On User Involvement in Research and Ageing and Health

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# Preliminary Content

## Acknowledgements

I want to thank a few people.

## Preface

This is an example of a thesis setup to use the reed thesis document class (for LaTeX) and the R bookdown package, in general.

## Dedication

You can have a dedication here if you wish.

## Abstract

The preface pretty much says it all.

Second paragraph of abstract starts here.

# Svensk sammanfattning

Placeholder

## Why use it?

## Who should use it?

# Original papers

The thesis comprises the following four studies, which will be referred to in the text by their Roman numerals.

Hejsan (Jonsson, Frögren, Haak, Slaug, & Iwarsson, 2021)

**I.** Quintana, M., Anderberg, P., Sanmartin Berglund, J., Frögren, J., Cano, N., Cellek, S., … & 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), 6816.20).

**II.** Frögren, J., Schmidt, S. M., Kylén, M., Jonsson, O., Slaug, B., Iwarsson, S. Awareness of and attitudes towards public involvement in research on ageing and health among older people in Sweden. Plos one, 17(6), e0269993.

**III.** Frögren, J., Granbom, M., Jonsson, O., Bergman, M. Iwarsson, S. Distinctive Participant Characteristics and Attitudinal Changes in a Citizen Science Initiative on Housing Accessibility Targeting Older Adults and People with Disabilities (Submitted in July 2022)

**IV.** 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.

# Definitions as used in the thesis

Ageing = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

Forms of knowledge = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

User involvement = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

Public involvement = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

Research in Ageing and Health = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

Older people = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

Older adults = Lorem ipsum dolor sit amet. Vel obcaecati enim et molestiae neque non magnam natus qui autem sunt qui sapiente minus ut asperiores quas et iure eveniet. Et voluptatem inventore ut soluta reiciendis aut deserunt facilis sed consequatur debitis et repellat adipisci (Reference, YYYY).

# Abbreviations

CASE Lorem ipsum dolor sit amet GDS Lorem ipsum dolor sit amet SMART4MD Lorem ipsum dolor sit amet SWEAH Lorem ipsum dolor sit amet UserAge UserAge is a 6-year research program with the aim to enhance the execution of high-quality research and to increase the knowledge about the added value stemming from user involvement in the research process.

# My journey

My entry point to this doctoral thesis was: \* Master’s studies in cognitive science \* A decade-long work as a speech service interpreter which resulted in an interest in how to support people’s abilities using strategies and technology. \* This led to starting a Phd at BTH in applied health technology which, and continuing doctoral studies in gerontology (medical science) at Lund University

# Introducing the research context

* Research has been carried out at the Department of Health at BTH + at Department of Health Sciences in the research group Active and Healthy Ageing, affiliated with Centre for Ageing and Supportive Environments at Lund University, Sweden
* Learning process has been supported by Swedish National Graduate School for Competetive Science on Ageing and Health (SWEAH).
* This thesis is on part of the research program “UserAge.” The program aims to increase our understanding of the opportunities and challenges presented by the participation of knowledge users in research on ageing and health.
* This thesis only one of several PhD theses based on the UserAge program.
* I entered my doctoral studies with a Master of Science in Cognitive Science and with … As a cognitive scientist… Together these perspectives have been valuable in….
* It has been inspiring, challenging to conduct this thesis… Authour constellations varies and represents different disciplnes and scientific traditions. The meetings this gave rise to have contributed to the content of this thesis
* Being part of SWEAH has also given rise to more perspectives, meetings with people from different disciplines and research environments, new theories have challenged me…

# Research projects linked to the studies

The four studies stemmed from four different research projects that all involved or targeted users in different ways:

SMART4MD (Support Monitoring and Reminder Technology for Mild Dementia) - a four year project co-financed by the European Union under the EU Framework Programme for Research and Innovation – Horizon 2020, with grant agreement number 643399, which aims to improve the quality of life of older people with cognitive decline or mild dementia and their carers, increase treatment compliance, reduce dementia-related costs by helping reduce the number of missed appointments and of hospital re-admissions and help reduce functional decline.

The Panel Study, an empirical project of the UserAge program that aims to determine the awareness and understanding of and attitudes toward user involvement in research among different categories of knowledge users and researchers over time.

The Housing Experiment (HX) was a large-scale CS initiative with housing accessibility as the topic in which older adults and people with disabilities were the main target groups. HX was implemented in collaboration between Public & Science and researchers at the Centre for Ageing and Support Environments (CASE) at Lund University, involving the three largest Swedish senior citizens’ associations (approximately 695,000 members in total) as partners as well as the software company MiThings. The aim of the HX was to engage people across Sweden to assess environmental barriers in the ordinary housing stock, using a mobile app developed for this purpose (Granbom, Slaug, Bronéus, Bergman & Iwarsson, submitted to Citizen Science: Theory and Practice). The mobile app was based on Housing Enabler, which is an instrument for valid and reliable assessment of housing accessibility (Iwarsson et al., 2012).

The project Decision Support System for Improved Accessibility in Multi-Family Housing with the overarching aim to develop, test, and evaluate a new decision support system for improved accessibility in multi-family housing, and to contribute to efficient collaboration among professionals involved in health care, planning, and housing provision, as well as citizens. The project team of this project consisted of researchers and two non-academic partners: a public housing company and a micro-sized software development company.

# Introduction

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## Theoretical considerations and core concepts

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## Summing up/Rationale

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# Aims

The overarching aim of this thesis was to extend and deepen the current knowledge of user involvement in research on ageing and health, where users refers to representatives of older adults as well as other societal groups and actors with a direct or indirect interest in the research being conducted. Moreover to contribute strategies for involving users in future research on ageing and health.

## The specific aims of the studies were as follows:

* Study I: Through usability testing with intended users, investigate the interest in and the potential usefulness and usability of a health-oriented app developed with the aim of supporting older people with cognitive impairment and their informal carers in everyday life.
* Study II: To explore the awareness and attitudes to public involvement in research on ageing and health among older people in Sweden.
* Study III: Based on a Swedish Citizen Science initiative on housing accessibility targeting older adults and people with disabilities, investigate characteristics of participants, and changes in attitudes after participation.
* Study IV: Through research circles with non-academic representatives and researchers, gain a better understanding of crucial variables for decision-making linked to the provision of accessible housing for the ageing population in Sweden.

# Methods

Placeholder

## Research approach

## Design (Overview of the four studies)

## Participants

### Recruitment/ sampling procedures

### Participant characteristics

### Data collection and analyses

#### Usability tests

#### Research circles

#### Statistical analyses

#### Deductive content analyses

## Ethical considerations

### Benefits and risks

### Autonomy

### Involvement in the research process

# Results

Placeholder

## Study I

## Study II

## Study III

## Study IV

### Limitations

# Discussion

Här kommer jag att inleda med ett kort, sammanfattande stycke om resultatet, samt eventuellt även att motivera varför och när det är användbart att beakta.

## Methodological considerations

## Strengths and limitations

## Conclusions

* Äldre människor en heterogen grupp med varierade kunskaper och förmågor, t.ex i förhållande till mobil digital teknik. Med andra ord med skiftande behov och perspektiv som utifrån en demokratisk aspekt är viktiga att ta i beaktning när syftet som forskare är att förklara, förstå och förbättra världen
* Samhälleliga problem såsom the provision of housing accessibility är wicked som är svåra att ringa in och hitta en lösning på som alla eller en majoritet av samhällets aktörer och representanter är nöjda med.
* MEN user involvement in research on ageing and health kan utgöra just ett sätt att göra komplexiteten begriplig och att fånga in flera dimensioner av problemet.
* Dock utgör det en begränsning om vissa key actors are not able or willing to participate, vilket i wicked-problem fallet var fallet med privata aktörer. Det riskerar att ett potentiellt centralt perspektiv i en komplex fråga faller bort.
* Eftersom forskning om åldrande och hälsa utgör just äldre personer en expertgrup (de är expert på sitt eget åldrande) och äldre är en heterogen grupp är denna grupp central när det kommer till user involvement in research on ageing and health. Men flera av studierna i denna avhandling indikerar att vissa kategorier/subgrupper av äldre personer are less willing or able to get actively involved. One limitation is thus that det som framkommer inte utgör en representativ bild av den verklighet i form av de problem och utmaningar som den äldre befolkningen i Sveige möter. Denna skevhet eller begränsade representativitet har visserligen indikerats i andra studier men inte på samma systematiska sätt som här (tänker på panelstudien).

Strategier framåt (= rekommendationer för framtida forskare inom fältet) kan utgöras av att:

* Använda dimensionsmodellen (i wicked problemartikeln) som en utgångspunkt för att säkerställa att ett komplext problem inte lyfts fram alltför ensidigt utan att flera perspektiv kommer fram
* Vid användandet av digital teknik i anslutning till user involvement beakta äldres heterogenitet och försök att hitta strategier för att den avsedda målgruppen kan ta den i bruk, och om deltagarna inte är representativa för den äldre gruppen i stort så var tydlig med att lyfta fram det som en begränsning i studien.

### Further research and development

Behövs ytterligare forskning för att undersöka hur dessa föreslagna strategier kan vara behjälpliga i att i högre utstäckning skapa förutsättningar för att även grupper som idag inte vill eller anser sig ha förmågan att delta i forskning om åldrande och hälsa.

# Acknowledgement

# (APPENDIX) Appendix

# The First Appendix

This first appendix includes all of the R chunks of code that were hidden throughout the document (using the include = FALSE chunk tag) to help with readibility and/or setup.

**In the main Rmd file**

# This chunk ensures that the thesisdown package is  
# installed and loaded. This thesisdown package includes  
# the template files for the thesis.  
if (!require(remotes)) {  
 if (params$`Install needed packages for {thesisdown}`) {  
 install.packages("remotes", repos = "https://cran.rstudio.com")  
 } else {  
 stop(  
 paste('You need to run install.packages("remotes")",  
 "first in the Console.')  
 )  
 }  
}  
if (!require(thesisdown)) {  
 if (params$`Install needed packages for {thesisdown}`) {  
 remotes::install\_github("ismayc/thesisdown")  
 } else {  
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 "You need to run",  
 'remotes::install\_github("ismayc/thesisdown")',  
 "first in the Console."  
 )  
 )  
 }  
}  
library(thesisdown)  
# Set how wide the R output will go  
options(width = 70)

**In Chapter :**

# The Second Appendix, for Fun

# References

Placeholder

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://doi.org/[10.3390/ijerph18031169](https://doi.org/10.3390/ijerph18031169)