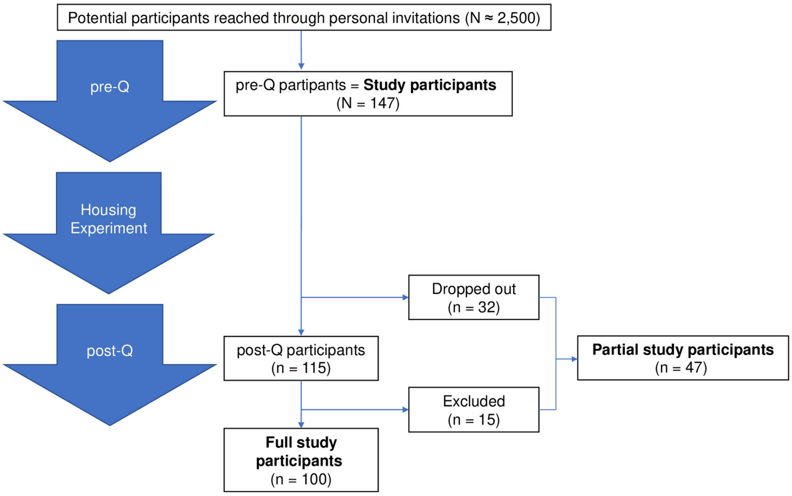

Figure 1 Flowchart of participation in the three parts of the study (pre-Questionnaire, pre-Q; Housing Experiment; post-Questionnaire, post-Q) resulting in the two groups compared in the study: Full study participants and Partial study participants.

The full study participants (n = 100) had a mean age of 72.9 (SD = 8.1) years; 56% women and 44% men. In terms of education, 16% stated elementary school as the highest level of education, 17% upper secondary school, and 67% tertiary education. The full study participants had substantially more experience downloading mobile applications compared to the partial participants.

Data collection

Study IV consisted of a survey with a quantitative before-and-after design with data collected via two online questionnaires to be answered before (pre-Q) and after (post-Q) the completion of the HX. The pre-Q included 27 questions, and the post-Q included 18. The questions concerned demographics, health and functioning, housing tenure, previous research experience, work experience in the housing sector, previous experience with mobile digital devices, involvement in the HX, attitudes towards housing accessibility and research and mobile digital literacy. For a more detailed description of the questions, see Appendix 7.

Data analysis

Univariate analyses were applied to describe the samples in terms of demographics and other characteristics as well as to describe the involvement of full study participants in the HX.

Bivariate analyses were applied to investigate a) differences in characteristics between full and partial study participants; b) how changes in attitudes or digital literacy related to demographics, functioning, housing tenure, previous research experience, work experience in the housing sector, and previous experience with mobile digital devices. The chi-square test ($\chi 2$) was used for variables that had a nominal scale, and the Mann Whitney test was used for variables that had either a continuous or an ordinal scale.

Moreover, a paired-sampled sign test was used to conduct a within-subjects comparison to investigate changes in attitudes and digital literacy from pre-Q to post-Q among the full study participants. Only those who reported different responses in the pre-Q and post-Q were included. In this way, the proportions of full study participants who rated their attitudes and digital literacy lower after participation in the HX was compared to the proportion who rated them higher. Descriptive statistics were used to account for the distribution of response alternatives for those who did not report any change.

Using an adapted conceptual tool to categorize the user involvement in or covered by studies I-IV

To address the overall aim of the thesis, additional categorizations were carried out based on Studies I-IV. This categorization was based on the first step in a deductive content analysis, which consists of the development of a categorization matrix (Elo & Kyngäs, 2007). A categorization matrix is usually based on previous work such as theories, models or literature reviews (Polit & Beck 2004, Hsieh & Shannon 2005). Thus, a categorization matrix was created, which was largely based on the conceptual tool (SAPO) containing four considerations of user involvement (Why?; Who?; When?; How much?) formulated by Jönson et al. (2021) as part of the UserAge program. For each of these four considerations, theories, models and literature reviews that contained appropriate categorizations were sought. The categorization matrix used is presented in Table 7.

The four considerations of the adapted conceptual tool

Regarding the type of aim, that is, the “Why?” of user involvement, a scoping review by Pedersen et al. (2022) identifying five types of aims of public involvement with participatory or community-based approaches was used, with a few adjustments to the terminology (see Table 7 for details).

In contrast to the considerations in Jönson et al., "Who?", "When?" and “How much?”, the concepts of “breadth”, “scope”, and “depth” were used, which were inspired by an interdisciplinary framework developed by Harder et al. (2013). Furthermore, the categorization of breadth (“Who?”) was also inspired by Harder et al. (2013). For the categorization of scope (“When?”), Gelling’s (2015) proposed division of the research process into ten stages was used. For depth (“How much?”), a categorization made by Harder et al. (2013) was used. In some cases, the terminology in these categorizations was slightly adapted to increase clarity and uniformity (see Table 7 for details).

The material used for this analysis consisted of the descriptions of the aims and methods from the original published papers for studies I-III and from the unpublished manuscript for Study IV. The categorization matrix was used as a grid to sort the various considerations of user involvement made into the listed categories.

How the categorization was applied to studies I-IV

As the four studies in this thesis differed in terms of their focus, it meant that the application of the categorization matrix was done in slightly different ways for the different studies.

For studies I & II, which consisted of research *with* user involvement, the categorization was based on the user involvement included in each study.

For study III & IV, which both consisted of research *about* user involvement, the categorization was based on what kind of user involvement the survey and questionnaires *covered* in terms of aims, breadth, scope and depth. Study III covered user involvement in research as a phenomenon rather than linked to a specific research project or occasion. In Study IV's case the user involvement covered the user involvement in the Citizen Science (CS) initiative, the Housing Experiment. For this study, the categorization was based on the user involvement by the study participants who in the second of the two questionnaires confirmed their involvement in the Citizen Science initiative.

Ethical considerations

The four studies included in this thesis were conducted in accordance with the Declaration of Helsinki (WMA, 2013) and the Swedish Ethical Review Act (SFS 2003:460). Formal ethical approval was obtained from the Ethical Review Board in Lund for Study I (No. 2016/470) and Study III (No. 2018/986) and from the Swedish Ethical Review Authority for Study IV (No. 2021/02256). As Study I was also conducted in Spain, ethical approval was sought and granted from the Consorci Sanitari de Terrassa Ethics Committee (25 April 2016). No formal ethical approval was considered necessary for Study II, as according to applicable legislation in Sweden, formal ethical approval is not required for studies that do not include material concerning sensitive personal data and do not include interventions involving human subjects.

Beyond formal and informal ethical approvals

Ethical considerations entail more than adherence to the Declaration of Helsinki and securing formal ethical approval from relevant ethics review authorities. Acting in an ethical manner is not primarily about meeting formal ethical requirements. A fundamental part of ethically sound research is ensuring that throughout the research process, researchers reflect on whether the potential benefits of the study outweigh the burdens and risks to the individuals involved in the research (WMA, 2013).

In this thesis, several such potential burdens and risks have been identified. One risk is that participants and user representatives may perceive that they have not been sufficiently informed about the study and what participation or involvement entails. Another issue could be that participants are concerned that sensitive information has not been handled properly. An additional risk may be that financial incentives have coerced or strongly pushed participants into involvement against their will. Below is an account of how these potential burdens and risks have been handled in the various studies in the thesis.

Ensuring that participants and users made informed decisions

In Study I, the user-carer dyads' first received written information about the SMART4MD project and the feasibility-usability study, which was sent to their home address. This information was further presented verbally at their first visit to the clinical site, to ensure that they fully understood what their involvement in the study entailed. If the user-carer dyads consented to participation, they were asked to sign an informed consent document. The original signed document was kept by the clinical site and a copy of the signed document was given to the user-carer dyad.

In Study II, the basic principles of research ethics were followed although formal permission was not considered necessary. All user representatives received written and verbal information about the background, context, aim and set-up of the research circle and were encouraged to ask questions if something was unclear. The user representatives signed an informed consent at the start of the first research circle session including information on voluntariness, the option to drop out, confidentiality, and on the storage and use of audio recording.

In Study III, the invitation letter that was mailed to all potential study participants included information on the background and purpose of the panel study (Kylén et al., 2020) in which the study was included. Potential study participants were informed that participation was voluntary, that they had the right to discontinue their participation at any time, and that data would be handled in accordance with the General Data Protection Regulation (GDPR) and local data protection guidelines. In addition, verbal information was provided by staff from the survey company who specialized in conducting telephone interviews and had undergone project-specific training. Each study participant signed an informed consent either by completing the survey online or on paper. Verbal informed consent was documented by the telephone interviewers.

In Study IV, the invitation email that was sent to all potential study participants included a link to the HX website with information on the background and purpose of the study. Before study participants could answer the pre-Q, they had to sign an informed consent. As part of the informed consent, the participants were asked to confirm that they had understood that participation was voluntary, that they had the right to discontinue their participation at any time, and that data would be handled in accordance with the General Data Protection Regulation (GDPR) and local data protection guidelines.

Safe handling of confidential data

Throughout the four studies all data was handled in accordance with the General Data Protection Regulation (GDPR) and local data protection guidelines.

In Study I, all confidential digital material was stored in secure folders on computers that were only accessible by the principal investigator at each site and the clinical study staff involved in the study. When not being used for the analysis, non-digital material, such as notes from the usability testing, were kept in secure lockers only accessible to the principal investigator and the clinical study staff at each site.

During the analysis stage in Study II, audio recordings and transcriptions were stored on a password-protected computer owned by the author of this thesis. When the data analysis was completed, the audio recordings and transcriptions were transferred to and stored in a high-security platform (LUSEC) at the Faculty of Medicine, Lund University.

In Study III, the data were encrypted and stored by the survey company in a secure database, then transferred to the researchers and stored in LUSEC. Only project researchers had access to the data. In Study IV, the data were stored in LUSEC with only project researchers having access to the data.

Compensation and financial incentives

In studies I & III, no compensation or financial incentive were offered. In Study II, the user representatives were offered financial compensation for their travel costs and refreshments were provided. In Study III, the persons participating in the user forum were offered compensation for travel costs and if they were unable to attend during their working hours, compensation of SEK 550 per meeting was provided. In Study IV, all study participants who answered both the pre-Q and post-Q received a lottery ticket (value SEK 30).

Ethical challenges and dilemmas arising from user involvement in research

User involvement in research has introduced new ethical challenges and dilemmas that have not been sufficiently addressed (Iwarsson et al., 2019). Active user involvement, including increased interactions and the establishment of more far-reaching relationships between researchers and users may result in unforeseen ethical dilemmas (Øye et al., 2019). This, in turn, may require researchers to alter plans and make new decisions during the course of the research process.

This thesis includes research conducted using conventional ways with study participants answering questionnaires (Studies III & IV), as well as research conducted using methods that include the involvement of user representatives (studies I & II). For example, in terms of user involvement in Study I, the researchers' and user representatives' roles were clearly defined beforehand. User involvement was limited to a certain part of the research process, and the types of ethical dilemmas described above did not arise. In Study II, the user representatives and researchers worked in an integrated manner during three research circle sessions. This implied that persons with different experiences related to housing and health were consulted, exchanged experiences, shared knowledge, and influenced the research process. This presented a number of challenges, as potential ethical challenges and dilemmas needed to be balanced against the need for trust building, dialogue, mutual learning, and consensus discussions in order to plan, adapt and clarify the distribution of roles in the research process.

Findings

The Findings section consists of two parts. In the first part, the results based on the specific aims that relate to the original questions from Study I-IV are reported. Next, the findings relating to the overall aim of the thesis is presented.

Evaluation of the design of an mHealth application (Study I)

The main finding in Study I was that the mHealth application was considered good enough to take the project SMART4MD forward to the next stage, which consisted of launching the full-scale RCT. The mHealth application approval was based on an 81% satisfaction rate for usability (see Appendix 8 for details). In addition, a summary of the user feedback and the lessons learned was developed (see Table 6).

Concerning the users' ability to use and attitude toward the tablet and the mHealth application, there were two major findings. First, the large differences in the users' mobile digital literacy, which is: ability to handle digital devices such as smartphones and tablets. Secondly, users had more difficulties than expected related to the use of the tablet itself (for example: how to turn it on and off, launch the mHealth application or find keyboard or specific keys).

When it comes to lessons learned related to the development of the mHealth application, one insight rooted in feedback from both users and researchers was that a closer relationship with more "common ground" between the software developers and the users would have made the process easier and required less iterations in the design process. This emerged in basic usability issues such as the font size that was way too small to be readable by most users, and cases where essential information was only displayed on the screen for a very short time. There were several such basic usability issues at the initial stage that required many iterations in the design process that could have been avoided if the distance between the software developers and the intended users had been shorter, both physically but also in terms of "common ground".

Table 6. Summary of the user-carer feedback and lessons learnt in Study I

Subject matter	**User feedback and lessons learned**
Users' ability and attitude towards tablet and mHealth application	Large variation in mobile digital literacy; while some had problems turning tablet on and off, others complained about limitations compared to what other applications could do.
	Many persons with mild cognitive impairment had difficulties in handling tablet and mHealth application, but also some informal caregivers.
	Level of literacy largely shaped the ease of handling the tablet and mHealth application was handled and the confidence in one's own ability.
	More difficulties than expected related to the use of the tablet itself (e.g. how to turn it on and off, launch the mHealth application or find keyboard or specific keys).
	People 90 years or older found tablet and mHealth application challenging, due to overall bodily function, (e.g. swollen fingers and limited vision), and reported having low motivation learn to use the. Application.
Introduction to and usability testing of mHealth application	An intro to the tablet and mHealth application adjusted to the level of the person in dyad with lowest mobile digital literacy seen as crucial to facilitate future usage.
	PwMCI with low mobile digital literacy would have preferred intro with more explicit instructions rather than exploring the mHealth application independently through usability testing.
	A paper-based manual as a complement to the introduction to the mHealth application was requested by some user-carer dyads in order to remember how to use the mHealth application.
Development of mHealth application	More "common ground" between developers of technology and intended users would make the process easier and would require less iterations.
Usability of mHealth application – aspects suggested as potential improvements	Increased clarity: Larger text and icons; clearer lines and contrasts between colours; more easily understood terminology; more explanatory text.
	Increased security: Option to confirm before adding or removing reminder; informative popup-text boxes requiring interaction rather than simply appearing and disappearing on screen.
	More functions: (More alarm signal choices and volume adjustments; better integration of the tablet's camera inside of the mHealth application).

Understanding decision-making about the provision of accessible housing for the ageing population (Study II)

The findings from Study II consisted of insights into crucial variables linked to the complex the problem of providing accessible housing for the ageing population in Sweden. It was argued that the provision of accessible housing meets the criteria to be defined as a wicked problem. Crucial variables were found in all five dimensions of the conceptual framework used as a grid for the analysis, although reasoning in the socioeconomic dimension dominated the discussions (see Appendix 9). Crucial variables belonging to the various dimensions were intertwined in a complex manner. Accessibility and affordability constituted illustrative examples that were raised in the discussions. For example, that major retrofits to improve accessibility in the existing housing stock were seen as risk for increased housing costs and a measure that could force more individuals into homelessness. Moreover, the prevailing organizational structure, which is characterized by a "silo" mentality, was seen as a critical factor and an obstacle to different forms of collaboration. The discussions also emphasized the importance of trying to get citizens in general, and actors within the planning, housing and care sectors specifically, to reflect and act more proactively in terms of accessibility in order to thereby create better conditions for a more accessible housing stock.

How older people perceive active involvement in research on ageing and health (Study III)

Response rate

A total of 3,427 people were informed about the study and asked to participate, and 881 completed the survey (26% response rate): 41% (n = 361) online, 32% (n=282) on paper, and 27% (n = 238) via phone.

Descriptive characteristics

The respondents were 60–97 years old with a mean age of 72.2 (SD=7.30) years. The sex distribution in the sample was 47% (n=412) men and 53% (n=462) women. Regarding education, 24% (n=210) stated elementary school as the highest level of education, 18% (n=155) upper secondary school, 23% (n=201) less than three years of college and 35% (n=302) three years of college or more. Regarding self-rated health, 39% (n=338) reported their health as good, 24% (n=210) as very good and 10% (n=91) as excellent, while 25% (n=216) reported their health as fair and 2.5% (n=22) as poor.

Awareness of and attitudes towards active involvement in research

It was found that 39% (n=343) of the study participants (N=881) were aware that they could be actively involved in research.

A low percentage (14%; n=119) answered that they previously had been involved in research in at least one way. Although only slightly higher than other forms of involvement, participation in communicating research findings was the most common form of involvement (6%; n=50). A similar proportion (5%; n=45) had experience of being part of a user board, reference group/council or similar, had had a consulting role in research, or had conducted interviews or taken measurements and communicated them for use in research.

Both awareness ($p < 0.001$) and previous active involvement in research ($p < 0.001$) were significantly associated with a higher level of education. Almost all study participants (95%; n=776) believed that the possibility for them to involve in research could improve the communication of research results and outreach, and a similar proportion (94%; n=805) thought that they should be actively involved because they could contribute valuable knowledge, insights, and experiences in relation to ageing. Furthermore, 91% (n=778) agreed that it was important for members of the public to be involved in research on ageing and health, especially in publicly funded research. A somewhat smaller proportion regarded their involvement as a way to exercise societal impact (88%; n=743) while an even smaller proportion saw it as a democratic right (83%; n=712). The two statements that the respondents felt were the least in line with their views were that the active involvement of members of the public in research risks jeopardizing the objectivity, independence, and integrity of the research (28%; n=227), and the statement that user involvement in research was only a form of tokenism and had no bearing on the results (15%; n=122).

Willingness to be involved in research

Regarding the willingness to be involved, when asked the question “Would you consider being actively involved in research on ageing and health?,” 41% (n=357) responded that it was something they would consider, 27% (n = 234) that they might consider it and 32% (n = 272) that it was something they would not consider.

A higher level of education was associated with higher odds of being willing to be involved in research. That is, an individual with a college degree of three years or more was 3.2 (95% CI, 2.1–4.9) times more likely to be willing to be actively involved in research compared to a person whose highest level of education was elementary school. For an individual whose highest level of education was upper secondary school, the corresponding odds ratio (OR) was 2.6 (95% CI, 1.6–4.2), and for an individual with a college degree of less than three years, the OR was 1.7 (95% CI, 1.1–2.6). Persons who had previous experience of being involved in research were, on average 5.4 (95% CI, 2.6–11.2) times more likely to be willing to be actively involved again.

Characteristics and attitudinal changes of older people and persons with functional impairments involved in a citizen science initiative (Study IV)

Participant characteristics

Full study participants had more recent experiences of downloading mobile applications to their smartphones or tablets, compared to the partial study participants (n=47) (i.e., those not confirming citizen science involvement). In terms of health and functioning, it was more likely that someone in the household of the partial study participants used a walker or wheelchair (p=0.01) and/or received home care (p=0.02).

Attitudes and attitudinal changes

In terms of attitudes towards housing accessibility, before their citizen science involvement, 89% (n=89) of the full study participants considered housing accessibility to be “quite” to “very” important, while 11% (n=11) considered it not so important. Similar proportions were found for attitudes towards research. In terms of mobile digital literacy, 83% (n=83) regarded themselves as “quite” to “very” knowledgeable when using a smartphone or tablet, while 17% (n=17) considered themselves not so knowledgeable.

In terms of attitudinal changes between pre-Q and post-Q, almost half of the full study participants reported no change in their attitude towards housing accessibility (47%) or research (49%). An even larger proportion reported no changes in their mobile digital literacy (70%).

The only significant attitudinal change that occurred in the study was in a negative direction and related to the attitude to housing accessibility. Here, the question posed to the study participants had been: “How important is physical accessibility in housing to you?” (Not at all important; not so important; quite important; important; very important). In the post-Q it turned out that among those who had changed their attitude towards housing accessibility (n=53; 54%) significantly more people (p = < 0.01) had changed their attitude towards housing accessibility in a negative direction compared to the number of people who had changed their attitude in a positive direction.

User involvement in or covered by studies I-IV

Using an adapted version of a conceptual tool (SAPO) developed by Jönson et al. (2021), outlined earlier in the Introduction section, the thesis studies were categorized to analyse the user involvement within or covered by the studies, see Table 7 below.

Table 7. The adapted conceptual tool[1] used for the categorization of the user involvement in or covered by studies I-IV, including the results of the categorization

Consider-ation	Source	Categorization		Studies			
				I	II	III	IV
Type of aim[2] – Why	Peder-sen et al., 2022[3]	Empowerment				X	X
		Facilitation of dialogue between different user groups and reseachers			X	X	X
		Identifying and understanding users' needs		X	X	X	X
		Ranking and negotiating needs		X	X	X	X
		Involvement in development, design, implementation and evaluation to ensure that interventions are feasible and acceptable		X		X	
Breadth of involve-ment – Who?	Harder et al., 2013	Decision-makers/ leaders			X		
		Project implementors/ staff managers			X		
		Project beneficiaries/ clients		X	X	X	X
		Wider society			X	X	X
Scope of involve-ment – When?	Gelling et al., 2015	Developing the research question				X	
		Searching and evaluating the literature				X	
		Selecting the research approach			X	X	
		Selecting research methods			X	X	
		Gaining access to the research site and data				X	
		Pilot study		X		X	
		Sampling and recruitment			X	X	
		Data collection/ Generating the analysis material			X	X	X
		Data analysis/ Analyzing the generated material				X	X
		Dissemination and implementation				X	X
Depth of involve-ment – How much?	Harder et al., 2013	Level 1: Learning About	Recognition of users with potentially differing views, invited to contribute through consultation, study or listening. However, unlikely that users' opinions will exert any major influence on decision-making.			X	X
		Level 2: Learning From	Active engagement with users, whose views substantially influence and inform decision-making, even if major decisions are still made without them.	X		X	
		Level 3: Learning Together	Interaction, meaningful exchange of information and shared responsibility for planning and decision-making		X	X	
		Level 4: Learning As One	The researcher-user dichotomy is here completely dissolved, and both parties consciously contribute knowledge and skills to achieve common goals. A level representing full partnership, where all decisions are made by consensus.			X	

[1] The adapted conceptual tool was created specifically for this thesis with inspiration from Jönson et al. (2021), Pedersen et al. (2022), Harder et al. (2013) and Gelling et al. (2015).

[2] Aim here refers to the aim(s) of the user involvement method(s) used in the study, which is not necessarily identical to the aim(s) of the study.

[3] Pedersen et al. (2022) use the terms 'participants' and 'participation' which have here been replaced by 'users' and 'involvement' respectively for a consistent terminology in the thesis. Furthermore 'public citizens and policymakers' has been replaced by 'different user groups'.

Type of aim – Why?

Study I – Type of aim(s) motivating the user involvement in the study

In relation to the type of aims listed in the conceptual tool, the main aim with the user involvement in Study I was categorized as *Involvement in development, design, implementation and evaluation to ensure that interventions are feasible and acceptable* (Table 7). The intervention was the mHealth application and the aim of the user involvement in Study I was primarily to provide input during the design process and approve that the mHealth application was feasible and usable for the target group before taking the SMART4MD project forward to the next stage in the research process, which consisted of launching the full-scale RCT. As part of the design work, user involvement in Study I can also be said to contain the aims *Identifying and understanding users' needs* and *Ranking and negotiation of the needs,* since design work is based on identifying and ranking users' needs. In this case, the identified, ranked, and negotiated needs of the users related to the content, aesthetics, and appearance of the mHealth application.

Study II – Type of aim(s) motivating the user involvement in the study

In Study II, the aim with the user involvement belonged to several categories (Table 7). First of all to the *Facilitation of dialogue between different categories of users and researchers.* This was due to that initiating a dialogue of this kind where different categories of users and researchers had the opportunity to meet, aimed to contribute to a greater mutual understanding. Secondly, the aim of user involvement was thus also here about *Identifying and understanding users' needs.* To understand the perspectives and needs of the various users was a prerequisite in order to approach an understanding of the wicked problem of providing accessible housing to the ageing population. In addition, the research circle's method included, in the third session, to identify potential customer segments and to develop a draft business plan for the new decision support system. Thus, the aim of the user involvement in Study II can also be attributed to the category *Ranking and negotiation of the needs.*

Study III – Type of aim(s) motivating the user involvement in the research that the study covered

The survey study revealed that the older participants viewed their involvement in research to a large extent as a means to improve the communication and outreach of research results, which in relation to the types of aims in the conceptual tool can be categorized as *Facilitation of dialogue between different categories of users and researchers*. A large proportion of older participants also regarded their involvement as a means to contribute with valuable knowledge, insights, and experiences of ageing. From a researcher's point of view, this could be seen as older people's involvement in research facilitates both *Identifying and understanding users' needs* and the *Ranking and negotiation of the needs*. The other statements in the survey that older participants largely agreed with were: a) that it was important for members of the public to be involved in research on ageing and health, especially in publicly funded research; b) that their involvement constituted a way of exercising societal impact, and c) that their involvement was to be considered a democratic right. What these three statements have in common is that they express that involvement in research constitutes a form of democratically motivated influence that also entails responsibility. It is not obvious what types of aims the statements corresponds to in the conceptual tool, but there are points in common with both *Involvement in development, design, implementation and evaluation to ensure that interventions are feasible and acceptable* and *Empowerment*. What is expressed together in the three statements (a), b) and c) is arguably a willingness to participate in the process to ensure that it is conducted in the right way but also as a way to give voice to the group that one as a user represents.

Study IV – Type of aim(s) motivating the user involvement in the research that the study covered

The research that Study IV covered was the citizen science (CS) initiative, namely the Housing Experiment (HX). The user involvement in the HX had two overarching aims. The first was to obtain data about the prevalence of environmental barriers in the Swedish housing stock. However, this data collection phase was seen as a steppingstone to the next step which was to, through the analysis of this data, obtain knowledge of which barriers were most common, and what accessibility looked like for different housing types, different municipalities and nationally. This knowledge was then, within HX, regarded as a way to approach the identification and ranking of how potential accessibility measures should be prioritized. Thus, in relation to the types of aims listed in the conceptual tool, this aim corresponds to both *Identifying and understanding users' needs* and *Ranking and negotiation of the needs*. The users refer here, for the sake of clarity, to the 100 full study participants who completed the HX. The understanding of "their" needs in this case is not about their needs as individuals, but the needs that they represent in the role of users, which they expressed through their measurements.

The second overarching aim of the HX, was that the involvement in the project might lead to certain benefits for the users involved. Such as that through their involvement, the users might get a clearer picture of what research could entail and perhaps thereby a greater interest in it. Or that the importance that they assigned to the issue of housing accessibility would increase after the HX. Since the involvement took place through the use of an application on a smartphone or tablet, a potential benefit was also that the involvement in the research had a potential to lead to a strengthening of the users' mobile digital literacy. Moreover, that the users would interact with the in-real-time-updated and successively growing database of registered environmental barriers presented on the HX website. The idea being that they could use this data as a support for further discussions about accessibility with, for example, policymakers, health care practitioners and with the wider society. Taken together, these potential benefits could be said to correspond to potentially leading to potential to *Empowerment* (among the types of aims listed in the conceptual tool), since they all aim to strengthen the abilities and influence of the individual users and the category or categories they represent. Nevertheless, as previously stated in the findings, none of these gains were subsequently actually obtained.

Breadth of involvement – Who?

Study I – Type of users involved in the study

The user-carer dyads involved were representatives of the intended target group and can thus be categorized as *Project beneficiaries/clients* (Table 7).

Study II – Type of users involved in the study

The users involved in Study II represented various categories of users with an interest and experience of issues related to housing and health. On an overall level, they can thus be categorized as *Project beneficiaries/clients* (Table 7) of the project who had the overarching aim to develop, test, and evaluate a new DSS and its outputs. In addition, certain users involved can also be said to belong to the category *Decision-makers/ leaders*, namely the chief executive officers (CEOs) of two public housing companies, an executive director of municipal health care, and a representative of the National Board of Health and Welfare, all of whom had the power to make influential decisions. Moreover, Study II also involved users who can be categorized as *Project implementors/ staff managers*, namely the representatives of companies working with innovation and development, the municipal building administration and the municipal health care administration. There was also one user involved in the research circle who represented *Wider society* as a member of a national senior citizens' organization.

Study III – Type of users covered by the study

Study III provided a way to acquire knowledge about how user involvement in research was perceived by older people in the general population of Sweden. It can be argued that it is knowledge deemed to be useful for researchers in the design of future studies with user involvement. However, it is also of potential benefit to today's and tomorrow's older people as the knowledge has the potential to improve research with the involvement of older people but also to contribute to improving the situation of older people in the long term, as well as to improving society at large. In that sense, the type of users that Study III covers can therefore be said to be *Project beneficiaries/clients* (Table 7) but also representatives of the *Wider society.*

Study IV – Type of users covered by the study

Considering Study IV, the aim with the user involvement covered in this study was twofold. It was partly about contributing to obtain a large, and for researchers alone inaccessible, amount of data about the prevalence of environmental barriers in the Swedish housing stock. There was also an ambition that the user involvement might lead to benefits for the users involved in terms of a greater interest in research and a stronger commitment to the issue of housing accessibility. Since the involvement occured through the use of an application on a smartphone or tablet, there was also a rationale that the involvement in the research had a potential to lead to a strengthening of the users' mobile digital literacy. It was the assessment of these gains that were the aim of Study IV. In terms of such potential gains, the type of users that Study IV covered can be said to be *Project beneficiaries/clients.* There was also a rationale that the users would be able to use the collected data of the prevalence of environmental barriers as support for further discussions about accessibility with, for example, policymakers and with the wider society. Additionally, that these kind of discussions supported by reliable data could in the long run lead to constructive accessibility measures and a more accessible society. From this perspective, the users covered by Study IV cannot simply be considered as *Project beneficiaries/clients* but can also be regarded as representatives of the general public, and thus the *Wider society.*

Scope of involvement – When?

Study I – Stages in the research process in which the users were involved

The usability testing constituted a type of pilot study as its aim was to ensure that the mHealth application was adequate to take the SMART4MD project forward to the launch of the full-scale RCT. Thus, the stage at which user involvement took place in Study I corresponds to the *Pilot study stage* (Table 7)

Study II – Stages in the research process in which the users were involved

User involvement occurred at several stages of the research process in Study II (Table 7), although for most users, involvement was limited to the research circle sessions, which can here be categorized as the *Generating the analysis material* stage. One of the housing companies took on a larger role in the research process, not least as the CEO was involved in developing the proposal for the research project. He can thus be said to have been involved in the stages *Developing research questions*, *Selecting the research approach*, and *Gaining access to the research site and data*, at least to some extent. In addition, he suggested other people who could be engaged in the research circle, including representatives of the municipal health care administration. Thus, he can be attributed an involvement in the *Sampling and recruitment* stage. Another user with extended involvement was the business developer who was involved in planning the setup before the third and final research circle session and assumed a more leading role during the session. He can thus be considered to have been actively involved in the stage *Selecting the research methods*, as the format of the final research circle session can be said to constitute a specific (design-oriented) approach.

Study III – Stages in the research process covered by the study

The survey in Study III contained questions directed to the study participants which corresponded to in which stages of the research process the older participants would prefer to be involved, should it be that they involved in research. Thus, it is here regarded that the survey covered all stages in the research process from *Developing the research question* to *Dissemination and implementation* of the research (Table 7).

Study IV – Stages in the research process covered by the study

The stage of the research process where older people and people with functional limitations were involved was primarily *Data collection*, because their involvement consisted precisely in collecting data on environmental barriers in their own home. In addition, the CS initiative was designed in such a way that users were given the opportunity and encouraged to interact with a successively growing database presented on the HX website which was updated in real time. By accessing the database, they could explore how registered environmental barriers generated accessibility problems for different profiles of functional limitations, as well as what accessibility looked like for different housing types, different municipalities and nationally. The idea was that the users could use this data as a support for further discussions about accessibility with, for example, policymakers and with wider society. In this way, there was an intention on the part of the researchers that i the users would also be invited to participate in *Data analysis* and *Dissemination and implementation*. However, it emerged from the results that very few people actually studied the data on the HX website.

Depth of involvement – How much?

Study I – Level to which users were involved in the study

The users were granted the power to influence the mHealth application design in terms limited to content, aesthetics and appearance. However, some of the major design decisions had already been made before the involvement of user-carer dyads, such as that the intervention would consist of an mHealth application on a tablet and that its central function would be to provide medication reminders. In addition to having a certain influence on the design of the application, the users were granted the power to evaluate the application based on criteria formulated by researchers.

Overall, the level to which the users were considered involved amount to ‘Level 2: Learning From’, which corresponds to *Active engagement with users, whose views substantially influence and inform decision-making, even if major decisions are still made without the users* (Table 7).

Study II – Level to which users were involved in the study

In Study II, not all the users took on the same role, with some having more influential roles than others, as described in the section ‘Scope of involvement’. Users maintained a divergent focus on the various aspects of the problem of providing accessible housing, thus emphasizing the problem’s complexity and nature as a “wicked” problem. In this way, their statements formed the basis of the knowledge that was produced. Overall, the level to which the users were considered involved in Study II was categorized as ‘Level 3: Learning Together’, which corresponds to *Interaction, meaningful exchange of information and shared responsibility for planning and decision-making.*

Study III – Levels of user involvement covered by the study

The survey in Study III contained questions directed to the study participants which corresponded to what their preferred depth of involvement would be as should they be involved in research. The response options covered all the listed levels of user involvement in the conceptual tool, starting from *Level 1: Learning About,* to *Level 4: Learning As One*.

Study IV – Level to which users were involved in the research covered by the study

The research with user involvement that Study IV covered, HX, is in this categorization based on the level of involvement that the full study participants’ reported in the second of the two questionnaires. Study IV highlighted that, as preparation for the HX, almost half (48%, n = 48) of the full study participants reported that they had visited the project website. About a third of those had watched the instructional video and three had read the detailed user guide available there. After completing the data collection, 5% reported that they had studied the results on the website. No significant changes in the ability to handle mobile digital devices before and after HX were found. Among those who changed their attitude, significantly more ($p = 0.006$) rated the importance of housing accessibility lower after HX participation compared to those rating it higher. Based on these findings, the estimation was made that the level to which the users were considered involved in the CS initiative corresponded to *Level 1: Learning About* – a level at which it was unlikely that users’ opinions did exert any major influence on decision-making.

Discussion

In the Discussion section, the main findings from all four thesis study findings will initially be summarized, followed by a discussion of the main considerations arising from these findings. Finally, the discussion puts forward suggestions of strategies for involving users in research on ageing and health.

The findings from the four thesis studies indicated that there seems to be a connection between the interest in becoming involved in research and higher levels of formal education. In Study III, where older people from the general population were included, it emerged that higher education was an important factor for both awareness of and willingness to get involved in research. In Study IV, where older people, but also people with functional impairments from associations (senior citizens and disability respectively) were included, it emerged that both the study participants who had become involved in the CS initiative and the study participants in general were characterized by higher levels of formal education. Furthermore, the Study I and Study II findings indicated that mobile digital literacy seems to be a prerequisite for older people and people with disabilities when it comes to the possibility of getting involved in research involving mobile technology.

The main benefits for getting involved in research as perceived by older people and other user groups were that it could lead to new insights into complex problems. This was evident in Study III where various user group representatives with an interest and experience of issues related to housing and health participated. However, the findings also indicated that user involvement does not always necessarily lead to benefits. From Study IV it emerged that the involvement in the CS initiative did not result in any major changes in attitudes nor any acquired skills. Therefore, as well as a consideration and an understanding of how various user groups perceive user involvement in research, the findings also indicated that it requires a sensitivity on the part of the researcher/s to the prerequisites of different user groups for getting involved as well as insights into what possible benefits it is reasonable to expect from the user involvement.

Finally, the adapted conceptual tool (Jönson et al. 2021) and the categorization made from it within this thesis, constitutes an attempt to systematically value user involvement. Namely, to what extent it has the potential to contribute to the development of generalizable knowledge and cumulative knowledge in research on ageing and health. The next section of the discussion focuses on the main considerations arising from the findings of the four thesis studies that are taken up in turn and discussed. These are firstly, the perceptions and prerequisites of older people and persons with functional impairments regarding user involvement in research with a focus on i) demographics and self-rated health; ii) awareness and previous experience of involvement in research; iii) attitudes towards being involved in research; iv willingness to be involved in research and associated factors.

Perceptions and prerequisites of older people and persons with functional impairments regarding user involvement in research

Study III: Demographics and self-rated health

What most clearly distinguishes the study sample from Sweden's population of people 60 years or older is the high level of education. That is, 58% (n=503) of the study sample had a post-secondary education compared to 17% in the overall 60+ population (SCB, 2022). However, it should also be pointed out that the 60+ sample contains a somewhat lower proportion of people 80 years and older (16%; n=141) compared to Sweden's 80+ population (20%), which may have some relevance as the level of education is generally lower in this age group in a Swedish context (SCB, 2022).

When it comes to self-rated health, 34% (n=301) reported their health as excellent or very good. This can be compared to a cross-sectional population-based sample of people 70 years or older from a Swedish cohort study (n=1,136) with 46% men (n=523) and 54% (n=613) women, where 50% (n=260) of the men and 47% (n=287) of the women reported their health as excellent or very good (Falk et al., 2019). It can also be compared to a study of "very old people" (M age=85; SD=3.0) in Sweden (n=397) where 72% (n=238) rated their health as at least good (Harschel et al., 2015), compared to 73% (n=662) in the study sample. Although increasing age does not always result in a decline in self-rated health as older people are often able to adapt to poorer health (Leinonena et al., 2001), these comparisons still give the impression that the ratings of health in the study sample were somewhat low for the age group studied.

Study III: Awareness and previous experience of involvement in research

The Study III findings indicated that about forty percent of older people (≥ 60 years) (n=343) in the general population of Sweden are aware of the possibility of being involved in research. However, it is a percentage that should be regarded with some caution given that the response rate was relatively low (26%). No previous studies have been found that explored the awareness of the possibility of being involved in research within the general Swedish population, which makes the study unique and groundbreaking, within a Swedish context.

Study III also indicated that 14% (n=119) of older people in the general population of Sweden have previously been involved in research, which is a relatively low figure compared to the results of Seifert et al's Swiss study (N=811) (2019), where the corresponding proportion was 24%. (n = 811). However, given that their study targeted a total of X older people at a senior university, rather than older people in the general population, then the divergence in results is perhaps not so surprising.

Study III: Attitudes towards being involved in research

Findings from Study III also indicated that older people (≥ 60 years) in the general population of Sweden have a high willingness to be actively involved in research, since 69% (n=591) expressed that this was something they would or might consider doing. This can be compared with two earlier studies in which the first, of Seifert et al., (2019) as outlined above, was directed at students at a senior university, of which 62% stated they were interested in research projects with public involvement (Seifert et al., 2019). In the second study, which was directed at 6,000 respondents in six European countries – and not limited to older people but directed to the general population and with respondents aged between 16 and 79 and a mean age of 46 years (SD=5.9) – 67% answered that they were willing to be involved in research in life sciences (Lakomý et al., 2020). In other words, the proportions are relatively similar even though the samples in the few previous larger studies were different.

Moreover, the Study III findings also highlighted that respondents to a large extent (95% n=776) considered the possibility for them to involve in research important since they regarded it as a way to improve the communication and outreach of research results. That their willingness to be involved in research is rooted in a desire to contribute to quality improvements is to some extent in accordance with previous research (Fudge et al., 2007). However, the driving force found in Fudge et al.'s study was about achieving a real change in practice, rather than facilitating or enriching the research process. Nevertheless, the Study III findings from the thesis gives a clear indication that the motivation to make a difference constitutes a central driving force for the involvement in research on ageing and health among older participants. Furthermore, the findings in Study III also underscored that 94% (n=805) regarded the possibility to be involved in research as a way of contributing with their valuable experiences regarding ageing. This view should also be seen in the light of three other attitudes that many respondents expressed. Firstly, that 91% (n=778) considered it was important for members of the public to be involved in research on ageing and health, especially in publicly funded research Secondly, that 88%; n=743 regarded their involvement as a way to exercise societal impact and thirdly, that 83%; n=712 saw it as a democratic right. Together, these four attitudes give a clear picture that older people within the general population to a large extent are not only positively disposed to the opportunity to get involved in research, but also see it as an opportunity for societal impact and as a way to exercise their civic power. However, this finding should also be considered in light of the relatively low response rate and the fact that 58% (n=503) of the study sample had a post-secondary education compared to 17% in the overall 60+ population (SCB, 2022).

Study III: Willingness to be involved in research and associated factors

With regards to willingness to be involved in research, Study III shows that for older participants there was a significant correlation ($p < 0.001$) between willingness and previous involvement. This association between previous involvement in research and willingness to be involved in further research is in line with the findings from of the aforementioned Swiss study (Seifert et al., 2019). Thus, it seems as if the experience of having been actively involved in research corresponds to a higher willingness to become involved in research in the future.

However, previous involvement was not the only factor associated with a willingness to be involved in research among older participants in Study III. Also, a higher level of education, was associated with a significantly higher ($p<0.001$) probability of being willing to be involved in research. In addition, a higher level of education was associated with an increased probability of being aware of the possibility to be involved in research, as well as with previous involvement in research. A plausible explanation is that the association between willingness to be involved in research and higher levels of education relates to linguistic ability. Familiarity with academic language is something that develops during schooling and could constitute a facilitator for approaching academic discourse. On the other hand, lack of familiarity could present an obstacle. This is something that is supported by linguist Michael Halliday's theory that learning consists of the development of 'registers', which move from the more concrete 'everyday language' to the more abstract 'language of education' (Halliday, 1993). Thus, the lack of sufficient academic registers could constitute a plausible explanation for this result (see Gibbons (2010) for a more elaborate discussion on the topic). The development of academic registers can be seen to relate to Archer et al.'s theory of ‘science capital’, which in addition to knowledge includes attitudes, behaviours, and social contacts and networks (Archer, 2015).

That the academic language could constitute an obstacle to approaching research could also be a partial explanation for the over-representation of study participants with higher education in the sample. Comments in free-text answers and experiences from listening-in on telephone interviews also indicated that the concept of ‘active involvement’, as well as the questions asked, were sometimes considered abstract and difficult to understand. This indicates a risk that the survey was perceived as intimidating by some respondents (Heerwegh, 2009). Furthermore, it highlights the difficulties of making academic language sufficiently accessible to people outside of academia.

Willingness to be involved in research and associated factors

In Study IV, the indications of the association between higher education and the willingness to participate in "research about research", of which both Study III and Study IV are examples, were strengthened. While in Study III, about 58% (n=503) of the study participants had a tertiary education, the corresponding numbers in Study IV was 52% (n=24) for the partial study participants and 67% (n=67) for the full study participants. Although the difference in educational level between partial study participants and full study participants here appears to be relatively large, no statistically significant difference could be established. The full study participants in Study IV are also to be regarded as “users” since they confirmed in the questionnaire that they had been involved in the CS initiative prior to responding to the post-Q questionnaire, In this way, Study IV confirmed that a sample of older people with higher education were not only more willing to get involved in research than older people with less formal education (as indicated in Study III), but also did become involved in research to a larger extent.

However, it is important to remember that Study IV concerned partly different user groups, namely people 65 years or older and persons with functional impairments, both living in their own home and members of interest organizations. The combined results from three partially different user groups (older people (>60 years) in the general population; older people (>65 years) living in their own home and members of senior citizens’ organizations; people with functional impairments living in their own home and members of a disability organisation) indicate that there is a strong connection between higher education and the willingness to be involved in research.

That a person's level of education may be of importance when someone decides whether to become involved in research is indicated by earlier research (Lakomy et al., 2020). Furthermore, the connection between higher levels of education and user involvement in CS initiatives is also confirmed by European Commission’s (EC) report on CS initiatives (Haklay, 2022), which states that across CS initiatives in

Europe, the proportion of citizen scientists with higher education has been at least twice that of the general population.

It appears that factors related to health and functioning may also affect the ability or interest in being involved in research among older people and persons with functional limitations. For example, in Study IV, it was found that it was more likely that someone in the household of the study participants *not* confirming involvement (=partial study participants) in the CS initiative used a walker or wheelchair and/or received home care, compared to study participants confirming involvement (=full study participants). This suggests that people living in a potentially strained situation due to their own or their partner's ill health may find it challenging to be involved in research, something that has been indicated in previous studies focusing on informal carers of older people (Malm et al., 2021). However, for Study IV, the connection between involvement in the CS initiative and functional ability must be taken with some caution. This is because it is not possible to establish with certainty that partial participants actually were involved in the CS initiative. The reason for this is that the only way to establish that the study participants also became involved in the CS initiative was to ask an explicit question about it in the post-Q, the second of the study's questionnaires. However, since not all study participants who answered the first questionnaire (pre-Q) continued to the next, there was uncertainty as to whether or not they had become involved in the HX or not.

With the same precaution, it emerged that study participants confirming involvement in the CS initiative had more recent experiences of downloading apps to their smartphones or tablets compared to study participants not confirming citizen science involvement. It indicates that familiarity with downloading applications from publicly available platforms was of importance for completing the CS initiative. This presumption was further strengthened by the fact that among the study participants who answered the second questionnaire but had not completed the CS initiative, almost 50% stated that they had tried to download the mobile applications but without success. Moreover, as indicated by experiences during the app development process, older people do not always have smartphones with sufficient memory space to download additional apps (Granbom et al., submitted); this imposes challenges that might also relate to economic resources (Olsson & Viscovi, 2022).

Moreover, in Study IV, study participants confirming CS involvement also expressed having a relatively good ability to handle mobile digital devices, confirmed by the fact that 83% rated themselves as "quite" to "very" knowledgeable in mobile digital literacy. The association between mobile digital literacy and ability to be involved in research also links to Study I where the users groups were older people (>55 years) with mild cognitive impairment and their informal carers. The main reason why this study was designed with users constituting user-carer dyads was mainly based on the presumed need for support for the persons with mild cognitive impairment when using the application. That in fact several persons with mild cognitive impairment had limited mobile digital literacy emerged during the usability testing of the application. It was also mentioned in the feedback given during the application's use and in the evaluation.

In Study I it also emerged that there was a large variation in terms of mobile digital literacy especially among persons with mild cognitive impairment, but also to some extent among informal carers. However, generally informal carers were seen to have higher mobile digital literacy than persons with mild cognitive impairment.

This reinforces the picture of heterogeneity in the ageing population and that some people are more in need of support than others (Olsson & Viscovi, 2022). At the same time, the study indicates that people with mild cognitive impairment have the ability to get involved in research on aging and health, albeit with some support. That a reduced cognitive ability does not have to be an obstacle to getting involved in research has been previously highlighted by Tanner (2012) who demonstrated that it is possible to meaningfully involve also older people with dementia in the research processes and that they can greatly benefit from it.

Regarding informal carers' involvement in research on ageing and health, a quantitative study by Malm (2021), suggested that informal carers have a strong interest and willingness to involve in research. Among the study's informal carer respondents (n=147), a majority (83%, n=121) were interested in research, and 32% (n=47) had previously been involved in research, assuming the role of a user. In relation to willingness to be involved in research 85% of the informal carers in the study with an education of more than high-school level and 74% of those with an education level of high-school or less were interested in being actively involved in research. Although in the study there was no significant difference between the groups with different levels of education, this further strengthens the picture of the connection between higher education and the willingness to be involved in research, and which has also been suggested by other researchers (Lakomý et al., 2020).

Further in relation to Study IV, in the original plan for how the CS initiative the Housing Experiment (HX) would be carried out, it was also intended that school classes would be involved, and that older people, with limited mobile digital literacy, would have the opportunity to receive support from these students for the practical implementation. However, the onset of the COVID-19 thwarted the possibility of this type of intergenerational collaboration which presumably could have made it feasible for more older people and not least more people with limited mobile digital literacy to get involved in the CS initiative. As well, for more study participants to participate in Study IV more fully.

In Study IV there were hopes that by making the HX database [The data on the presence of environmental barriers in the homes of the users participating in the HX] available publicly online, the participants confirming their CS involvement would initiate and accomplish certain simple analyses of the data collected and use their conclusions from such analyses in the communication with policymakers and other decision-makers in order to influence the implementation of more accessible housing – or at least to raise public debate. However, of those study participants confirming their involvement in the Citizen Science initiative, only a few entered the database presented at the Housing Experiment website. A partial explanation for this could be that due to the low response and participation rates the database was not as comprehensive – and information-rich – as had been anticipated and planned for. The next section of the discussion focuses on the benefits of user involvement as perceived by older users and people with disabilities.

Benefits of user involvement among older people and persons with functional impairments

Benefits of user involvement here refers to that the involvement in research has brought about a positive change for the user in terms of insights, attitudinal changes or acquired abilities. In Study II the benefit consisted of opportunities of learning together, Moreover, acting upon the crucial variables identified in this study could contribute to progressive decision-making and more efficient ways to develop and provide accessible housing to promote healthy ageing.

In Study IV, there was an idea that the users' involvement in the CS initiative might lead to certain benefits in terms of insights, attitudinal changes or acquired abilities. There have been indications in other studies with users involved research that it may lead to an improved understanding and application of research methodology among users (Bremer et al., 2019; Haywood et al., 2016), as well as opportunities for older people to develop new skills (James and Buffel, 2022). In relation to the involvement in CS initiatives, there have been studies indicating that it may lead to increased awareness and commitment to the societal issues at stake (Bremer et al., 2019; Haywood et al., 2016), although with a limited lifespan (Jordan et al., 2011).

However, the only significant change in terms of acquired ability or attitudinal change in Study IV that occurred was in a negative direction and related to the attitude to housing accessibility were the question posed to the study participants was: "How important is physical accessibility in housing to you?" (Not at all important; not so important; quite important; important; very important). In the post-Q [the questionnaire that the full study participants (n=100) answered after their involvement in the HX] it turned out that significantly more people had changed their attitude towards housing accessibility in a negative direction compared to the number of people who had changed their attitude in a positive direction.

The underlying reasons for the decline in interest in housing accessibility can only be speculated about. The free-text answers did not indicate what this could be about.

However, this decline should also be seen in the light of the very high proportion of the full study participants who considered the issue of housing accessibility to be "quite" to "very" important before the CS initiative. It should thus be kept in mind that almost half of the full study participants did not change their views regarding accessibility, or their interest in research. This indicates that CS involvement had a limited influence on attitudes, which is a finding supported by several previous studies (Evans et al., 2005; Jordan et al., 2011; Oturai et al., 2021). However, other studies have indicated that participant attitudes changed in a positive direction after CS involvement (Bremer et al., 2019; Haywood et al., 2016). What distinguishes the latter studies is mainly that they are evaluations of projects that extended over a relatively long time and contained recurring training and guidance by peers in performing the data collection. This allowed participants to make mistakes and learn through them, hence creating conditions for "deep learning" (Jordan, 2011). It raises the question of whether a more co-creation form of Citizen Science rather than contributory would have led to different outcomes in Study IV. While contributory CS is researcher-initiated, co-creating citizen science usually derives from a grassroots movement with members of the public (often constituting a community) involved in most or all of the process (Wiggins and Wilbanks, 2019). In the case of HX, senior citizen associations took on a supportive role before and during the implementation of the project. However, this occurred from a top-down rather than grassroots level. Judging by the low response rates for both HX and this study, we did not succeed sufficiently in getting a high number of individuals involved in HX or participating in this study. With more resources to reach out locally to citizens with information about the HX, as well as the possibility of providing support to manage the app, it would probably have made a difference.

There are also reasons to believe that mobile digital literacy had an influence on the outcome. Up-to-date data show that among people in Sweden born in the forties, as many as 38% state that they need help using digital technology, while the figure is considerably lower for younger adults (Swedish Internet Foundation, 2022). Aware of this digital divide, during the app development process before the HX, great emphasis was placed on usability testing with representatives of the intended target groups (Granbom et al., submitted). Pedagogical material was created in the form of detailed guides and an instructional video, available on the project website. Support functions were created through a telephone and Facebook group. In Study IV, however, it emerged that only about half of the 100 full study participants had accessed the website, and of these, only three people had read the guide.

Finally, the findings from Study IV highlights important aspects to take into account when designing similar CS initiatives. It is also useful for policymakers and the wider society through its contribution to the understanding of what benefits can be expected based on the efforts made. Further research is warranted to investigate how user involvement in form of CS initiatives that target older people and persons with functional impairments could be designed, prepared, and executed to attract a wider group and to create conditions for greater benefits. The next section focuses on a consideration of the response and complete rates in studies III and IV.

Response and completion rates in studies III-IV

In Study III, the low response rate (26%) makes it difficult to draw more general and far-reaching conclusions about the awareness of and attitudes towards user involvement in research among older people in the general population in Sweden. However, it is nevertheless an indication that there seems to be a relatively low interest among older people, within the general population in Sweden, to participate in "research about research". This has also been confirmed in previous research by Malm et al. (2021) regarding informal carers' (of older and disabled people) involvement in research and by Lakomy et al. (2020) concerning citizens' involvement in life science research (Malm, 202; Lakomý et al., 2020).

In Study IV, the response rate was even lower (6%) than in Study III, which reinforces the finding of the difficulty to attract older people- in this case from senior citizens organisations- and also persons with functional impairments from disability organisations, to be involved in "research about research".

One explanation for the low response rates is the complex design of both these studies, where respondents were not only requested to answer a single questionnaire, but where their participation required a greater commitment of time and commitment. In the case of Study III, the baseline survey – upon which the current study was based – had a planned follow-up survey two years later (Kylén, 2020). The reason for this was that the project on which the study was based ran over several years and the project included following up how attitudes developed over time. The participants who were asked to participate in the baseline survey were thus also asked to participate in the follow-up survey. Experiences from the telephone interviews indicated that this very commitment was a reason why many potential participants refrained from answering the survey.

In Study IV, it was planned that the study participants, in-between the two study questionnaires, were expected to be involved in the Housing Experiment. In comparison to answering a single survey, the time and commitment required of potential Study IV participants was therefore considerable. Further an additional factor is the complex study design was rather challenging to present to potential participants in an accessible way.

It is important to note that the HX project and Study IV took place during the COVID-19 pandemic which negatively affected recruitment as it limited the possibility for meetings in real life with potential participants. Further, with regards to the impact of the pandemic, the data collection for studies I-III occurred prior to the pandemic, while for Study IV, the HX had to be postponed and also somewhat redesigned due to the pandemic. For example, the intergenerational element in the HX had to be removed, which likely had a negative effect on the response rates of both the HX project and Study IV. The original idea was that school pupils would support older people's measurements and registration of environmental barriers and also provide support in using the mobile digital devices the assessments required. Unfortunately, this intergenerational support element disappeared and the opportunity for potential participants with low mobile digital literacy to participate in HX was likely affected as a consequence.

Another factor affecting the response rate is the way/s in which potential participants were invited to answer the survey and questionnaires. In Study III, potential participants were given three options to complete the survey, namely online, paper, and telephone, while in Study IV they were only invited to complete the questionnaires online. In Study III, even though the online response option was the most widely used option, the distribution between online, paper, and telephone responses was relatively even. While the response rate was nevertheless low, the fact that respondents were offered several options for responding might have increased the response rate compared to if they had only been offered one response mode (Dillman, 2017), which was the case in Study IV.

Nevertheless, it can be argued that Study IV required a level/s of digital literacy as it was via the help of an app on a mobile or tablet that the measurements in the HX were registered. Thus, the study design as a whole and prerequisite digital literacy skills may well have had a more decisive effect on the response rates, rather than the limited response options “per se”.

An important consideration is also the choice to target potential participants directly or to go via interest organisations. In Study III, the choice was made to target the general public and not specifically people who are active in interest groups–even if such individuals were included in the actual study sample. In contrast, in Study IV it was decided to contact the boards of a number of local senior citizens associations and disability associations. These boards in turn sent out emails to their members with information about the study and it was in this way that participants were recruited. Further in Study III, a professional organization was used for the practical implementation of this outreach and data collection, which was not the case in Study IV.

The low interest in getting involved in the HX project among the expected target groups as well as the low interest in analyzing the results simultaneously raises questions about what appears to be a clear difference between the interest in this form of research at an organizational level (senior citizens’ organisations and disability organizations) compared to at the grassroots level when citizens are invited to be involved in research in this way.

In summary, Study III from several aspects had better conditions for achieving a higher response rate, which is what happened. However, at the same time, since studies III and IV are distinctly different in their design, it is difficult to make a direct comparison, but the aspects highlighted above hopefully explain what the conditions looked like for the two studies. As the first three sections of the discussion above have had many discussion points that related primarily to Study III and Study IV, the following section below will mainly, but not exclusively, discuss aspects related to Study I and Study II.

Importance of study design for the outcomes of user involvement in research on ageing and health

This fourth section of the discussion is based on the four considerations of the adapted conceptual tool (Jönson et al., 2021) in relation to studies I-IV: 1. Why user involvement should take place? (Type of aim); 2. Who should be involved (Breadth of involvement); 3. Within which parts of the research process the involvement should be seen (Scope of involvement); 4. How much influence the users should have in the process (Depth of involvement).

Type of aim – Why?

In relation to motives for user involvement in the four studies, a division can be made between the different foci of the thesis studies, namely research *about* and *with* user involvement. Research *with* user involvement here refers to that one or several categories of users have been involved in the research process of the study. Research *about* user involvement here means that the focus of the research has primarily been to cover the phenomenon of user involvement, for example by investigating one or several categories (groups) of users' perceptions of, or benefits of user involvement in research.

Research with user involvement

Both studies I and II had a similar point of departure, namely that the ageing population in a large part of the world, including Sweden, means that increased demands are placed on society as a result of demographic ageing trends (Christensen et al., 2009; van der Wel, 2019; Tsuchiya-Ito et al., 2019).

In the case of Study II, the point of departure was: a) that the growing number of people living longer with physical disabilities places increased demands on the physical environment, including housing; b) that affordable, accessible housing can help facilitate an active and healthy life for people ageing with a range of physical disabilities (Slaug et al., 2020).

In Study I, the point of departure was: a) that with advanced old age there is an increased risk of developing dementia (Doblhammer et al., 2013); b) that cognitive difficulties in old age represent a societal challenge as governments need to be able to offer people ageing with a variety of disabilities a dignified life with access to good quality long term care (Higgs & Gilleard, 2017); c) a belief that technology and innovation should be able to make important contributions, including the possibility for ageing in place (Jarke, 2020). However, even if studies I and II were both aimed at tackling complex societal problems, their approaches were different from each other.

In Study I, intended users were invited to be involved in the design process of a potential technical solution - an application on a tablet - to explore whether a technical solution via which older people with presumed incipient dementia (mild cognitive impairment, Jessen et al., 2014) and their informal carers may access support, which could potentially help to improve their everyday quality of life. More specifically, the role of the intended users here was to test the usability of the application and to approve that the technical solution was sufficiently feasible and usable to be rolled out and tested on a wider scale in an RCT.

In Study II, the aim was instead to invite non-academic actors, such as representatives from civil society with an interest in and knowledge about housing accessibility to meetings during which the complex issue of providing accessible housing in Sweden could be discussed. The aim here was to untangle the problem and identify "crucial variables" for decision-making related to the provision of accessible housing in Sweden.

The two different approaches relate to the question of to what extent a complex problem can and should be properly understood before any solution to it can or should be launched (Rittel & Webber, 1973; Jones, 2014). Furthermore, which role user involvement should serve in order to enable a sufficient level of understanding of complex problems (Zivkovic, 2018). The focus on primarily a compensatory solution to a complex problem related to functional loss (as in Study I) or on the situational contextual understanding of it (as in Study II), reveals a more foundational ontological divide between a view of human behavior as primarily rational and striving for independence (Study 1), or as essentially contextual and striving for meaningfulness (Study II).

Within ageing and health research, this divide has been actualized through the low uptake of health-oriented interventions and health-oriented technology by older people (Fischer et al., 2020) in research projects with a similar structure as SMART4MD (Anderberg et al., 2019). Critical voices (Peine et al., 2021; Fischer et al., 2020) have argued that this low uptake is due to a limited understanding - among researchers and other stakeholders in the research projects - of the role that technology plays in people's lives. Rather than perceiving the uptake of technology as a matter of acceptance (with facilitating conditions surrounding it) (Venkatesh, 2015; Venkatesh et al., 2016), it is argued that technology usage more rightfully should be studied in light of the motivation and ability among the users to integrate the technical solution in a meaningful way within their everyday life (Östlund et al., 2015); thus focusing on the “domestication” (Frennert & Östlund, 2015) of technology, rather than on the acceptance of it.

To relate back to Study I, where the aim with the user involvement was to test and approve that the mHealth application was feasible and sufficiently usable to be launched in the full-scale RCT, clearly this was an aim that was undoubtedly achieved. In other words, based on the role that the user involvement was intended to have in the study the outcomes were satisfactory. However, as the discussion above illustrates, it is important to be aware that there are reasons to question whether such an approval constitutes an appropriate measure of a technology's usability for the intended users, pointing to the need for more contextual outcomes such as domestication of the technology, within their daily life.

Moreover, when using the adapted conceptual tool to categorize the ‘Type of aim’ for Study I and Study II, several aspects were noticeable (Table 5). First, it can be questioned whether *Facilitation of dialogue between different categories of users and researchers* out of necessity does not require both *Identifying and understanding users’ needs* and *Ranking and negotiating needs*. However, it might depend on how the word ‘facilitation’ is understood. In the case of Study II, the aim of the user involvement was categorized as *Facilitation of dialogue between different categories of users and researchers* since the reason for inviting all the main user representatives to untangle the complex problem together was partly to identify needs as well as to discuss and “negotiate” the needs. It should also be said that the categorization of goals into these different types has been taken not from research but rather from 'public involvement in the planning, development and implementation of community health services'. In its original version, 'different categories of users' was not used, but 'public citizens and policymakers', which may also explain how the difficulty arose. In order to avoid a similar ambiguity arising in a possible future development and application of this adapted conceptual tool, it is worth taking this ambiguity at the conceptual level into consideration.

Furthermore, although the user involvement in both Study I and Study II were categorized as aiming for *Identifying and understanding users’ needs* and *Ranking and negotiating needs*, it is important to emphasize that the studies deal with needs at different levels. While Study I, as mentioned, is focused on the form and content of the mHealth application, the needs presented by the different user representatives in Study II have a much greater scope. In this case, it can be considered a criticism of the types of aims listed in the categorization tool that such different kinds of needs fall within the same categories.

Research about user involvement

Regarding Study III and Study IV, it is important to emphasize that the user involvement *covered* by these studies is in focus. In other words, the studies themselves are *about* user involvement in research.

In the case of Study III, it made the categorization somewhat difficult since it is not entirely clear what 'covered' in this case refers to. In the categorization that was made, it was interpreted as which aims were covered by the survey that was sent out. As previously reported in the Findings section, it turned out that the survey covered all types of aims that were listed in the adapted conceptual tool.

In the case of Study IV, categorization was also challenging. The user involvement that was covered by Study IV was considered here as the CS initiative. The difficulty on a conceptual level was that not all of the study participants had been involved in the CS initiative, the Housing Experiment (HX). The second issue was the extent to which the categorization would apply to the goals that were the intention of HX or the goals that had de facto been achieved. The choice here fell on categorizing according to the goals that corresponded to the intentions with HX. During the categorization it then emerged that none of these goals (Identifying and understanding users' needs, Ranking and negotiation of the needs and Empowerment) had in the true sense been achieved. Overall, it can be said that when it comes to categorizing types of aims for studies that constitute user involvement *about* research, it is a much more complex task, compared to research *with* user involvement.

Breadth of aim – Who?

Research with user involvement

Findings from Study II showed that the research circle is a suitable form for the type of motive for user involvement that was intended. The format together with the analysis made it possible to recruit a wide range of user groups and to bring out many different aspects of the issue in focus. Study II findings also testify that it is important not only which user categories are represented, but also what distinguishes the people who assume the role of representatives. Even if this goes beyond what Harder et al. (2013) defined as breadth of involvement, it can still be argued that it is a related matter because the motive behind the involvement of different user groups is to elicit different perceptions and perspectives. Moreover, the success of such efforts is often based on the users' abilities to reason and communicate their views, as well as their perceptions being rooted in relevant experiences. While a broad representation is considered important, Brown et al. (2019) highlighted the importance of involving individuals capable of "individual and independent thinking" with the ability to shed light on a complex issue from many different angles in transdisciplinary dialogues. It highlights an important aspect to consider when conducting this kind of research, namely that it is not only important which user groups are represented at the table, but that it is important to consider what distinguishes the individuals who constitute their representatives and what abilities they possess. Such qualities do not have to be desirable in all user involvement in research on ageing and health but are related to the role that the users are expected to play in the specific study. Study II clearly included such individuals, which can be deemed to be important for the dialogues to be sufficiently broad and encompass many dimensions. To what extent it was a conscious decision on the part of the research team to include people with these qualities in Study II is not clear, but highlighting the significance here may be a way to take this into more active consideration when recruiting users for similar studies in the future.

To summarise, the importance of representativeness in a study with or about user involvement in research on ageing and health, arguably varies. The variation is partly due to the role(s) that the intended group or groups of users are expected to play in the study as well as what constitutes the aim of the study.

In Study III & IV, which were relatively large-scale quantitative studies about user involvement in research, the representativeness is essential because the users or study participants are expected to reflect the targeted population at large and the purpose of the study is precisely to be able to draw general conclusions about what distinguishes the chosen user groups. Study II indicates that in smaller, more qualitatively oriented studies where a large space is provided for users to express themselves, it is also important to strive to involve users capable of individual and independent thinking as opposed to purely focusing on their degree of representativeness.

Scope of involvement – When?

Research with and about user involvement

In Study I, users were granted the power to influence the mHealth application design in terms limited to content, aesthetics, and appearance. The way that the user involvement was employed – through a small-scale pilot to ensure the feasibility of the intervention prior to the launch of the full-scale RCT - is common in studies focusing on evaluating mHealth technology interventions (Free et al., 2013; Hamine et al., 2015; Ramey et al., 2019) However, as mentioned earlier criticism has been levelled against this set-up of larger medical technology RCTs for their tendency to make essential design decisions without real anchoring in the target group (Fischer et al., 2020; Poli, 2021). They have also been criticized for not sufficiently taking into account the contextual factors connected to the technology the target group is expected to use (Franz et al., 2015; Hornbaek, 2006; Fischer et al., 2020). With regards to the mHealth application in Study I, major design decisions had already been made before the involvement of users, namely that the intervention would consist of an mHealth application on a tablet and that its central function would be to provide medication reminders.

What is advocated as an alternative approach is to involve users earlier on in the research process, to study users' real perceived needs in the everyday context where they arise, and to use such observations as a starting point for the design of technical solutions to the perceived problems (Peine et al., 2021). In Study III it appears that a large number of older people emphasize user involvement in research in ageing and health as a way for them to contribute valuable knowledge, insights, and experiences in relation to ageing. It also appears from Study IV that the stages which older people who are members of senior citizens' organisations have a greater interest in engaging are stages where they get to assume a more influential role in the research process, such as being involved in the planning and design of research projects or being a member of a reference group.

Based on that assuming more influential roles in research is something that there are indications that both older people themselves express and that there are indications that it has the potential to lead to a better uptake of technology directed to older people (Fischer et al., 2020) then it can be argued that this is an area that merits further attention within user involvement in research on ageing and health.

In the form of user involvement that Study IV concerns, namely the HX, the involvement took place through users themselves collecting data. Earlier in the thesis, the low response rates in Study IV as well as the small number of participants in HX has been brought forward. In that context, it is interesting to highlight that in Study III it emerged that involvement in the practical research work, for example collecting data, is something that older people are considerably less interested in compared to other parts of the research process including the planning stage mentioned above.

Depth of involvement - How much?

Research with user involvement

It can be argued that what took place during the research circle can be compared to a form of "boundary work" (Langley et al., 2019), which is a concept gaining an increased interest in organization and management science. The concept denotes "purposeful individual and collective effort to influence the social, symbolic, material, or temporal boundaries; demarcations; and distinctions affecting groups, occupations, and organizations" (Langley et al. 2019; p. 704). Boundary work refers to individual and collective efforts regarding different types of boundaries and, for example, the opening of these. In this case, the boundaries constituted the obtained critical factors for decision making related to the provision of accessible housing.

Several critical factors were found to be related to socio-economic and organizational factors.

The questioning of the organizational structure’s influational power relates to a concept in strategic design called "dark matter" (Hill, 2012), which refers to the blockages at an organizational scale or at a policy level preventing people from doing the changes they want to make in the physical matter. It refers, for example, to the kind of organizational silo structures described in Study II as obstacles to building more accessible housing. Study II gave space to the various user groups involved to question the premises and the basic assumptions upon which the research project and the study rested. Such as for example the necessity of a Decision Support System and what good it could do, to which extent ageing in one's own home was really preferable, and whether there were other values that should be prioritized above accessibility. This space for the users to challenge the researchers' starting points and knowledge means that in this project and in this study it is possible to speak of mutual learning.

In Study I, the users were not invited to a discussion where they were given the power to question or influence what could be said to correspond to "dark matter". The problem upon which the suggested solution rested had already to a large extent been defined by the researchers before the users were allowed to enter the research process. The solution was instead based to a large extent on earlier research and on discussions with other stakeholders than the intended users. In other words, there was no room for mutual learning with the users in the same unconditional way as in Study II, and this means that the depth of involvement here is assessed as less deep.

From a critical perspective, the role assumed by the users in the CS initiative can be said to constitute a form of "sensors" (Chiou, 2020). This term refers to a role limited to the recording or collecting of data, in which one is not being included in the process of defining the actual problem and where the design and data analysis were primarily developed and determined by the researchers (Chiou, 2020). Strasser et al. (2019) have divided different types of engagement in CS epistemic practices, i.e. a description of which cognitive function or role the participating users are expected to take on in the process. Here the division is made into: "sensing"; "computing"; "analyzing"; "self-reporting" and "making". It is described by the authors as a typology that does not hierarchically classify but that neutrally tries to make a distinction between different kinds of tasks that can be included in CS. Based on that typology, the main task for users within the framework of the HX can be judged to have been "sensing" in the form of the registration of environmental barriers. The ambition was that the users would also carry out both "computing" and "analyzing", with the support of the public database on the HX website consisting of the collected data. However, this does not seem to have been carried out by anyone except a few people.

To what extent can a categorization tool advance knowledge on user involvement in research on ageing and health?

This thesis indicates that the categorization tool SAPO, put forward by Jönson et al. (2021) as part of the UserAge program can be a fruitful way to advance the knowledge in research on ageing and health. With the help of the overall four categories that the tool embraces, many different aspects based on different studies with and about user involvement can be highlighted. Differences and similarities between studies can be brought up and discussed in a structured way that would probably not be possible without the support of this conceptual tool.

At the same time, the thesis shows that the subcategories and their different steps and levels that were adapted to the tool, made it rather challenging to categorize the studies accordingly. Further research is needed in order to explore the adapted tool's potential. The next section of the discussion focuses on a consideration of the main strengths and limitations of the thesis.

Strengths and limitations

To summarise, the overall strengths of the thesis include the diversity of user groups and approaches involved; the adequate and effective application of different research designs and methodological approaches; the use of quantitative studies exploring the perspectives of large samples of older people; rigorous analysis of data; and the discussion of how multiple critical variables and actors are involved in the issue of providing accessible housing.

Study limitations can be linked also to the diversity of user groups and the thesis covering several areas, thus not offering the opportunity of more detailed descriptions of the individual studies nor the research projects they were part of.

Moreover, the lack of in-depth qualitative feedback from the study participants and users involved is a notable limitation of the thesis. As for the study participants, the quantitatively oriented studies (Study III & IV) could have been strengthened by complementary qualitative interviews for a more in-depth understanding of the phenomena being investigated. Such interviews would have been valuable to discern both context and causes (Wehn et al., 2021), and could have brought about valuable insights for further studies. For the same reasons, it would also have been desirable to qualitatively evaluate how the users involved in Studies I and II experienced their involvement in the respective studies. However, this type of in-depth qualitative feedback was unfortunately not feasible within the specified time frames that existed and with the resources that were available in the respective project and associated study.

Study III was based on data collected from the baseline survey to be followed up every other year on at least two occasions, and it would have been interesting to be able to include data from several points in time in order to analyze the attitude changes over time, but for obvious reasons this was not feasible within the specified time frames for the thesis. Further details about how that work was done is beyond the focus of this thesis. However, it indicates that it can be difficult to assess what in a research process is to be considered as user involvement and what is not. In this thesis, the delimitation has been to assess the involvement of the users who were included in the study itself from where I myself entered the process, but it is possible that if I had found myself in a different role being more involved in the planning of research, I would possibly have assessed user involvement differently.

In addition, the low response rates in Study III, and especially Study IV, limit how far-reaching conclusions can be drawn based on the results of these studies. The ambition in both studies was to reach target groups representative of the population within the specified age range. The marked bias towards people with higher education and functional ability implies that the conclusions drawn from these studies require certain precautions. That even older people in a potentially vulnerable situation due to functional impairments may have the possibility to be involved in research has been highlighted in previous research, and requires specific considerations (Berge, 2021). Reflecting on Study I, based on previous studies it can be assumed that there was a certain bias regarding the mobile digital literacy and functional ability. Another factor, which was not explicitly reported in the individual studies is ethnicity, but it appears from Study III that a significantly larger proportion of the respondents were born in Sweden in comparison with the corresponding national population, and a qualified assumption is that this applies to studies I and IV as well. However, this bias has its basis to some extent in the study's design, as knowledge of Swedish was a criterion for participating in the study.

Further, a shortcoming in Study II is that actors from the private housing sector were not included in the study, as those invited were not able or willing to participate. Their absence was raised as an issue by key actors from public housing companies with the argument that they are both players in the same market. The final part of the discussion provides suggestions of strategies for involving users in research on ageing and health building on a consideration of the main thesis findings.

Suggestions of strategies for involving users in research on ageing and health

A number of strategies for involving users in research on ageing and health can be extracted from the insights from the studies conducted within the framework of the thesis:

- To carefully reflect on what characterizes the overall problem that the study has an ambition to explain, understand or to improve and what role user involvement can and should play in order to meet the ambitions as much as possible.
- To consider who is suitable to be involved partly based on what and who they represent but also based on their ability to think individually and independently where this is of particular value for the study
- To consider that studies with user involvement are more likely to exclude people with cognitive or functional abilities and/or people with low digital literacy skills and that it is necessary to find constructive ways to deal proactively with these situations already at the planning stage.
- To be aware of and sensitive to the fact that the users one wishes to involve have preferences regarding which stages in the research process and in what way/s they prefer to be involved in the research and that this may affect their degree of involvement.
- To consider that the later users are involved in the research process, the less influence they are likely to have over the decisions made in the research process; and that initial delimitations of the projects and the design of the studies constitute a form of design decision that has a significant influence on the delimitation of the problem and thus the character of the final results.
- To reflect that the depth of user involvement is strongly linked to the aim of the study and the aim/s of the involvement and that this can look very different depending on the nature of the study in question.

Conclusions

- The willingness to get involved in research among older people was associated with prior involvement and higher levels of formal education. The association between higher education and involvement in research was strengthened by an additional study in the thesis directed to older people and persons with functional impairment.
- Older people preferred to be involved in the planning, and overall decision-making in the research process rather than in more tangible research work such as being involved in collecting data.
- The older people and persons with functional impairments who had been involved in research could not be attributed to any clearly improved ability or changed attitude afterwards, and to a large extent both abilities and attitudes remained unchanged. Although, this should be seen in light of the predominantly positive attitudes before their involvement and judged on the basis that their involvement had a limited depth.
- The response rates for the two large quantitative studies were lower than anticipated and thus illustrated the difficulties in recruiting respondents to "research about research". Highly educated people were overrepresented in both studies.
- In two different technology-centered studies, it was made clear that low mobile digital literacy led to difficulties in users participating mainly due to a lack of ability to manage the pre-conditions for what constituted the actual "technical solution", such as being able to navigate a tablet or being able to download an application.
- Regarding the importance of the study design for representativeness and recruitment of a diversity of users, it emerged that there was a reluctance of older people to participate in studies that ran over a longer period of time.
- The conceptual tool enabled a comparison between different types of studies both with user involvement and about user involvement. The tool made it clearer and easier to identify similarities and differences between the studies. However, it proved challenging to include studies in the model with a focus on *about* user involvement and the way that this was solved

created a certain lack of clarity in terms of which phenomena had actually been categorized.

- Taken together, these insights into the value, challenges and limitations associated with different forms of user involvement in research, reflecting a range of topics and approaches and varying levels of involvement has the potential to contribute the development of generalizable knowledge and cumulative knowledge building in research on ageing and health.

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Appendices 1-9

Appendix 1. Eligibility criteria (Study I)

The screening consisted of two instruments, the Mini Mental State Examination (MMSE) and the Geriatric Depression Scale (GDS), and a number of demographic questions considered relevant for the study. The MMSE was used to briefly assess the cognitive functions of the PwMCI. It includes questions about orientation, attention, recall, and language ability. It is also used to estimate the severity and progression of cognitive impairment and to follow the course of cognitive changes in an individual over time. To be included in this study, individuals must score between 20 and 28 points on the scale. The use of an MMSE cutoff value of 28 is not common and has some risks but has been used in other studies . O'Bryant et al. showed that an MMSE cutoff score of 28 gave the best sensitivity and specificity for detecting mild dementia in a population with self-reported memory complaints.

The GDS was used as an exclusion criterion, screening for depression in PwMCI. If participants score above 11, they will be excluded from the study. As people who are physically ill and living with mild to moderate dementia have short attention spans and/or feel easily fatigued, we used the short form of the GDS (GDS-15) consisting of 15 questions. The GDS is commonly used as a routine part of a comprehensive geriatric assessment. The grid sets a range of 0 to 4 as "normal", 5 to 8 as "mildly depressed", 9 to 11 as "moderately depressed", and 12 to 15 as "severely depressed".

Eligibility Criteria

Inclusion Criteria

- A participant will be eligible for inclusion in this trial only if all of the following criteria are met:
- Participants score 20 to 28 points on the Mini Mental State Examination (MMSE) whether or not a diagnosed neurodegenerative disease is present;
- A professional assessment of the patient's own experience of memory problems over a substantial period of time (more than 6 months);

- Participants are older than 55 years;
- Participants are home care recipients;
- Participants have an informal carer;
- Participants take prescribed medication and are in charge of their own medication use;
- Participants have no specific conditions reducing their physical ability to use the app, for example, visual, hearing, or motor impairments.

Exclusion Criteria (Persons with Mild Cognitive Impairment Only)

- A participant will not be eligible for inclusion in this study if any of the following criteria apply:
- Participants have a terminal illness with less than 3 years of expected survival;
- Participants score above 11 on the Geriatric Depression Scale (GDS-15) or have another known significant cause of disease as an explanation for cognitive impairment such as abuse and other psychiatric diagnoses such as bipolar disorders, schizophrenia, and developmental disorders.

Appendix 2. Task analysis (Study I)

Task Description

The tasks that were requested of the participants in the user testing were the following:

Reminders for activities

- Add a reminder that you today in 30 minutes' time from now should "call theatre and change tickets". Set the reminder to remind you 10 min before the phone call.
- Add a reminder that you tomorrow at 10 am will have a general health checkup.
- Add a reminder USING A VOICE COMMAND that you tomorrow at 2 pm will have a general health checkup.
- Check the reminders you have added for today and tomorrow.

People I know

- Add the professional staff (CST) and the professional staff (BTH) as a contact in the "People I know" section of the app.

Games and Resources

- Go to the Games and Resources section and check what is included there

Medicine reminders

- In the section "My Health", add a medicine reminder to take the medicine Plavix, 2 times per day at 9 AM, and 6 PM starting from today.
- Check medicines that have been added.
- Delete medicines that have been added.

My Health: Symptoms

- In the "My Health" section of the app, add that you have experienced a symptom. The symptom I want you to add that you have experienced is headache. Write that it started today and that the severity is 4 on a scale from 1 to 10.
- Check the symptoms that have been added.

Share with others

- Now, I want you to share your symptom with others. The person I want you to share your symptom with is the professional staff (CST)/the professional staff (BTH) who has the email address xxxxx@hotmail.com.

About dementia

- Go to the About dementia section and check the information presented.
- Click on the different chapters and skim through them.

General tasks

- Turn on the tablet.
- Start the SMART4MD application.

Appendix 3. Participants (Study II)

The Research Circle participants consisted of twelve persons representing various categories of non-academic actors and institutions (i.e., key actors) and three researchers with different academic backgrounds (design sciences, health sciences and cognitive science) (See table). The key actors' perspectives were considered as essential to better understand the complexities in individual thinking related to the wicked problem of providing accessible housing for the ageing population. The recruitment was based on the fact that the key actors were interested in and potential beneficiaries of the new knowledge produced from research on housing accessibility, had competence, knowledge, experience of and opinions on issues related to housing and health.

Characteristic	**Total (N = 15)**
Sex	
Men	9
Women	6
Key actors	
Public housing company	3
Municipal building administration	2
National senior citizens' organization	1
Municipal health care administration	2
Private service provider within the assistive device sector	1
Private architecture and engineering consultancy	1
National public authority (National Board of Health and Welfare)	1
Business developer	1
Researchers	1
Lund University employee (authors O.J., M.H. & J.F.)	3

Appendix 4. Attributes of wicked problems (Study II)

As described by Rittel and Webber, wicked problems have 10 important characteristics:

1) They do not have a definitive formulation.
2) They do not have a "stopping rule." In other words, these problems lack an inherent logic that signals when they are solved.
3) Their solutions are not true or false, only good or bad.
4) There is no way to test the solution to a wicked problem.
5) They cannot be studied through trial and error. Their solutions are irreversible so, as Rittel and Webber put it, "every trial counts."
6) There is no end to the number of solutions or approaches to a wicked problem.
7) All wicked problems are essentially unique.
8) Wicked problems can always be described as the symptom of other problems.
9) The way a wicked problem is described determines its possible solutions.
10) Planners, that is those who present solutions to these problems, have no right to be wrong. Unlike mathematicians, "planners are liable for the consequences of the solutions they generate; the effects can matter a great deal to the people who are touched by those actions."

Appendix 5. Five-dimension framework (Study III)

Five-dimensional framework to address wicked problems.

Dimension	Description
Biophysical (measurements)	The biological and physical environment in which an issue is set. Arrived at by observations, measurements, and formal reports.
Socioeconomic (stories)	The social environment, including cultural rules and the socioeconomic systems (a prevailing emphasis in Western culture). Arrived at through reflecting on a cultural framework and/or a personal commitment to a way of life or a religion.
Ethical (principles)	The principles governing relationships between individuals and society and between individuals and the environment.
Artistic/Aesthetic (patterns)	Sensitivity to the patterns in natural and in social systems, arising from the capacity for inspiration within each human being. Arrived at by both expressing and rebelling against cultural norms.
Sympathetic/Empathetic (feelings)	Recognizing a shared understanding with another human being or group. Arrived at through feelings of openness, trust, and shared experience.

Note: After Brown, Lambert & Harris (2019)(p. 34–37).

Appendix 6. Survey questions (Study III)

Awareness and attitudes

The survey included 27 questions divided into the following sections: Awareness of and previous experience of public involvement in research (Q1-4); Attitudes towards public involvement in research (Q5); Interest in research and willingness to be actively involved in research (Q6-8); Facilitators and barriers for public involvement in research (Q9-13); Demographic questions (Q14-22); Self-rated health and frailty (Q23-27). For a detailed description of the questions, see Appendix 6.

LUNDS UNIVERSITET
CASE
CENTRE FOR AGEING AND
SUPPORTIVE ENVIRONMENTS

Institutionen för hälsovetenskaper
Professor Susanne Iwarsson

Inbjudan att svara på en enkät – en del av forskningsstudien ”Panelstudie om Brukarmedverkan i forskning om åldrande och hälsa”

Hej,

Vi skickar det här brevet till dig för att bjuda in dig till deltagande i en enkätstudie. Enkätstudien genomförs på uppdrag av forskare vid Lunds universitet och ingår i forskningsprogrammet UserAge som handlar om brukarmedverkan i forskning. Till skillnad från att delta i en studie genom att t ex bli intervjuad eller lämna prover innebär brukarmedverkan att man samarbetar med forskarna i forskningens genomförande.

Det långsiktiga målet är att skapa bästa möjliga effekter av sådan brukarmedverkan. Målet med enkätstudien är att samla in information om olika uppfattningar om att privatpersoner eller företrädare för intresseorganisationer aktivt medverkar i forskning. Vi vill studera om sådana uppfattningar förändras över tid.

I detta dokument får du information om en enkätstudie som du nu inbjuds att delta i, vad det innebär att delta i denna och hur du går tillväga för att delta.

Varför blir jag tillfrågad om att delta?

Du har slumpmässigt valts ut bland personer över 60 år, folkbokförda i Sverige. Vi har fått dina kontaktuppgifter från Statens personadressregister. Professor Susanne Iwarsson vid Institutionen för hälsovetenskaper, Medicinska fakulteten och CASE vid Lunds universitet (https://www.case.lu.se/) har det vetenskapliga huvudansvaret för studien. Flera forskare är engagerade, med biträdande forskare, fil dr Oskar Jonsson som kontaktperson.

Hur går studien till?

Föredrar du att besvara enkäten via internet kan du göra det via länken http://sifologin.tns-sifo.se/ och ange användarnamn och lösenord nedan.

Användarnamn:	
Lösenord:	

Vill du hellre fylla i bifogad pappersversion gör du det och returnerar sedan enkäten i det frankerade svarskuvertet.

Enkäten tar cirka 15 minuter att besvara och innehåller frågor om din syn på att privatpersoner aktivt medverkar i forskning om åldrande och hälsa.

Enkätstudien blir bättre ju fler som svarar. Därför kan du komma att få påminnelser. Ett identifikationsnummer på enkäten används för att kunna pricka av inkomna svar och förhindra onödiga påminnelser.

Om du väljer att svara på denna enkät kommer dina kontaktuppgifter och svar att skickas till Lunds universitet och endast användas för forskningsprojektets ändamål.

Du kan komma att bli återkontaktad om ca två år med frågan om att delta i en uppföljande enkät. Om du blir kontaktad igen är det helt frivilligt för dig att välja att vara med eller inte. För att forskarna ska kunna följa de övergripande resultaten över tid så behöver kontaktuppgifter för de som deltar sparas och kunna kopplas ihop med personernas svar.

Vad händer med mina uppgifter?

Vi på Sifo och Lunds universitet behandlar dina svar och kontaktuppgifter i enlighet med GDPR och våra integritetspolicys*. Dina kontaktuppgifter och svar kommer att lagras separat, men vara möjliga att kopplas ihop med en så kallad nyckel som förvaras i enlighet med gällande lagstiftning. Dina personuppgifter kommer att lagras i som mest tre år och dina svar i som mest 10 år och raderas sedan. Du kan också när som helst kontakta Lunds universitet för frågor. Dina svar kommer inte på något sätt att kunna kopplas till dig som person eller identifieras via de övergripande resultat som presenteras.

Möjliga följder och risker med att delta i studien

Vi bedömer att det inte föreligger några risker med att delta i studien. Skulle du efter det att du gett ditt medgivande till att delta välja att avbryta din medverkan medför detta inga som helst negativa konsekvenser för dig.

Hur får jag information om resultatet av studien?

Vill du ta del av resultaten och/eller medverka aktivt i vår forskning kommer det ges möjlighet till detta efter att du deltagit i enkätstudien.

Deltagandet är frivilligt

Deltagande i studien är frivilligt och du kan när som helst välja att avbryta din medverkan. Om du väljer att avstå eller avbryta ditt deltagande behöver du inte uppge varför. Vill du avstå från att delta kan du höra av dig via telefon eller e-post och ange ditt användarnamn.

Ansvariga för studien

Oskar Jonsson

Telefon *046 222 19 96*

SMS/Mobil *072 711 24 25*

E-post *oskar.jonsson@med.lu.se*

Susanne Iwarsson

Telefon *046 222 19 40*

SMS/Mobil *070 317 31 11*

E-post *susanne.iwarsson@med.lu.se*

För att kontakta Kantar Sifo, kontakta projektledare Mikaela Ekblad *mikaela.ekblad@kantarsifo.com*, eller ring 0200 110 510.

HÖR GÄRNA AV DIG OM DU HAR NÅGRA FRÅGOR!

*https://www.lu.se/start/behandling-av-personuppgifter-vid-lunds-universitet

Kantarsifo.se/intregritet

Enkät om brukarmedverkan i forskning

Privatpersoner kan delta i forskning om åldrande och hälsa på många olika sätt, och företräda olika grupper eller intresseorganisationer. Det är vanligt att privatpersoner svarar på enkäter, deltar i intervjuer etc., men med denna studie vill vi veta mer om din syn på att privatpersoner aktivt medverkar i själva genomförandet av forskning.

OBS! Vi ber bara dig som personligen fått det här brevet att svara på enkäten och svara enbart för dig själv.

Vi är tacksamma för om du vill svara på frågorna i enkäten som tar cirka 15 minuter att slutföra.

Kantar Sifo och Lunds universitet behandlar dina svar och kontaktuppgifter i enlighet med GDPR och våra integritetspolicys.

Om du väljer att svara på denna undersökning kommer dina kontaktuppgifter och enkätsvar att skickas till Lunds universitet och endast användas för forskningsprojektets ändamål. Du kan komma att bli återkontaktad om ca 2 år med frågan om att delta i en ny enkät. Dina kontaktuppgifter kommer att lagras i som mest tre år och raderas när de inte längre behövs.

Resultaten kommer bara att redovisas på en övergripande nivå så att enskilda individer inte ska kunna identifieras. Men för att forskarna ska kunna följa de övergripande resultaten över tid så behöver kontaktuppgifter för de som deltar också att sparas och kunna kopplas ihop med intervjupersonernas svar. Dina kontaktuppgifter och svar kommer att lagras separat, men vara möjliga att kopplas ihop med en så kallad nyckel som förvaras i enlighet med gällande lagstiftning.

Om du blir kontaktad igen för en förfrågan om att delta i den nya undersökningen är det helt frivilligt för dig att välja att vara med eller inte. Du kan också när som helst kontakta Lunds universitet (oskar.jonsson@med.lu.se, 046 222 19 96) för frågor eller om du skulle vilja återta ditt samtycke.

Genom att besvara och skicka in enkäten samtycker du till detta.

---

1. Har du som privatperson tidigare deltagit i forskning?
Flera alternativ är möjliga.

Svarat på en enkät	☐ Ja	☐ Nej
Testat ett nytt läkemedel, behandlingsmetod, tjänst eller produkt	☐ Ja	☐ Nej
Lämnat prover	☐ Ja	☐ Nej
Blivit undersökt, testad eller observerad	☐ Ja	☐ Nej
Blivit intervjuad enskilt eller i grupp	☐ Ja	☐ Nej
På annat sätt, nämligen:	☐ Ja	☐ Nej

Nu frågar vi istället om dina erfarenheter av att medverka aktivt i själva genomförandet av forskning.

2. Känner du till att du som privatperson kan medverka aktivt i själva genomförandet av forskning? *T.ex. ge synpunkter på ett frågeformulär, medverka i brukarråd, hjälpa till vid rekrytering eller sprida forskningsresultat.*

☐ Ja

☐ Nej

☐ Tveksam/vet ej

3. Har du som privatperson tidigare medverkat aktivt i själva genomförandet av forskning? *Flera alternativ är möjliga.*

Medverkat i ett brukarråd, referensgrupp, styrelse eller liknande	☐ Ja	☐ Nej
Agerat som rådgivare (t.ex. gett synpunkter på forskning eller frågeformulär)	☐ Ja	☐ Nej
Hjälpt till vid rekrytering av deltagare	☐ Ja	☐ Nej
Gjort intervjuer eller mätningar och förmedlat dem för användning i forskningssyfte	☐ Ja	☐ Nej
Hjälpt till med tolkning av det forskningsmaterial som tagits fram	☐ Ja	☐ Nej
Har hjälpt till med att sprida forskningsresultat	☐ Ja	☐ Nej
På annat sätt, nämligen:…………………………………………	☐ Ja	☐ Nej

Om du svarat nej på alla delfrågor i fråga 3, gå till fråga 4. Gå annars vidare till fråga 5.

4. Om du tidigare inte har medverkat aktivt i forskning, vilken var anledningen?
Flera alternativ är möjliga.

☐ Ingen har frågat eller bett mig

☐ Jag tycker att forskning är svårt/jag förstår inte

☐ Jag är rädd att min anonymitet och integritet inte ska respekteras

☐ Jag har inte tid

☐ Jag orkar inte/det är för krävande

☐ Jag vågar inte

☐ Jag är inte intresserad

☐ Jag tror inte att jag skulle ha något att bidra med

☐ Jag tycker att det är meningslöst

☐ Forskare lyssnar ändå inte

☐ På grund av min sjukdom, funktionsnedsättning eller situation

☐ Annat, nämligen……………………………………………………………………

Frågorna 5a–5i handlar om din syn på att privatpersoner medverkar aktivt i forskning om åldrande och hälsa. I vilken grad stämmer följande påståenden överens med din uppfattning?

	Stämmer inte alls	Stämmer inte	Stämmer ganska bra	Stämmer precis
5a. De människor som berörs av sådan forskning bör ha rätt att tycka till om vad forskningen ska handla om och hur den bedrivs.	☐	☐	☐	☐
5b. För mig personligen är det viktigt att vara delaktig i beslut som gäller sådan forskning.	☐	☐	☐	☐
5c. Eftersom privatpersoner i allmänhet kan bidra med egna värdefulla erfarenheter av att åldras bör de medverka aktivt i sådan forskning.	☐	☐	☐	☐
5d. Att engagera privatpersoner i sådan forskning innebär att forskningens objektivitet, oberoende och integritet äventyras.	☐	☐	☐	☐
5e. Att engagera privatpersoner i sådan forskning kan förbättra spridningen av forskningens resultat.	☐	☐	☐	☐
5f. Det är viktigt att privatpersoner medverkar aktivt i sådan forskning, särskilt sådan som finansieras med skattemedel.	☐	☐	☐	☐

	Stämmer inte alls	Stämmer inte	Stämmer ganska bra	Stämmer precis
5g. Det är en moralisk skyldighet för mig att medverka aktivt i sådan forskning eftersom forskningsresultaten kommer andra människor till gagn.	☐	☐	☐	☐
5h. Att engagera privatpersoner i sådan forskning är endast ”ett spel för gallerierna”, dvs. det är endast till för att uppfylla politiska målsättningar och har ingen betydelse för resultaten.	☐	☐	☐	☐
5i. En förutsättning för att sådan forskning ska leda till förändringar i samhället är att privatpersoner medverkar aktivt i forskning.	☐	☐	☐	☐

Frågorna 6–8 handlar om ditt intresse för, om och på vilket sätt, du skulle kunna tänka dig att medverka aktivt i forskning om åldrande och hälsa, som privatperson. Detta betyder inte att vi förväntar oss att just du ska engagera dig i sådan forskning, men vi vill få en generell bild av vad som skulle kunna vara möjligt i framtiden.

6. Hur intresserad är du av forskning som handlar om åldrande och hälsa?

Inte alls	☐
Lite	☐
Måttligt	☐
Ganska mycket	☐
Väldigt mycket	☐

7. Skulle du kunna tänka dig att medverka aktivt i forskning om åldrande och hälsa? *T.ex. hjälpa till med rekrytering av deltagare eller ge synpunkter på ett frågeformulär.*

☐ Ja → *Gå till fråga 8*

☐ Nej → *Gå till fråga 11*

☐ Kanske → *Gå till fråga 8*

8. Om du fick möjlighet, hur sannolikt är det att du skulle vilja medverka genom att…

	Inte alls	Lite	Måttligt	Ganska mycket	Väldigt mycket
8a. ... bidra till planering och utformning av forskningsprojekt? *T.ex. identifiera forskningsfrågor eller hjälpa till med att ta fram informationsmaterial och frågeformulär.*	☐	☐	☐	☐	☐
8b. ... ingå i ett i ett brukarråd, referensgrupp, styrelse eller liknande? *T.ex. diskutera forskningsaktiviteter eller ge synpunkter på forskningen.*	☐	☐	☐	☐	☐
8c. … genomföra uppgifter i forskningsprojekt? *T.ex. rekrytera deltagare, genomföra intervjuer*	☐	☐	☐	☐	☐
8d. … analysera det forskningsmaterial som tagits fram? *T.ex. hjälpa till med tolkning av resultat.*	☐	☐	☐	☐	☐

	Inte alls	Lite	Måttligt	Ganska mycket	Väldigt mycket
8e. … **sprida forskningsresultat?** *T.ex. ge synpunkter på texter eller presentera resultat vid offentliga möten.*	☐	☐	☐	☐	☐
8f. … **bidra till en ansökan om forskningsfinansiering?** *T.ex. föreslå forskningsfrågor så att de speglar målgruppens behov.*	☐	☐	☐	☐	☐

8g. Finns det något annat sätt du skulle kunna tänka dig att medverka på?

☐ Nej ☐ Ja, Vänligen ange hur:

………………………………………..…………………………………………………

Frågorna 9–13 handlar om vad som kan underlätta eller hindra att privatpersoner medverkar aktivt i forskning.

9. Via vilka kanaler föredrar du att bli informerad om möjligheter att medverka aktivt i forskning om åldrande och hälsa? *Flera alternativ är möjliga.*

☐ Utskick med brev

☐ Annons eller artikel i tidning

☐ Internet/sociala medier

☐ Personligt telefonsamtal, möte

☐ E-post

☐ SMS

☐ Tv/radio

☐ Offentligt möte, konferens eller föreläsning

☐ Annons på anslagstavla

☐ På annat sätt, nämligen: ……………………………………………………………

10. Av vem/vilka föredrar du att få information om möjligheter att medverka aktivt i forskning om åldrande och hälsa, som privatperson?

Flera alternativ är möjliga.

☐ Intresseorganisationer

☐ Regional hälso- och sjukvård

☐ Kommunal hälso- och sjukvård eller socialtjänst (t.ex. hemtjänst)

☐ Privat hälso- och sjukvård

☐ Forskare

☐ Företag

☐ Rekryteringsfirma

☐ Familj, vänner eller bekanta

☐ På annat sätt, nämligen: ……………………………………………………………

11. Hur intresserad skulle du vara av att delta i en kurs eller informationsträff för att lära dig mer om forskning och metoder som används i forskning?

Inte alls	☐
Lite	☐
Måttligt	☐
Ganska mycket	☐
Väldigt mycket	☐

12. Vad skulle kunna motivera dig att medverka aktivt i forskning om åldrande och hälsa?

Flera alternativ är möjliga.

☐ Att få förtur till tjänster (t.ex hälso- och sjukvård, social omsorg, service, boende etc)

☐ Att få känna mig betydelsefull

☐ Att få reda på mer om min situation

☐ Att bidra till samhället

☐ Att jag inte har något att förlora

☐ Att forskningen bör gå framåt (dvs. någon måste ställa upp)

☐ Att få kontakt med andra i samma situation

☐ Att vara hjälpsam mot forskaren

☐ Att få bättre tjänster och produkter

☐ Att få reda på vad studien kommer att leda till

☐ Att forskningen handlar om något som jag tycker är viktigt

☐ Annat, nämligen……………………………………………………………………………

☐ Inget, jag vill inte medverka aktivt i forskning

13. Vad skulle du uppleva som hinder för att medverka aktivt i forskning om åldrande och hälsa? *Flera alternativ är möjliga.*

☐ Min brist på förståelse för forskning

☐ Svårigheter att förstå de sätt som forskare uttrycker sig på

☐ Forskarnas brist på kompetens vad gäller att engagera privatpersoner

☐ Skillnader i förväntningar mellan forskare och mig själv

☐ Olikheter mellan deltagare

☐ Brist på tid

☐ Alltför krävande för mig

☐ Egen sjukdom, funktionsnedsättning eller på annat sätt hindrande privat situation

☐ Tror inte att det leder till förändringar av min situation

☐ Annat, nämligen..…………………………………………………………………

Bakgrundsfrågor

14. Är du medlem/engagerad i någon intresseorganisation med relevans för området åldrande och hälsa, t.ex. pensionärs- eller patientorganisation?

☐ Ja, vilken?..

☐ Nej

15. Är du politiskt aktiv?

☐ Ja ☐ Nej ☐ Vet ej

16. Är du anhörigvårdare? *Med anhörigvårdare menar vi er som regelbundet ger vård, hjälp eller stöd till närstående.*

☐ Ja ☐ Nej ☐ Vet ej

17. Har du som yrkesverksam arbetat, eller arbetar, inom något av följande områden? *Flera alternativ är möjliga.*

☐ Forskning

☐ Hälso- och sjukvård eller socialtjänst

☐ Bostadsbranschen

☐ Media

☐ Annat område

☐ Nej, jag har inte arbetat eller vill ej uppge inom vilket område

18. Vilken är din huvudsakliga sysselsättning just nu?

Obs! Ange endast ett alternativ.

☐ Pensionär

☐ Förvärvsarbetar, anställd

☐ Egen företagare

☐ Studerar

☐ Arbetssökande

☐ Långtidssjukskriven (mer än 3 månader)

☐ Annat, nämligen……………………………………………………………………..

19. Är du ensamstående eller gift/sambo?

☐ Ensamstående ☐ Gift/sambo

20.Vilket av följande alternativ tycker du själv bäst beskriver din ekonomiska situation?

☐ Dålig ☐ Någorlunda ☐ God ☐ Mycket god ☐ Utmärkt

21. Vilken är din högsta utbildning? *Obs! Ange endast ett alternativ*

☐ Grundskola (folkskola/flickskola/realskola)

☐ Gymnasium (folkhögskola)

☐ Eftergymnasial utbildning, mindre än tre år (yrkeshögskola/kvalificerad yrkesutbildning)

☐ Eftergymnasial utbildning, tre år eller mer

☐ Forskarutbildning

☐ Annat, nämigen:…………………………………………………………..

22. Är du född i ett <u>annat land</u> än Sverige?

☐ Ja ☐ Nej

Om ja, vilket är ditt modersmål?...

Eftersom enkäten berör forskning om åldrande och hälsa handlar frågorna 23–27 om ditt hälsotillstånd. Dina svar på hälsofrågorna kommer att ge forskarna ökade möjligheter att göra gruppjämförelser.

23. Orkar du gå en promenad på cirka 15–20 minuter? ☐ Ja ☐ Nej

24. Har du känt dig allmänt trött eller upplevt nedsatt ork de senaste tre månaderna? ☐ Ja ☐ Nej

25. Upplever du att du ramlar ofta eller är rädd för att ramla? ☐ Ja ☐ Nej

26. Behöver du hjälp med att handla, det vill säga att ta dig till affären, plocka varor, betala och bära hem varorna? ☐ Ja ☐ Nej

27. I allmänhet skulle du säga att din hälsa är (markera ett av alternativen):

☐ Dålig ☐ Någorlunda ☐ God ☐ Mycket god ☐ Utmärkt

Varmt tack för Din medverkan!

Referensnummer: xxxxx

Appendix 7. Questionnaires (Study IV)

HX

The pre-Q included 27 questions, and the post-Q included 18. The questions concerned demographics, health and functioning, housing tenure, previous research experience, work experience in the housing sector, previous experience with mobile digital devices, involvement in the HX, attitudes towards housing accessibility and research and mobile digital literacy. For a more detailed description of the questions, see Appendix 7.

Samtycke

Välkommen till studien Utvärdering av Bostadsförsöket 2021

Här hittar du information om studien och om vad det innebär att delta.

Om du vill vara med behöver vi först veta din epostadress så att vi kan kontakta dig för deltagande i en andra uppföljande webbenkät efter din medverkan i Bostadsförsöket 2021.

Vi behöver också ditt samtycke som du ger oss genom att i rutorna här nedanför fylla i 'Ja' och därefter trycka på 'Submit' för att bekräfta.

Då kommer du till själva enkäten som tar cirka 10 minuter att besvara.

OBS! För att ångra dina svar tryck på den blå texten 'reset' intill det svar som du har angett.

Vänligen ange din epostadress	__________________________________
Vänligen ange din epostadress igen	__________________________________
De epostadresser du angav är inte identiska.	○ not equal
Vänligen kontrollera att de epostadresser du angav är korrekta. Välj sedan "Bekräfta".	○ Bekräfta
Jag intygar att jag ännu inte har genomfört mätningarna i Bostadsförsöket 2021. (För att vara behörig att svara på denna första enkät i Bostadsförsöket får du ännu inte ha genomfört mätningarna i Bostadsförsöket 2021. Tanken är att denna första enkät besvaras INFÖR ditt deltagande i Bostadsförsöket 2021.)	○ Ja
Jag har läst informationen om Utvärdering av Bostadsförsöket 2021. Jag kan kontakta forskarna via de kontaktuppgifter som anges i informationen om jag vill ställa några frågor. Jag samtycker till att delta i studien Utvärdering av Bostadsförsöket 2021.	○ Ja
Jag samtycker till att de uppgifter som samlas in behandlas på det sätt som beskrivs i informationen om Utvärdering av Bostadsförsöket.	○ Ja

Vänligen klicka på knappen 'Submit' här nedanför för att bekräfta att du godkänner villkoren för att delta i studien.

Förenkät Bostadsförsöket

Utvärdering av Bostadsförsöket 2021 - Första enkäten

Den här enkäten handlar om din syn på och intresse för Bostadsförsöket 2021, samt din syn på och erfarenhet av tillgänglighet (i bostäder), forskning och digital teknik.

Enkäten tar ungefär 10 minuter att besvara.

OBS! För att ångra dina svar tryck på den blå texten 'reset' intill det svar som du har angett.

Några frågor om din syn på Bostadsförsöket 2021

1. Vilket av följande påståenden stämmer bäst överens med vad du vet i dag om Bostadsförsöket 2021?	○ Det enda jag vet om Bostadsförsöket är det jag läste i inbjudan till denna studie ○ Jag kände till Bostadsförsöket sedan tidigare eftersom vi har diskuterat det i min förening ○ Jag kände till Bostadsförsöket sedan tidigare eftersom jag har läst/hört om det på nyheterna ○ Jag kände till Bostadsförsöket sedan tidigare eftersom jag har varit inne på Bostadsförsökets hemsida ○ Jag kände till Bostadsförsöket sedan tidigare genom att...
Vänligen ange på vilket sätt	______________________________
2. Har du tänkt vara med i Bostadsförsöket 2021?	○ Ja ○ Nej ○ Jag vet inte/ Har inte bestämt mig
Hur kommer det sig att du är tveksam till, eller inte vill, vara med i Bostadsförsöket 2021? (Du kan ange ett eller flera svarsalternativ.)	☐ Jag vill inte medverka i forskning. ☐ Det verkar inte vara tillräckligt intressant. ☐ Det verkar ta för lång tid. ☐ Jag har ingen smartphone eller surfplatta. ☐ Det verkar vara alltför svårt att göra. ☐ På grund av att... ☐ Vet ej
Vänligen ange anledning här:	______________________________

Några frågor om din syn på forskning

3. Hur intresserad är du av forskning?	○ Inte alls intresserad ○ Inte så intresserad ○ Ganska intresserad ○ Intresserad ○ Mycket intresserad

4. Har du tidigare varit med i något forskningsprojekt? (Du kan ange ett eller flera svarsalternativ.)	☐ Nej ☐ Ja, jag har besvarat enkät. ☐ Ja, jag har deltagit i telefonintervju. ☐ Ja, jag har besökt forskningscentrum/vårdinrättning för att göra tester (t.ex. minnestest eller provtagning). ☐ Ja, jag har varit med och samlat in data (t.ex. rapporterat in fåglar vid årlig inventering). ☐ Ja, jag har använt dator, surfplatta eller smartphone när jag lämnat uppgifter till ett forskningsprojekt (t.ex. besvarat enkät). ☐ Ja, jag har medverkat i en styrgrupp eller referensgrupp knuten till ett forskningsprojekt. ☐ Ja, forskningsuppgifter ingår eller ingick i mitt lönearbete. ☐ Ja, jag har deltagit genom att... ☐ Vet ej
Vänligen ange på vilket sätt:	________________________________

Några frågor om din syn på fysisk tillgänglighet i bostäder

5. Är frågan om fysisk tillgänglighet i bostäder angelägen för dig?	○ Mycket angelägen ○ Angelägen ○ Ganska angelägen ○ Inte så angelägen ○ Inte alls angelägen
6. Har du funderat på hur tillgänglig din bostad är för personer med funktionsnedsättningar?	○ Ja, har funderat mycket på det ○ Ja, har funderat lite grann på det ○ Nej, inte alls
7. Hur tror du att tillgängligheten i din bostad är i förhållande till genomsnittsbostaden i Sverige?	○ Bättre än genomsnittsbostaden ○ Som genomsnittsbostaden ○ Sämre än genomsnittsbostaden ○ Vet ej
Motivera gärna ditt svar	________________________________
8. Tror du att tillgängligheten i din bostad skulle kunna förbättras?	○ Ja ○ Nej ○ Vet inte
Motivera gärna ditt svar	________________________________
9. Tror du att tillgängligheten i din bostad är tillräckligt bra för en person som använder rollator inomhus?	○ Ja ○ Nej ○ Vet inte
Motivera gärna ditt svar	________________________________

10. Har du, eller har du tidigare haft, ett yrke där det ingår att planera, utforma, bygga, anpassa eller förvalta bostäder?	○ Ja ○ Nej ○ Vet inte

Några frågor om din syn på och erfarenhet av digitala verktyg såsom dator, smartphone och surfplatta

11. Använder eller har du använt digitala verktyg såsom dator, smartphone eller surfplatta i ditt yrkesutövande?	○ Ja ○ Nej ○ Har inte yrkesarbetat
12. Har du tillgång till internet i hemmet?	○ Ja ○ Nej ○ Vet inte
13. Under de senaste tre månaderna, hur ofta har du använt en smartphone eller surfplatta?	○ Dagligen ○ Flera gånger i veckan ○ Någon gång i veckan ○ Någon gång i månaden ○ Någon enstaka gång ○ Aldrig ○ Vet inte
14. När laddade du senast själv ner en app på en telefon eller surfplatta?	○ Senaste veckan ○ Senaste månaden ○ Senaste året ○ Har aldrig laddat ner någon app
15. Hur kunnig anser du dig vara när det gäller användning av en smartphone eller surfplatta?	○ Inte alls kunnig ○ Inte särskilt kunnig ○ Ganska kunnig ○ Mycket kunnig

Avslutningsvis några frågor om dig, din bostad och ditt hushåll

16. Vilket år är du född?	________________________ (Vänligen ange ditt födelseår med fyra siffror annars kommer ett felmeddelande att dyka upp.)
17. Vad identifierar du dig som?	○ Man ○ Kvinna ○ Icke-binär ○ Vill ej uppge
18. Vilken är din högsta avslutade utbildning?	○ Grundskola (folkskola/flickskola/realskola) ○ Gymnasium (folkhögskola) ○ Eftergymnasial utbildning, mindre än tre år (yrkeshögskola/kvalificerad yrkesutbildning) ○ Eftergymnasial utbildning, tre år eller mer (högskola/universitet) ○ Vill ej uppge

19. Vilken typ av bostad bor du i?	○ Lägenhet ○ Friliggande villa/hus/gård ○ Radhus/kedjehus/parhus ○ Kollektivhus/kooperativt boende ○ Inneboende, studentlägenhet/rum ○ Seniorboende/ trygghetsboende ○ Vård- och omsorgsboende ○ Annan typ av bostad, nämligen...
Vänligen ange vilken typ av bostad.	________________________________
20. Äger du din bostad, helt eller delvis?	○ Ja ○ Nej
21. Hur många personer totalt bor i ditt hem/hushåll?	○ 1 ○ 2 ○ 3 ○ 4 ○ 5 eller fler
22. I allmänhet skulle du säga att din hälsa är (markera ett av alternativen):	○ Dålig ○ Någorlunda ○ God ○ Mycket god ○ Utmärkt
23. Använder någon i hushållet rollator eller rullstol regelbundet?	○ Nej ○ Ja, både inom- och utomhus ○ Ja, endast inomhus ○ Ja, endast utomhus ○ Vet inte
24. Är det någon i hushållet som har hemtjänst från kommunen eller privat företag?	○ Ja ○ Nej ○ Vet inte
25. Är du född i Sverige?	○ Ja ○ Nej ○ Vill ej uppge
26. Är/var båda dina föräldrar födda i Sverige?	○ Ja ○ Nej ○ Vill ej uppge
27. Hur stor, på ett ungefär, är hushållets inkomst varje månad efter skatt? (inkluderar alla medlemmar i hushållet samt både lön, pension, privat pensionsförsäkring, bidrag m.m.)	○ 12 500 kr eller mindre ○ 12 501 kr till 17 000 kr ○ 17 001kr till 21 500 kr ○ 21 501 kr till 26 000 kr ○ 26 001 kr till 30 500 kr ○ 30 501 kr till 35 000 kr ○ 35 001 kr eller mer ○ Vill ej ange

Vänligen klicka på knappen 'Submit' här nedanför för att skicka in dina enkätsvar.

Kontrollera gärna att du har besvarat alla frågor innan du skickar in.

Utvärdering av Bostadsförsöket 2021- Andra och avslutande enkäten

Utvärdering av Bostadsförsöket 2021- Andra och avslutande enkäten

Den handlar om dina erfarenheter av att medverka i Bostadsförsöket 2021.

Enkäten tar ungefär 10 minuter att besvara.

OBS! Om du inte laddat ner appen Bostadsförsöket och gjort mätningarna, så behöver du göra det INNAN du svarar på denna enkät. Har du en iphone eller ipad hittar du appen Bostadsförsöket i App Store eller genom att klicka här. Har du en annan typ av smartphone eller surfplatta hittar du appen Bostadsförsöket i Google Play eller genom att klicka här.

Några frågor om Bostadsförsöket 2021

1. Vilket påstående stämmer bäst in på dig och Bostadsförsöket 2021?	○ Jag försökte ladda ner appen, men fick det inte att fungera. ○ Jag laddade ner appen, men genomförde ingen mätning. ○ Jag laddade ner appen, påbörjade mätning men slutförde inte alla frågor i appen. ○ Jag laddade ner appen, slutförde mätningen och svarade på alla frågor i appen. ○ Jag deltog inte.

Om du inte deltagit i Bostadsförsöket 2021, inte laddat ner appen eller inte genomfört några mätningar, vänligen svara på nästa delfråga om vad som bidrog till att du INTE deltog/genomförde mätningarna.

Vad bidrog till att du INTE deltog/genomförde mätningarna? (Du kan ange ett eller flera svarsalternativ.)	☐ Det var inte tillräckligt intressant. ☐ Jag har ingen smartphone eller surfplatta. ☐ Det tog för lång tid. ☐ Det var alltför svårt att göra. ☐ Appen fungerade inte. ☐ Frågorna och instruktionerna i appen var inte tillräckligt tydliga. ☐ På grund av att...
Ange anledning här:	__________________________________

Fråga 2-17 kan du som INTE gjort några mätningar hoppa över eftersom dessa frågor endast är till för de som deltagit i Bostadsförsöket 2021.

Däremot får du gärna svara på fråga 18 och där skriva hur du tycker att ett eventuellt nytt massexperiment om bostäder bör vara utformat.

Vad bidrog till att du INTE slutförde alla frågorna i appen? (Du kan ange ett eller flera svarsalternativ.)	☐ Det var inte tillräckligt intressant. ☐ Det tog för lång tid. ☐ Det var alltför svårt att göra. ☐ Appen fungerade inte. ☐ Frågorna och instruktionerna i appen var inte tillräckligt tydliga. ☐ På grund av att...
Ange anledning här:	__________________________________

2. Genomförde du mätningarna av bostaden själv eller tillsammans med någon/några?	○ Själv ○ Tillsammans med en eller flera personer.
3. Delade du upp mätningarna på flera tillfällen?	○ Nej, jag gjorde det vid ett tillfälle. ○ Ja, på två tillfällen. ○ Ja, på tre eller flera tillfällen.
4. På vilken apparat/enhet installerade och använde du appen?	○ Smartphone ○ Surfplatta ○ Vet ej
5. Ungefär hur lång tid tog det totalt att genomföra mätningarna?	○ 10 minuter eller mindre ○ 11-20 minuter ○ 21-30 minuter ○ 31-60 minuter ○ Mer än 60 minuter ○ Vet ej
6. Hur upplevde du att det var att svara på frågorna i appen?	○ Mycket lätt ○ Ganska lätt ○ Varken lätt eller svårt ○ Ganska svårt ○ Mycket svårt
7. Upplevde du några praktiska problem i samband med mätningarna?	○ Ja ○ Nej ○ Vet inte
Vänligen ange på vilket eller vilka sätt.	__________________________________
8. Vad stämmer bäst in på dig? (Du kan ange flera alternativ.)	☐ Innan jag började mäta, läste jag om Bostadsförsökets syfte och bakgrund på Bostadsförsökets hemsida. ☐ Innan jag började mäta, tittade jag på instruktionsvideon på Bostadsförsökets hemsida. ☐ Innan jag började mäta, läste jag igenom den 30-sidiga handledningen med bakgrundsinformation och instruktioner på Bostadsförsökets hemsida. ☐ Innan jag började mäta, tog jag INTE del av någon ytterligare information om Bostadsförsöket utöver den som jag fått via mejl från min förening och från Lunds universitet. ☐ Innan jag började mäta tog jag del av information om det praktiska genomförandet på annat sätt, nämligen...
Ange på vilket sätt:	__________________________________
9. Har du studerat resultatet av dina och andras mätningar i databasen på Bostadsförsökets hemsida?	○ Ja ○ Nej, jag kände inte till att man kunde göra det. ○ Nej, jag hade inte tid. ○ Nej, jag hade inte intresse av att göra det. ○ Nej, eftersom...

Ange orsaken:	________________________________
Hur lärorikt tyckte du att det var att studera resultatet?	○ Mycket lärorikt ○ Ganska lärorikt ○ Inte särskilt lärorikt ○ Inte alls lärorikt
10. Har din syn på hur tillgänglig din bostad är förändrats genom att vara med i Bostadsförsöket?	○ Nej ○ Ja, jag har insett att min bostad INTE är så tillgänglig som jag trodde. ○ Ja, jag har insett att min bostad är MER tillgänglig än jag trodde.
Motivera gärna ditt svar.	________________________________
11. Är frågan om fysisk tillgänglighet i bostäder angelägen för dig?	○ Mycket angelägen ○ Angelägen ○ Ganska angelägen ○ Inte så angelägen ○ Inte alls angelägen
12. Tror du att tillgängligheten i din bostad skulle kunna förbättras?	○ Ja ○ Nej ○ Vet inte
Motivera gärna ditt svar.	________________________________
13. Tror du att tillgängligheten i din bostad är tillräckligt bra för en person som använder rollator inomhus?	○ Ja ○ Nej ○ Vet inte
Motivera gärna ditt svar.	________________________________
14. Hur kunnig anser du dig vara när det gäller användning av en smartphone eller surfplatta?	○ Inte alls kunnig ○ Inte särskilt kunnig ○ Ganska kunnig ○ Mycket kunnig
15. Hur intresserad är du av forskning?	○ Inte alls intresserad ○ Inte så intresserad ○ Ganska intresserad ○ Intresserad ○ Mycket intresserad

16. En idé med att bjuda in allmänheten till att vara medforskare i massexperiment (såsom Bostadsförsöket) är att det ska vara ett sätt att lära sig mer om forskning. Tycker du att du har lärt dig mer om forskning genom att vara med i bostadsförsöket?	○ Ja ○ Nej ○ Vet inte
Motivera gärna ditt svar.	____
17. Skulle du kunna tänka dig att medverka i ett massexperiment igen?	○ Ja ○ Nej ○ Kanske
18. Om man skulle göra ett nytt massexperiment om bostäder, hur tycker du att det skulle vara utformat?	____

Vänligen klicka på knappen 'Submit' här nedanför för att skicka in dina enkätsvar. Kontrollera gärna att du har besvarat alla aktuella frågor innan du skickar in.

Appendix 8. Usability evaluation sheet (Study I)

	Number tested	**Minimum Score**	**Maximum Score**	**Mean Score**	**SD**
All	37	11	25	17.8	3.5
PwMCI CST	10	12	25	18.6	3.8
PwMCI BTH	8	12	21	16.3	3.4
PwMCI All	18	12	25	17.6	3.7
Carer CST	10	11	22	17.9	3.2
Carer BTH	9	13	24	18.2	3.7
Carer All	19	11	24	18.1	3.4
Accessibility	37	2	5	3.51	0.99
Safety	37	1	5	3.78	1.84
Perceivability	37	2	5	3.57	0.96
Understandability	37	2	5	3.76	0.96
Empowerment	37	1	5	3.19	1.10

Appendix 9. Conceptual framework (Study II)

Dimension [1]	Category	Critical Variable
Biophysical (measurements)	Different opinions on the meaning and definition of housing accessibility prevail	Definition of housing accessibility
		Environmental barriers—who is affected?
		Level of detail of housing accessibility
	Systematic inventories are warranted but must be comprehensive	Systematic inventories of environmental barriers
		Degrees of housing accessibility—how to classify and label?
		Embrace variations in human functioning
	Evidence and convincing arguments for housing accessibility are important but lacking	Objective and comparable information on housing accessibility
		Evidence on the benefit to public health and societal economy
Socioeconomic (stories)	The ageing-in-place policy is significant for decision-making	Coherent policy Agreed objectives
	Organization and distribution of resources suffer from “silo-thinking”	Transparent cross-sectorial and multilevel communication
		Efficient distribution of resources and responsibilities
		Systems thinking
	Varying practices and competing priorities among the actors	Demand from the market on housing accessibility
		Efficient financial policy
		Awareness, knowledge and competence
	Absence of clear housing accessibility guidelines and goals	Organizational culture
		Cross-boundary collaboration
		Reasonable distribution of responsibilities among the various actors
Ethical (principles)	Balance between individual freedom of choice and societal solidarity	Fair and reasonable use of resources Acknowledge individual’s right to chose
	Ambiguous social responsibilities of housing companies	Maintain the welfare state
		The needs and interests of other groups
	Balance between housing accessibility and affordability	Allow for different alternatives
Artistic/Aesthetic (patterns)	Actions with the intention to provide accessible housing might jeopardize attractiveness	The proportions and compositions of rooms
		Affective experiences of housing accessibility—messages sent and received
		Suit the specific context
		Attractive locations and attributes
Sympathetic/Empathetic (feelings)	Lack of empathy leads to lack of understanding of others’ situations and perspectives	Proactive thinking to predict behavior Thoughtful communication

[1] Brown, Lambert & Harris’s five dimensions [19] (p. 34–37).

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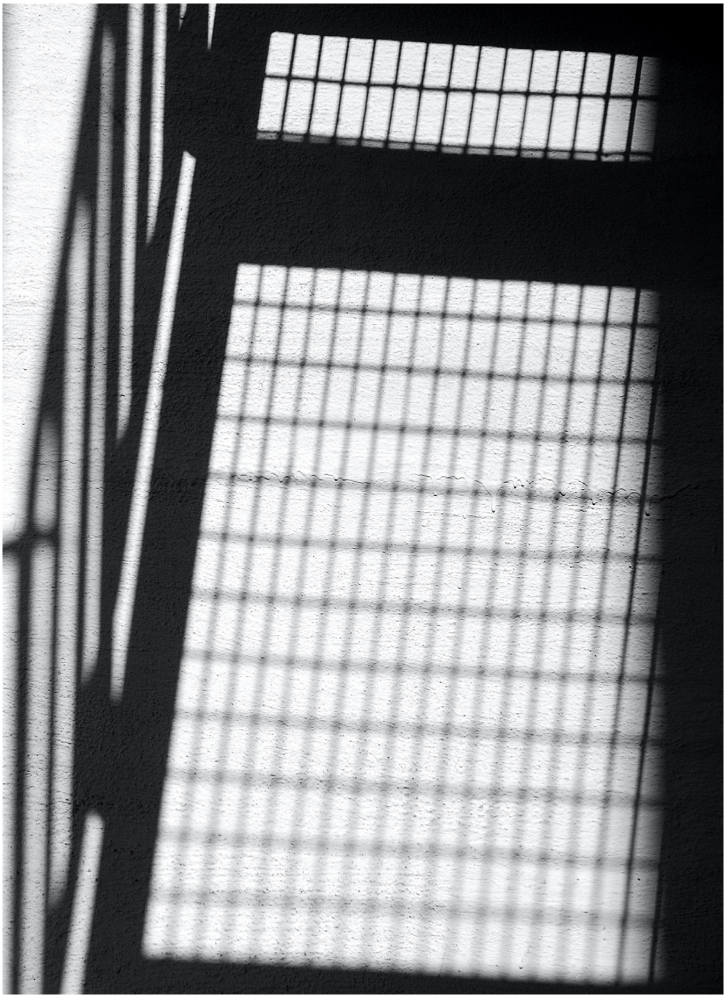

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