# Older Adults and Assistive Technology to Facilitate Occupation and Participation: A complex intervention

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*Nothing about them without them – older people should be actively involved in discussions on issues that concern them.*

WHO Action for Ageing 2015

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# Summary

This PhD study is part of the Assisted Living Project (2015-2019) and explores assistive technology as a complex intervention to facilitate occupation and participation in everyday life among home-dwelling older adults, both with and without mild cognitive impairment and dementia (MCI/D). The demographic changes with bigger cohorts in the oldest age groups challenge the future healthcare services. Assistive technology refers to devices or systems whose purpose is to maintain or improve an individual's functioning and independence, to facilitate occupation and participation, and to enhance overall well-being, and is perceived as means for independent living, to improve the quality of healthcare services and to avoid costs. In the past decade, several research projects have aimed to support older adults at home, facilitate their independent living and safety, provide cognitive stimulation and entertainment, and contribute to their ageing in place. Despite many examples of technological failures, false alarms and a lack of infrastructure robustness a general optimism about technology is evident. Access to assistive technology may foster or hinder participation in meaningful occupation in older home-dwelling citizens. Implementation of assistive technology is seen as a complex intervention. The Medical Research Council (MRC) framework was used in this PhD study to explore this complexity and develop new knowledge.

Occupational science emphasises human occupation as important for health and well-being and provides a theory for understanding human occupation through the life course as a dynamic and transactional process; i.e. a dynamic on-going interaction between human, occupation and objects within a specific context.

This thesis is based on four studies; a systematic literature review (Paper I), a study of health care workers' experiences of using assistive technology with care recipients with MCI/D (Paper II), a technology feasibility study (Paper III), and a user inclusion study on technology development (Paper IV).

Study I found that a wide variety of assistive technologies was used to support home-dwelling older adults and their family caregivers. The types of technologies can be categorised into four groups; for 1) safe walking indoors and outdoors; 2) safe living; 3) independent living; and 4) entertainment and social communication. Users; i.e. persons with MCI/D, family caregivers, staff or other older adults were involved in different research occupations such as focus groups, workshops, technology trials and interviews. A major finding was that user inclusion was both necessary and important to learn about the design features required to

enhance usability and acceptability. Surprisingly, less than half the studies reported on citizens with MCI/D's experiences of technology use regarding quality of life, occupational performance, or human dignity. Rather family caregivers and staff were asked about feasibility and technical functionality.

Study II explored how community healthcare workers talked about and worked with assistive technology for care recipients with MCI/D. Twenty-four healthcare workers with different professional backgrounds took part in focus group discussions about technology to support people with MCI/D at home. We found that the participants' knowledge and practice of technology varied. Some regarded technology as efficient services provision, such as physical training programmes to several patients at the same time, and remote monitoring of patients via screens. Others feared that technology might increase loneliness and confusion in the care recipients and was motivated only by economic reasons. Technology did not appear to be in the repertoire of healthcare workers' clinical practice due to low knowledge of and competence in technology, and lack of management. This study demonstrated that home-dwelling older citizens with MCI/D who are deprived access to supportive assistive technology may experience occupational injustice.

Study III described the feasibility of the implementation of environmental sensors in one of eight apartments, in order to learn about the strengths and weaknesses of the implementation process and of the technology. This process evaluation drew on the Medical Research Council (MRC) framework. A major finding was that a feasibility study was important for identifying strengths and weaknesses of the intervention, critical evaluation of the research plan to facilitate implementation in the other apartments.

Study IV sought to investigate how eight older adults in an assisted living facility evaluated user inclusion in a 3-year technology development project. Individual structured interviews, dialogue cafés, interventions with environmental sensors, follow-up home visits and a final focus group discussion constituted sites for development of knowledge. The older adults with and without documented MCI/D could nevertheless meaningfully contribute with opinions about needs and preferences. One major finding was that they wanted to contribute with their opinions. User inclusion of older citizens in research projects may contribute to extended knowledge about user needs and technology requirements, as well as user inclusion processes. Applying a critical occupational perspective raised awareness regarding sociocultural assumptions about older adults in assisted living facilities, which may reinforce ageist and ableist stereotypes, as well as promote occupational injustice.

# Sammendrag

Denne PhD studien er en del av Assisted Living prosjektet (2015-2019) og utforsker velferdsteknologi for å fremme aktivitet og deltakelse hos hjemmeboende eldre med og uten kognitiv svikt (MCI) og demens (D). Demografiske endringer med større kohorter i de eldste aldersgruppene er en utfordring for helse- og velferdstjenestene i framtida. Velferdsteknologi kan bidra til økt selvstendighet hos eldre, økt kvaliteten i tjenestene og unngåtte kostnader. Flere prosjekter har det siste ti-året vist at teknologi kan fremme selvstendighet og mestring, sikkerhet og trygghet, men også å tilby kognitiv stimulering og underholdning.

Velferdsteknologi er produkter og løsninger som har til hensikt å vedlikeholde eller bedre individets fungeringsevne og selvstendighet, og å fremme aktivitet og deltakelse, og sikre generelt velvære. Til tross for mange eksempler på tekniske feil, falske alarmer og manglende eller utilstrekkelig teknologisk infrastruktur, er det stor optimisme omkring teknologi som framtidig løsning i helsetjenestene. Tilgang til velferdsteknologi, eller mangel på dette, kan fremme eller hemme deltakelse i meningsfulle dager for hjemmeboende eldre.

Aktivitetsvitenskap (occupational science) anser menneskets deltakelse i aktiviteter og sosialt liv som viktig for helse og trivsel, og som en moralsk rettighet. Aktivitetsvitenskap forstår menneskelig aktivitet og deltakelse gjennom livsløpet som en transaksjonalistisk prosess, en dynamisk interaksjon mellom mennesket, aktiviteten og objektene i en gitt kontekst. Implementering av velferdsteknologi anses som en kompleks intervensjon. Rammeverket MRC (Medical Research Council) ble benyttet i PhD-studien for å utforske denne kompleksiteten og utvikle ny kunnskap.

Avhandlingen baseres på fire studier; en systematisk litteraturstudie (artikkel I), en studie av ansatte i hjemmetjenestens erfaringer med teknologi til hjemmetjenestemottakere med MCI/D (artikkel II), en mulighetsstudie med teknologi (artikkel III), og en studie om eldre i en omsorgsbolig og brukerinkludering i teknologiutvikling (artikkel IV).

Studie I viste stor variasjon av typer teknologi som var prøvd ut med hjemmeboende personer med MCI/D og deres pårørende og ansatte. Disse kan kategoriseres i fire grupper; Teknologi for 1) gå trygt inne og ute; 2) trygg i egen bolig; 3) selvstendighet i hverdagen; og 4) underholdning og sosial kommunikasjon. Brukerne deltok i fokusgrupper, workshop, utprøvinger og intervjuer som fokuserte på design-prosessen og på evaluering av utprøvinger i hjemmet. Et viktig funn var at brukerinvolvering var både nødvendig og viktig for å adressere

brukerbehov og brukerkrav for å forbedre bruk og aksept av produkter/løsninger. Under halvparten av studiene rapporterte erfaringene om teknologibruken i forhold til livskvalitet, aktivitetsutførelse og verdighet fra personer med MCI/D. I stedet ble pårørende og ansattes oppfatninger av teknologiens muligheter og funksjonalitet rapportert.

Studie II handlet om hvordan ansatte i hjemmetjenestene snakket om og arbeidet med velferdsteknologi til hjemmetjenestemottakere med MCI/D. Tjuefire helsearbeidere med ulik profesjonsbakgrunn ble invitert til fokusgruppediskusjon om teknologi til personer med MCI/D i hjemmetjenesten. Vi fant at deltakernes kunnskap om og praksis med velferdsteknologi varierte. Et viktig funn var at mens noen så teknologi som en styrke for å kunne tilby treningsprogram til flere samtidig eller å ha tilsyn med mange eldre via en skjerm, var andre redde for at teknologi kunne forsterke ensomhet og forvirring. Teknologi synes ikke å være på repertoaret i hjemmetjenestens kliniske praksis. Årsaker til dette var lav teknologikompetanse hos ansatte, og manglende organisering av tjenesten. Konsekvenser er at hjemmeboende personer med MCI/D ikke fikk tilbud om teknologi som kan støtte dem og deres pårørende.

Studie III var en mulighetsstudie der sensorene som skulle benyttes i til sammen åtte leiligheter først ble montert i én leilighet for å lære om styrker og svakheter ved implementeringen. En prosessevaluering ble gjennomført i tråd med MRC's anbefalinger. Hovedfunnet var at det er viktig å gjøre en slik forstudie for å lære om teknologiens styrker og svakheter, om forskningsplanen holder mål og for å forberede en effektiv implementering i de andre leilighetene.

Studie IV undersøkte hvordan åtte beboere i en omsorgsbolig, evaluerte deltakelsen i et tre-årig forskningsprosjekt om teknologi. Metoder som individuelle strukturerte intervju, dialog-kaféer, fokusgruppeintervju, samtaler under oppfølgingsbesøk, og deltakelse i en intervensjon med omgivelsessensorer ble benyttet i brukermedvirkningsprosessen. Eldre med og uten dokumentert MCI/D formidlet egne behov og preferanser. Et viktig funn var at deltakerne ønsket å være til nytte, og bidra med sine meninger. Eldres deltakelse i forskningsprosjektet bidro til mer kunnskap om brukerbehov og brukerkrav til teknologi, og om brukermedvirkningsprosesser. Ut ifra et kritisk aktivitetsperspektiv bidro studien til å skape bevissthet omkring sosiokulturelle antakelser om eldre som kan forsterke diskriminering på grunn av alder og funksjonssvikt, og retten til å delta i aktiviteter - «occupational injustice».

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# List of scientific papers

I. Torhild Holthe, Liv Halvorsrud, Dag Karterud, Kari-Anne Hoel, Anne Lund (2018)
**Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review.**
Published May 4, 2018 Open Access DOVE medical press: Clinical Interventions in Ageing. Accepted Jan 22, 2018. DOI: **https://dx.doi.org/10.2147/CIA.S154717**

II. Torhild Holthe, Liv Halvorsrud, Erik Thorstensen, Dag Karterud, Debbie Laliberte Rudman, Anne Lund
**Community health care workers' experiences on enacting the policy on technology to citizens with mild cognitive impairment or dementia.**
Published online June 2, 2020 in Journal of Multidisciplinary Healthcare 2020:13.
DOI: **https://dx.doi.org/10.2147/JMDH.S246180**

III. Torhild Holthe, Flavia Dias Casagrande, Liv Halvorsrud, Anne Lund (2018)
**The Assisted Living Project: A process evaluation of implementation of sensor technology in a community care-dwelling. A feasibility study.**
Published Oct 14, 2018 in Disability and Rehabilitation: Assistive Technologies.
DOI: **https://dx.doi.org/10.1080/17483107.2018.1513572**

IV. Torhild Holthe, Liv Halvorsrud, Anne Lund
**A critical occupational perspective on user engagement of older adults in an assisted living facility in technology research over three years.** Published online May 13, 2020 in Journal of Occupational Science.
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# Abbreviations

| **Abbreviations** | **Meaning** |
|---|---|
| AAL | ambient assisted living |
| ADL | activity of daily living |
| AI | Artificial Intelligence |
| ALP | Assisted Living Project |
| ALT | Assisted Living Technology |
| AT | Assistive Technology |
| CDR | Clinical dementia rating scale |
| COPM | Canadian Occupational Performance Measure |
| D | Dementia |
| EAT | Electronic Assistive Technology |
| ETUQ | Everyday Technology Use Questionnaire |
| EU | European Union |
| GDPR | General Data Protection Regulation |
| GP | general practitioner |
| GPS | Global Positioning Systems |
| HAAT | Human–Activity–Assistive Technology |
| HADS | The Hospital Anxiety and Depression Scale |
| HCW | Health care worker |
| IAT | Intelligent assistive technology or Innovative assistive technology |
| ICD | International Classification of Disease |
| ICT | Information and Communication Technologies |
| MCFSI | Mail-In Cognitive Function Screening Instrument |
| MCI/D | Mild Cognitive Impairment |
| MeSH | Medical Subject Headings terms |
| MMAT | Mixed-Method Appraisal Tool |
| MMSE | Mini Mental State Examination |
| MRC | Medical Research Council |
| NSD | Norsk Samfunnsvitenskapelig Datatjeneste |
| NVP | Norsk Velferdsteknologi Program |

|  |  |
|---|---|
| OT | Occupational Therapist/y |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PROSPERO | The international prospective register of systematic reviews |
| RAND-12 | Norwegian short version of US RAND (Research And Development) Corporation |
| RRI | Responsible Research and Innovation |
| SWOT | Strengths- Weaknesses – Opportunities – Threats Analysis |
| TV | television |
| WHO | World Health Organization |

# 1 Introduction

This thesis explores assistive technology as a complex intervention to facilitate occupation and participation in everyday life among home-dwelling older adults, both with and without mild cognitive impairment and dementia (MCI/D). Assistive technology refers to:

> *devices or systems whose purpose is to maintain or improve an individual's functioning and independence and to facilitate occupation and participation, and to enhance overall well-being (World Health Organization [WHO] 2018).*

The thesis:

- investigated previous research on technology interventions among the target group (Paper I);
- explored community healthcare workers' experiences with assistive technology for care recipients with MCI/D (Paper II);
- carried out a feasibility study on environmental sensors in one assisted living facility (Paper III);
- engaged residents in assisted living facilities in technology research over three years, including participating in a technology intervention study in their own apartment (Paper IV).

This thesis is embedded in occupational science (Wilcock, 2007), which explores human occupation and its form, function and meaning. It assumes that, by nature, humans are active beings in a reciprocal dynamic relationship with their own health and with contextual factors, such as social, cultural and economic resources. Occupational science offers a lens through which to explore human occupation with assistive technology in the context of an assisted living facility. The dynamic relation between person, tasks and context, is described as occupational transactionalism (Cutchin & Dickie, 2013; Cutchin, Dickie, & Humphry, 2017). A human's occupation will change during their lifetime but will always be connected to their context. Occupational science and transactionalism are further described in Chapter 4.

## 1.2 The Assisted Living Project

This thesis was a part of the Assisted Living Project (ALP) 2015–2019, funded by the Norwegian Research Council, number 47996. The overall aim of the ALP was to advance responsible research and innovation (RRI) in the field of technology development, implementation and research. It emphasised user inclusion, values, research methods and purposes and addressed different stakeholders (Norwegian Research Council, 2015; Stilgoe, Owen, & Macnaghten, 2013). The ALP had four tasks:

a) to map how stakeholders and experts perceive state-of-the-art, responsible technologies; focusing on assisted living technologies, in Norway and internationally;

b) to develop assisted living solutions for users with MCI and dementia, through an RRI approach;

c) to use an integrated health technology assessment approach to judge whether technologies introduced through an RRI process score better than currently implemented technologies;

d) to create a wider dialogue on responsible technologies for the future, that reflects alternatives and options (ALP group, 2016).

This PhD study was involved in tasks a, b and d (see Table 5.0).

## 1.3 Structural Coherence of the Thesis

The introduction presents the focus of this thesis, and its connection to the ALP.

Chapter 2 presents the background: the target group of older citizens who receive community healthcare services; their relationship to assistive technology; contextual issues and central concepts to this study.

Chapter 3 presents the aims and objectives of this study.

Chapter 4 looks at occupational science as the theoretical background for this dissertation.

Chapter 5 presents the different methods used in the four studies (systematic literature review, feasibility study and focus group discussions).

Chapter 6 presents the results of each study and answers the research question.

Chapter 7 discusses the findings of the four studies.

Chapter 8 looks at methodological considerations, strengths, weaknesses and clinical implications, and future research needs.

Chapter 9 draws the main conclusions.

# 2 Background

Governments and policymakers worldwide are greatly concerned by their ageing societies and consequent growing needs for healthcare services. The WHO recommends aligning health services to better address the needs of older adults, and claims that a transformation is needed, that is, fundamental changes in service organisation, funding and transdisciplinary collaboration, to “ensure affordable access to integrated services that are centred on the needs and rights of older people” (WHO, 2016).

Technology implementation is part of this societal transformation, and there is currently huge optimism about technology in connection with governmental wishes to innovate public services for older adults. Although Norwegian policy encourages the use of technology in community healthcare services (Helsedirektoratet, 2012, 2014a, 2014b, 2015, 2017), they seem slow to adopt it (Batt-Rawden, Björk, & Waaler, 2017; Ipsos, 2018; Nilsen, Dugstad, Eide, & Eide, 2016; S. T. M. Peek et al., 2014).

Research in the field of technology to support older citizens at home is growing, broad and optimistic. It is growing due to global interest in technology’s potential to care for others. It is broad, given the variety of technology that has been explored. It is optimistic because technology promises efficient services and opportunities for all.

Technology research among those with MCI/D is complex, time consuming and challenging, and usually has few participants. A complex intervention involving technology research entails user involvement at all stages of the research process and a systematic description of the technology intervention. The Medical Research Council (MRC) framework offers four-phase guidance in planning/modelling the intervention, and for testing, evaluating and implementing it (Craig et al., 2008). This is presented in more detail in Chapter 5.1.

User inclusion in research refers to a dialogue between researchers and users to learn what topics are of interest to the users, and to increase the utility and quality of the research by developing knowledge. Although it is not yet a legal requirement (RHF, 2018), user inclusion is required by the research council for democratic and ethical reasons (Østensjø & Askheim, 2019).

This chapter describes the study’s targets of:

- home-dwelling older citizens with MCI/D (see Sections 2.1.1 and 2.1.2);

- older citizens in assisted living without documented MCI/D, who receive care from community healthcare services (Section 2.1.3);
- community health care workers working with home-dwelling older adults with MCI/D (Section 2.2);

and

- their relationship to assistive technology (Section 2.4).

It then describes:

- policy and current technology (Section 2.5);
- previous research and projects with the target group (Section 2.5.1);
- the research gap and the rationale for the current study (Section 2.5.2)

## 2.1 Older Citizens

The demographic challenge of an ageing population in Norway, as in the rest of the world, is referred to as one of the “grand challenges” of our time. According to the WHO, the global population of over-60s will have doubled by 2050 (WHO, 2018a), and EU member states expect a 70% increase in the number of over-65s by 2050 (EU Commission, 2019). By 2060, life expectancy in Norway is predicted to increase by six or seven years (from 81 to 87 for men, and from 84 to 90 for women); by 2035, there will be more Norwegians over 65 than aged 0–19, since the last decade’s modest mortality rates are expected to continue (Statistisk sentralbyrå, 2018). One expected consequence of the “aging society” is greater pressure on public healthcare services (Helsedirektoratet, 2014a, 2014b, 2015, 2017; KS, 2019), which forces governments, social planners and researchers to envision innovative care services.

What characterises an older person? The ageing process can be described as chronological, biological, psychological and/or social, and is usually a mix of these (Daatland & Solem, 2011). Although older adults are healthier than previously, they often live longer with a chronic condition (Kommunal og regionaldepartementet, 2009); (Folkehelseinstituttet, 2018). Importantly, older adults are not a homogeneous group; they will always have different life stories (Fromholt et al., 2003), health capital (Bergland & Slettebø, 2014; Blaxter, 2010), coping strategies (Lazarus & Folkman, 1984), generalised resistance resources (Antonovsky,

1987) [1] and psychological needs (Kitwood, 1997). However, inequality in health increases with age (Blaxter, 2010), and an ageing population is at risk of various health issues. One great societal concern is regarding the prevalence of dementia and cognitive impairment in older adults, and its expected rise over the next decades (Alzheimer Europe, 2019).

### 2.1.1 Older Adults With MCI

The 2018 International Classification of Disease (ICD-11) introduces the term *mild neurocognitive impairment*, which it defines as:

> *Mild neurocognitive disorder is characterized by the subjective experience of a decline from a previous level of cognitive functioning, accompanied by objective evidence of impairment in performance on one or more cognitive domains relative to that expected given the individual's age and general level of intellectual functioning that is not sufficiently severe to significantly interfere with independence in the person's performance of activities of daily living. The cognitive impairment is not entirely attributable to normal ageing. The cognitive impairment may be attributable to an underlying disease of the nervous system, a trauma, an infection or other disease process affecting specific areas of the brain, or to chronic use of specific substances or medications, or the etiology may be undetermined. (WHO, 2019b)*

The construct of MCI was introduced in the literature in 1988. This thesis puts to ground Winblad et al.'s (2004) recommendations regarding criteria for MCI:

(i) The person is neither normal nor has dementia
(ii) There is evidence of cognitive deterioration shown by either an objectively measured decline over time and/or subjective report of decline by self and/or informant in conjunction with cognitive deficits; and
(iii) ADL [activities of daily living] are preserved and complex instrumental functions are either intact or minimally impaired (Winblad et al., 2004, p. 241).

Cognition encompasses attention, concentration, memory, comprehension, reasoning and problem solving. According to Winblad et al. (2004), MCI was a useful clinical and research

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[1] Generalised resistance resources are defined as any phenomenon that is effective in combating a wide variety of stressors and may be internal or external (Antonovsky, 1987).

term. MCI may progress to dementia, remain stable or gradually recover, but the mortality risk is high (Winblad et al., 2004). The standardised tool “Clinical dementia rating scale” (CDR) is a popular means of detecting early dementia and MCI (Peterson, Mitseva, Mihovska, Prasad, & Prasad, 2009). Hedman et al. (2015) studied functioning in older adults with MCI and found that they exhibited different patterns – stable, fluctuating, descending or ascending. A pattern may change over time, and indicates that individual support for everyday living is needed (Hedman, Nygard, Almkvist, & Kottorp, 2015).

### 2.1.2 Older Adults with Dementia

The number of those with dementia was estimated at 9,7 million in Europe in 2018 (Alzheimer Europe, 2019), and 50 million worldwide in 2019 (WHO, 2019a) and is expected to rise to 82 million in 2030 and 152 million in 2050 (WHO, 2017). In Norway, the estimate is more than 77,000 people, which is expected to double by 2040 (Alzheimer Europe, 2019; Nasjonalforeningen for folkehelsen, 2019). Dementia is a huge challenge for next of kin, estimated to number 350,000 in Norway (Nasjonalforeningen for folkehelsen, 2019), who are put under severe strain (Bjorge, Kvaal, Smastuen, & Ulstein, 2017; Raggi, Tasca, Panerai, Neri, & Ferri, 2015) and need support from healthcare and social services and from financial and legal systems.

Dementia is a neurodegenerative condition due to a disease of the brain. It is either chronic or progressive and influences cognitive, psychological, behavioural and motor skills, which has consequences for quality of life and competency in everyday life (Engedal & Haugen, 2018). Dementia increases with age, and 60%–70% of cases are caused by Alzheimer’s disease (Engedal, 2019). In 1994 the WHO presented four criteria for dementia in ICD-10:

1) impaired memory;
2) clear consciousness;
3) impaired emotional control, motivation or social behaviour;
4) the condition must have lasted for at least 6 months (Engedal & Haugen, 2018, p. 19).

This was further defined in ICD-11:

> *Onset is insidious with memory impairment typically reported as the initial presenting complaint. The characteristic course is a slow but steady decline from a previous level of cognitive functioning with impairment in additional*

> *cognitive domains (such as executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities) emerging with disease progression. Dementia due to Alzheimer disease is often accompanied by mental and behavioural symptoms such as depressed mood and apathy in the initial stages of the disease and may be accompanied by psychotic symptoms, irritability, aggression, confusion, abnormalities of gait and mobility, and seizures at later stages. (WHO, 2019b)*

Dementia is divided into mild, moderate and severe stages, depending on the extent to which the condition influences everyday living. Assessments of dementia are mainly carried out by general practitioners (GPs), sometimes in collaboration with a municipality dementia team of nurses, occupational therapists (OTs) and other professionals. A diagnostic assessment is important to legitimise adequate treatment and support, as well as to prepare the person and their family for the consequences on everyday living and quality of life (Aldring og helse, 2019).

### 2.1.3 Assisted Living Residents

One target group for this study was assisted living residents, counting as home-dwelling citizens. For access to an assisted living facility an applicant must meet government-stipulated criteria; be above 67 years of age; have lived in Norway for the previous two years; be able to live independently to some degree. An applicant may have a functional impairment, such as: a) physical disabilities (i.e. impaired mobility); b) mental health problems, such as depression, anxiety and so on; or c) decreased function due to extreme old age (those aged 80+ qualify).

Those with cognitive impairments or chronic, prolonged and severe mental problems do not qualify for an apartment in an assisted living facility (Lovdata, 2011). However, residents may develop cognitive impairments after moving in, or there may not have been a clear manifestation of symptoms at the time of the application. A GP must usually verify the application. Assisted living residents thus have impairments, which entitle them to assistance from community healthcare services.

## 2.2 Healthcare Workers

Health care workers are key persons in implementation of assistive technology to support home care recipients in different ways. Thus, it is of interest to learn how they enact the current policy on procurement of assistive technology to support everyday living in older adults with MCI/D. All municipalities are legally required to offer healthcare services to their residents. In this study, the term community healthcare worker refers to those health professionals and applied services that are usually included in Norwegian community healthcare services: nursing, home help (for practical assistance such as cleaning and shopping), physiotherapy, and occupational therapy. One consequence of each local authority making its own decisions is that supporting services are organized differently in each municipality or city district, in line with what they see as the most pressing tasks and issues (Vabo, 2012). This stakeholder group is described in Sections 6.2 and 7.2.

## 2.3 The Context of an Assisted Living Facility

One assisted living facility was selected as a base for the ALP. It consisted of lifetime care dwellings for older adults who did not need to be in a nursing home, but who did have significant challenges in managing to live alone in their own home. The accommodation is physically adapted for older people and connected to an activity centre, a cafeteria and a staffed reception. Qualified staff are available 24/7, however, during the evening and at night emergency calls are transferred to nurses' community healthcare night team (Lovdata, 2011).

Assisted living is a complex term, on which there is no international consensus (Zimmerman & Sloane, 2007). However, assisted living facilities are often built as complementary to nursing homes and institutions for older adults. In the US, assisted living can be seen as a high-intensity housing plus services approach. It is particularly important for those with disabilities, those who need greater supervision or assistance with unscheduled activities and those who need nursing to cope with hygiene, nutrition, medication and so on (Pynoos, Liebig, Alley, & Nishita, 2005). Freedman and Spillman suggest offering three of levels of residential care: independent living, assisted living, and institutional care, such as nursing homes (Freedman & Spillman, 2014), which fits Norwegian policy. The nature of assisted living can vary between municipalities and countries, according to national legislation and local values.

In Norway, assisted living facilities are called "Omsorgsbolig", a term first introduced in 1994 by the Norwegian State Housing Bank (Husbanken), in connection with government subsidies for building physically adapted care facilities for older adults as a supplement to nursing homes and institutions. Municipalities can still apply for grants to build housing for older citizens with dementia by addressing special criteria (Husbanken, 2019). Assisted living apartments are usually 30–50 m$^2$ with a kitchen and bathroom, plus access to common facilities such as a canteen, hobby rooms and a garden. Such apartments are recognised as private homes, and residents must pay rent and for practical assistance, such as meals and cleaning. They need to apply for community healthcare services in the same way as other home-dwelling older adults, although nursing services are free under Norwegian law.

## 2.4 Assistive Technology

The word technology consists of techno (from the Greek word *techne*, meaning art, skill, dexterous), and logy (derived from *logia*, meaning theory or knowledge) and can be applied to many concepts, including technical knowledge in a society (Wikipedia, 2020). Several terms are used in the literature and in healthcare policy to frame technology for supporting people in need of care, such as, assistive technology (WFOT, 2019a; WHO, 2018b), assisted living technology (Thorstensen et al., 2020 - to be published), telecare (Berge, 2016), eHealth (Jakobsson, Nygård, Kottorp, & Malinowsky, 2019), intelligent assistive technology (Ienca, Wangmo, Jotterand, Kressig, & Elger, 2018), innovative assistive technology (Thordardottir, Malmgren Fänge, Lethin, Rodriguez Gatta, & Chiatti, 2019), ambient assistive living (Nordic Innovation and Nordic Welfare Centre, 2019), everyday technology (Malinowsky, Kottorp, & Nygard, 2013; Nygård, Rosenberg, & Kottorp, 2015) and, welfare technology (Helse- og omsorgsdepartementet [Ministry of Health and Care Services], 2011; Helsedirektoratet, 2014a; Nordic cooperation, 2019). This section explains some of these terms and why I have chosen to use assistive technology.

Welfare technology (*velferdsteknologi*) was initially the major term used in ALP (ALP group, 2016). The concept was introduced by the Nordic Council of Ministers (Nordic cooperation, 2019) and in the white paper Innovation in the Care Services (Helse- og omsorgsdepartementet, 2011), because new and digital technology had the potential to support citizens' independence and welfare, as well as being cost-effective for community healthcare services. Technologies to support older adults and citizens with disabilities were divided into four domains: 1) for safety and security; 2) for coping with independent living; 3) health technologies; and 4) for well-being (Helse- og omsorgsdepartementet, 2011). Welfare technology is defined as:

> *Welfare technology refers first and foremost to technological assistance that contributes to increased safety, security, social participation, mobility, and physical and cultural activity, and strengthens the individual's ability to cope with everyday life despite illness and social, mental or physical impairment. Welfare technology can also*

> *act as technological support for relatives and otherwise contribute to improving accessibility, resource utilization and quality of service provision. Welfare technological solutions can in many cases delay the need for services or admission in institutions (Helse- og omsorgsdepartementet, 2011) [own translation]*

Welfare technology indicates the use of one or more digital devices, connected to a digital service, to enable an older citizen to cope with everyday living in their own home (Helsedirektoratet, 2012). For example, a medicine dispenser connected to the internet that monitors medication, saves nurses' travel time and costs while addressing a citizen's wish to cope independently and to take their medication securely. This cost-effective solution enables community health services to save time and resources and thereby provide more efficient services.

The ALP description also used the term assisted living technology (ALT), to denote a range of ICT-based technologies for those who, based on an assessment carried out by themselves or others, are deemed to have a specific bodily and/or cognitive need for assistance in their everyday lives (Thorstensen et al., 2020 - to be published). ALT can include telecare, in which sensors and monitors in an environmental control system support older people in need of care, enabling them to live at home for longer (Berge, 2018).

The term everyday technology (in Norwegian: *hverdagsteknologi*) was introduced in Sweden to cover household aids, electric tools, computers, TVs, mobile phones, ticket vending machines and self-service check-in at airports and hotels (Nygård et al., 2015). This study used the Everyday Technology Use Questionnaire (ETUQ) to explore what everyday technology participants were using at the time and what they had stopped using (Paper IV).

The translation of terms is challenging, but I use the internationally accepted term *assistive technology* in this thesis, which is in line with WHO's policy:

> *Assistive technology refers to devices or systems whose purpose is to maintain or improve an individual's functioning and independence and to facilitate occupation and participation, and to enhance overall well-being (WHO, 2018b)*

Assistive technology seems to be the most appropriate term within the OT field to describe technology that supports those in need of care. The term is recommended by UK OT colleagues, it is used in UK government papers and in Alzheimer's Association publications.

The broader term *technology* is used interchangeably with assistive technology in this dissertation. According to the WHO, assistive technology is an umbrella term covering the systems and services related to the delivery of assistive products and services (WHO, 2018b). If it is provided at the right time, technology can enable older citizens to cope with everyday living, can contribute to feelings of competency and safety, and can enhance living at home, despite health challenges. In other words, technology can offer practical, clever and viable solutions for home-dwelling older citizens with and without MCI/D.

In research, as in clinical practice, it is wise to distinguish between different types of assistive technology and their potential. Gibson (2016) suggested a distinction between technology used *by*, *with* and *on* people with dementia (Gibson et al., 2016):

- Technology used *by* people with dementia were devices that the person used them self in the early phases of dementia to cope with such daily tasks as remembering appointments, taking medication, keeping track of time with easy-to-read clocks and calendars, verbal/sound reminders and so on;
- Devices used *with* people with dementia involved a carer (either next of kin or care worker), to enable social communication, entertainment or safety;
- That used *on* persons with dementia were devices and systems used by next of kin or healthcare workers to care for a person with dementia; examples are monitoring systems, environmental sensors, cameras, alarms and so on (Gibson et al., 2016).

Such distinctions may be important for both researchers and for healthcare services when identifying suitable technology for assessed needs.

However, the implementation of technology can be complex. Both research and empirical findings (Dugstad, Eide, Nilsen, & Eide, 2019; Nilsen et al., 2016; Pols, 2017; Stokke, 2017) (Røhne, Ausen, Solberg, & Larsen, 2016; Øderud et al., 2013; Ørjasæter & Kistorp, 2016) show that implementation is not straightforward. It is therefore important to investigate how older adults and community healthcare workers perceive and utilise technology, and to identify barriers and optimise opportunities for its implementation and management both in private homes (Frennert & Baudin, 2019) and in nursing homes (Dugstad et al., 2019; Nilsen et al., 2016).

In ALP, the aim was to develop new assistive technology together with a group of assisted living residents, based on their perceived needs and preferences.

## 2.5 Current Policy on Technology in Community Healthcare Services

By 2008, WHO had developed the “Home care in Europe” strategy to address this challenge. Important remedies were to introduce modern technology and innovation in care services:

> *Technological innovation together with new and modern forms of service delivery organization can represent a viable solution to developing home care in Europe provided that health care systems can further enhance integration and coordination (Tarricone & Tsouros, 2008)*

The WHO strategy states that “Promoting healthy ageing, and building systems to meet the needs of older adults, will be sound investments in a future where older people have the freedom to be and do what they value” (WHO, 2016). It contains guidelines for future strategies and plans regarding care and well-being for older adults and encourages nations to promote healthy ageing. This is in line with the EU’s Horizon 2020, which also has four aims to support healthy ageing by personalising healthcare:

- To improve our understanding of the causes and mechanisms underlying health, healthy ageing and disease;
- To improve our ability to monitor health and to prevent, detect, treat and manage disease;
- To support older persons to remain active and healthy;
- And to test and demonstrate new models and tools for health and care delivery. (EU Commission, 2018).

Several Norwegian policy papers encourage municipalities to use information and communication technologies (ICT) as well as digital technologies to improve the quality of their healthcare services and to be more cost effective (Helse- og omsorgsdepartementet, 2011, 2013, 2018). The push to implement technologies in Norwegian community healthcare services is motivated by the hope of bridging the gap between a future scarcity of employees in home care services and supporting home care residents to be more self-sufficient in everyday living (Helsedirektoratet, 2012, 2014b, 2015, 2017; KS - Kommunesektorens organisasjon, 2017, 2019). Other Nordic countries have policies that emphasise technology as a means of meeting future needs in an ageing society, in line with WHO and EU policies.

However, this huge optimism about technology is in great contrast to the complexity of procurement, as well as a resistance to the use of technology (Batt-Rawden et al., 2017;

Dugstad et al., 2019; Nilsen et al., 2016; Peek et al., 2014; Stokke, 2017). The consequences of such resistance are non-use of technology and the creation and/or maintenance of a digital divide, which can disadvantage older adults and lead to occupational injustice. The concept of occupational justice is defined as "equitable, or fair opportunities and resources to do, be, belong and become what people have the potential to be and the absence of avoidable harm" (Wilcock & Hocking, 2015, p. 414). Occupational injustice is the lack of such. A digital divide resulting from lack of access to assistive technology can prevent people from doing, being, belonging and becoming their potentials and thereby have negative consequences for coping with everyday living, self-efficacy, health and well-being. Therefore, healthcare services must work to avoid social exclusion (Morville & Enemark Larsen, 2017). Moreover, ageist attitudes can influence healthcare cultures by reproducing assumptions that older adults are frail and not capable of learning new things, such as how to handle technology. Ageism is defined as

> *an attitude that makes assumptions about older persons and their abilities and puts labels on them. Ageism is also a tendency to view and design society on the basis that everyone is young. Age discrimination is a consequence of ageist attitudes (Townsend & Polatajko, 2007, p. 250)*

These assumptions may hinder access for older adults to assistive technology, and thus represent an occupational injustice.

## 2.6 Research on Assistive Technology for Older Citizens with and without MCI/D

There has been an increase in the number of international and national research projects on technology to support older citizens with MCI/D and their next of kin. Some European examples are COGKNOW (Meiland et al., 2010), ROSETTA (Hattink et al., 2016), and NOCTURNAL (Augusto et al., 2011). These projects focused on the usability of different technologies for older people with MCI/D at home and found that they could benefit both the person with MCI/D and their family caregiver.

In Norway, the Norwegian welfare technology programme NVP (2013–2015), initiated by the Norwegian Directorate of Health, ran small-scale trials with different technologies in 34 municipalities to improve service efficiency to older adults receiving home care services (Helsedirektoratet, 2014b). The findings formed the basis for national recommendations for all municipalities to include electronic medicine dispensers, global positioning systems (GPS) for locating lost persons, and electronic door locks to secure access for community healthcare workers to clients' homes (Helsedirektoratet, 2015). This programme had a clear economic interest and referred to the "realisation of benefits", that is, avoiding cost, saving time and increasing the quality of the services (Helsedirektoratet, 2015; 2017).

In 2016, Norway's biggest cities carried out technology trials with older citizens receiving home care services. Two projects in Bergen (Bjørkheim et al., 2016; Røhne et al., 2016) and one in Oslo (Ørjasæter & Kistorp, 2016) demonstrated that the technology was not reliable, simple to install and use, nor was it cost effective. None of the projects described their participants regarding MCI/D, however one Norwegian study found that 41.5% of the home care recipients had dementia (Wergeland, Selbaek, Hogset, Soderhamn, & Kirkevold, 2014), therefore it is plausible that the participants may be a mixed group.

The first project in Bergen tested a range of technologies to improve safety and coping at home among 101 older home-dwelling care recipients; digital social alarm; bed sensor to detecting absence at night; motion sensor in the sitting room to alert a lack of activity within 17 hours; door sensor to register arrivals and departures from the house; fall sensor with alarm button to detect sudden changes in posture that could indicate a fall; smoke detector to alert a response centre and the fire department; and an alarm string in the bathroom. The researchers concluded that the project provided good insight into how technologies functioned. There were many obvious benefits to implementing them, but the product suppliers must develop their solutions to work more reliably and with simpler interfaces. The efficiency of installation must also improve to realise its benefits and to free up resources for the municipality. Moreover, technological integration required changes to current work practices and service processes (Røhne et al., 2016).

The second Bergen project (2011–2016) tried out telecare solutions that used 12 different sensors to enhance safety and security for 250 older adults at home (Bjørkheim et al., 2016). A three-way partnership of research institution, municipality and UK telecare vendor was expected to yield mutual gains (Berge, 2018). However, the telecare solutions were not easy to deploy in a Norwegian context, and the vendor, unable to fulfil its obligations, withdrew from the project. This demonstrates that real-life projects are unpredictable and risky, and require trust, communication, commitment, exchanged values and the will to act in favour of the partnership (Berge, 2018).

The third example comes from four Oslo districts that tried out three different technologies for home care recipients (Ørjasæter & Kistorp, 2016). The Pilly medicine dispenser with SMS messaging had sound and light alerts at medication times and notified home care services if the medication was not taken. Health-check, for those with chronic diseases such as COPD, took measurements and submitted the patient's health status to home care services. And mobile social alarms, such as mobile phones with GPS and an alarm button. Results showed evidence of cost-effectiveness, but the technologies had an impact on care recipients' identity, daily routines and dialogue with family carers. The technologies were found to be vulnerable and required a thorough implementation process to be of benefit. The selection of users was a challenge and follow-up procedures and further adaptations of the technology were needed, which required innovations to current care services (Ørjasæter & Kistorp, 2016).

Other recent studies have contributed to more knowledge; One Norwegian study, with nine respondents, found that older citizens without MCI/D perceived assistive technology as something that could improve their everyday lives, making it easier and safer, and enabling them to stay at home for as long as possible (Sanchez, Anker-Hansen, Taylor, & Eilertsen, 2019). Another Norwegian study in a nursing home showed that community healthcare staff were not prepared to take on the responsibility for implementing technology as part of community healthcare services (Nilsen et al., 2016).

A Swedish study concluded that although technology providers seemed positive about deploying "welfare technology" in community healthcare services, organisational structures and cultures were resistant to change, due to the lack of infrastructure, uncertainties about financing the technology, staff responsibilities and the law. However, older citizens were generally able to embrace technology that enabled them to stay safely at home, rather than move to a nursing home (Frennert and Baudin, 2019). Further, a Danish study on older citizens without MCI/D and their incorporation of assistive technology, which found that users who became acquainted with it by using it in their everyday lives enabled them to take part in meaningful occupations and social meetings. This strengthened their inner selves and their sense of belonging and becoming (Larsen, S. M., Hounsgaard, L., Brandt, Å., & Kristensen, H. K., 2019).

This shows an openness to technology in older adults, rather than a rejection, and supports policy visions for active and healthy ageing in most countries worldwide. According to Larsen et al (2019), the process of becoming a user of assistive technology, as an older citizen, was closely linked to the person's self-image. Thus, community healthcare workers must encourage the user's emotional adjustment to a new self-image in addition to following-up technology use (Larsen et al., 2019).

Moreover, on 23–24 January 2020 I carried out a new literature search to explore systematic reviews on assistive technology to older adults with MCI/D, and if and how this field had developed since 2017. I used the same search strategy as in 2016, for the same five databases, limited to three years of publications (2017–2020) and 404 references were found via PsychINFO (49), Medline (120), Embase (188), Amed (1) and Cinahl (46). This was an increase on the 369 references found for the decade of 2007–2017, the period defined for the first literature search (Paper I). The 404 references were screened to identify the following criteria: MCI/D, technology, home-dwelling. Table 2.0 in the appendix provides an overview of review studies published during 2017–2020 (N=15).

The types of technologies reported in the 15 reviewed papers were compared to the findings of the 2017 review. The technologies in the 2020 review varied a great deal and were more multifunctional, which made it challenging to categorise them in the 2017 matrix, as presented in Paper I (Table 2.1).

| Domains | 2017 Primary studies (Paper I) | 2020 Review studies |
|---|---|---|
| Safe walking indoors and outdoors | Location and navigation; six papers. GPS and wayfinding | GPS, geofence alarm, fall detectors, wearable fall detectors |
| Safe living | Enhancing safe living; ten studies. Monitoring systems, night-time security | Automatic shut-off devices, water-tap controls, water/gas monitoring controls, sensors for flooding, activity bracelets and tablets with health information or alarm functions, home-based systems for dementia care, video monitoring, sensors, sensor-based surveillance and monitoring systems<br>Ambient assisted living (AAL) tools for 1) physical impairment, 2) cognitive impairment, 3) smart-home technologies, 4) social participation and communication, and 5) to reduce caregiver burden |
| Independent living | Improve occupational performance/coping; six papers. Multifunctional technology with reminders, verbal instruction, easy to use videophone | Clock/calendars, pill dispensers, boil alerts, reminder displays, smoke alarms, motion sensor lighting, modified telephones, devices to enhance operating TV and radio, mHealth app on tablet/mobile phone/personal digital assistant/computer, personal care/companion robots, handheld devices, wearables and touchscreens, personal computers, web interface, brain–computer interface |

|  |  |  |
|---|---|---|
| Entertainment and social communication | Leisure occupations; four papers. Touchscreens, camera for recollection of events, digital board | Virtual reality technology, touchscreens, games and entertainment apps, multimedia reminiscence apps, old-fashioned TV/radio.<br>Easy to use phones, video-conferencing through socially assistive robots (SAR), 'Talking Mats' |

TABLE 2.1. COMPARATIVE OVERVIEW OF TYPES OF TECHNOLOGIES: LITERATURE SEARCHES 2017 AND 2020

The review revealed several terms used to describe assistive technology, which can be confusing:

- IAT was used as an abbreviation for both Intelligent Assistive Technology (Ienca et al., 2018) and Innovative Assistive Technology (Thordardottir et al., 2019)
- EAT was used for Electronic Assistive Technology (Song & van der Cammen, 2019)
- Authors also used the term ICT-based applications (Pinto-Bruno, García-Casal, Csipke, Jenaro-Río, & Franco-Martín, 2017), or everyday technology (Klimova, Valis, & Kuca, 2018)
- AAL, Ambient Assistive Living, was used by one author (Ganesan et al., 2019).

This diversity of terms is not surprising in a growing field and adds to Chapter 2.4. This underlines the huge variety of products and solutions that could support and challenge our understanding and familiarity of such technology.

However, review studies are retrospective and analyse previously published studies. To learn what types of technology newer primary studies had explored, a brief review of Ovid Auto Alerts, from January 2018 to January 2020 was conducted. Fifteen relevant papers were identified, with the selection criteria of MCI/D, technology and home-dwelling. These papers reported on robot technology (homecare robots, robot pets) (Cruz-Sandoval & Favela, 2019; Darragh et al., 2017a; Rantanen, Lehto, Vuorinen, & Coco, 2018), and on a personalised music player for people with dementia and challenging behaviour (Murphy et al., 2018). Some papers explored the ethical dilemmas of technology for citizens with MCI/D, such as artificial intelligence (AI), robotics and wearable computing (Wangmo, Lipps, Kressig, & Ienca, 2019) and of monitoring (Bantry-White, 2018). Two reviews, reported on GPS (Pulido Herrera, 2017) and Exergames (van Santen et al., 2018) (an overview of these papers is presented in Appendix 1.)

A wide range of technologies to promote living safely at home for longer have been tried out in real-life settings, as well as technology for cognitive stimulation and entertainment. Despite many examples of technological failures, false alarms and a lack of infrastructure robustness (Berge, 2018; Røhne et al., 2016; Ørjasæter & Kistorp, 2016), a general optimism about technology is evident. Moreover, even though it is possible to save money and to raise the quality of services, the technological implementation can be an issue. Even if technologies could support older citizens in being independent and coping with everyday living, it can be difficult to get the technology ‘up and running’ in a trustworthy manner.

## 2.7 The Research Gap and the Rationale for this Thesis

To summarise, there is currently quite a lot of research on assistive technology to support older citizens with and without MCI/D at home. This is important, because more knowledge on how technology works in practical settings is needed, especially since many studies report immature and unreliable technology and that technology is not easy to exchange between countries and different digital platforms (Berge, 2018). Many studies reflected aspirations to support older citizens’ independence and everyday living, although they did not offer recommendations for how researchers could succeed with technology interventions.

Assisted technology interventions for older adults with or without MCI/D seem to be complex and the rationale for this PhD is to elaborate on this complexity by including older adults in an assisted living facility in a dialogue and a mutual learning process that would result in more suitable and age-friendly assistive technology. As earlier described, many research projects have been conducted worldwide, with various degrees of user inclusion. Inclusion of users with MCI/D, who constitute an increasing stakeholder group, has shown to be important, however challenging. Many older adults are not properly diagnosed, which may delay access to supporting services and assistive technology that may enable occupation and participation in daily living. Moreover, the healthcare services; i.e. the healthcare workers are key persons for procurement of assistive technology to address the care recipients’ needs and for adopting it to the person in question. Person-fitted technology is required to enable the older citizens’ occupation and participation in society. This requests the technology to be usable and acceptable for older citizens, as well as robust and trustworthy.

# 3 Aims, Objectives and Research Questions

This thesis focuses on older adults and assistive technology that enables occupation and participation, by investigating research literature in the field (Paper I) and asking community health care workers about their current practice with assistive technology for care recipients with MCI/D (Paper II). One part of this PhD studied older adults in assisted living and their engagement in a project to develop assistive technology based upon their perceived needs to facilitate activity and participation in everyday life (Paper III and IV). Assistive technology interventions are complex; they involve many different stakeholders and several steps during the phases of development, implementation and evaluation.

Embedding this study in occupational science enables the exploration of how access to assistive technology can influence everyday living and give a meaningful occupation to older adults with and without MCI/D.

## 3.1 Aims

This thesis explores how current assistive technology – as a complex intervention with home-dwelling older adults, both *with* and *without* MCI/D –facilitates occupation and participation in everyday life. It also describes a feasibility study carried out with one resident that informed the assistive technology intervention in the ALP. Following which, one technological solution was to be deployed in the residents' private apartments and tested in real-life settings over six months. This assistive technology solution came from the partnership with older adults.

## 3.2 Objectives

- To explore the usability and acceptability of assistive technologies – focusing on the consequences for occupational performance, quality of life and human dignity – by carrying out a systematic literature review on technology trials with older adults with MCI/D and their family carers (Paper I).
- To explore and describe how community healthcare workers worked with technology for home-dwelling care recipients and how they talked about it to citizens with MCI/D (Paper II).
- To carry out a feasibility study with one resident without MCI/D in their apartment, to pilot environmental sensors for the ALP (Paper III).

- To evaluate participants' opinions on participation in a technology development project and their opinions on the environmental sensors they tested in their apartment (Paper IV).

## 3.3 Research Questions

The research questions for this thesis reflect the understanding that access to assistive technology enable occupation and participation. This dissertation builds on four studies: a systematic literature review; a focus group study with community healthcare workers; a feasibility study; and a longitudinal assistive technology trial study. The research questions for the four studies were:

1. What types of technologies have been explored with home-dwelling older adults with MCI/D? What is current knowledge about usability and acceptability of such technologies with regard to occupational performance, QoL and human dignity for independent living? How are users involved in the reviewed technology studies? (Paper I)
2. What are healthcare workers' experiences with assistive technology for home care recipients with MCI/D? How do HCW talk about AT to older adults with MCI/D? How do HCW enact current policy on AT? (Paper II)
3. How can a feasibility study on environmental sensors inform a complex assistive technology intervention for supporting assistive living residents? How can a process evaluation inform future interventions?
   (Paper III)
4. How did eight older adults in an assisted living facility experience participating in a 3-year project involving various research-based occupations and testing environmental sensors in their apartments for seven months? (Paper IV)

Figure 3.1 shows the sub-questions for each paper.

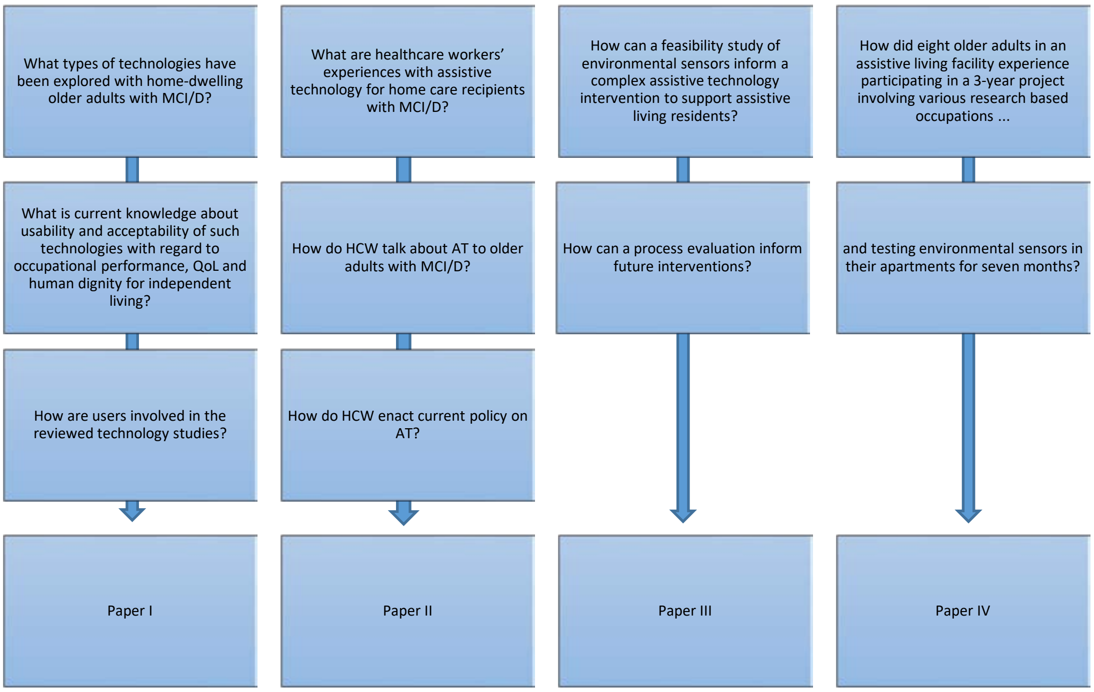

FIGURE 3.1 OVERVIEW OF RESEARCH QUESTIONS AND PAPERS

## 3.4 My Pre-understanding

This study was constructed on the assumption that assistive technology can support older adults in everyday living, if it is provided at the right time and is tailored to the individual's needs, resources, habits and context. After working on assistive technology with people with MCI/D since 2001, I know it can offer more to older citizens than safety and independent self-care. It has potential for social contact with family and friends, for entertainment and for coping with such daily challenges as remembering appointments and keeping track of night and day. In my experience, the usability of technology is dependent on several factors other than personal characteristics (e.g. age, mobility, cognition, technological literacy, needs and motivation). The success of individual tailoring depends on the usability and robustness of the technology and on user acceptance.

The second assumption on which this study is based is that assessing needs for assistive technology is a basic right so that those in need of such can cope with everyday living, occupation and participation. If older adults are not given a fair opportunity to continue developing and thriving by taking part in occupations that promote health and well-being, and social contacts this will create a risk of occupational injustice. Therefore, a needs assessment must be available. Moreover, if older adults are involved in technology development projects, one might expect this would result in products that are far more usable and acceptable.

# 4 Theoretical Background Related to Occupational Science

This study is embedded in occupational science. This chapter explains occupational science from ontological and epistemological standpoints and how it is applied in this study, using central occupational science concepts.

Occupational science focuses mainly on human occupation and how occupational engagement impacts on health and well-being and on experienced meaningfulness for individuals. It recognises the complexity of human occupation in social and political, as well as historical and cultural contexts as important sites for knowledge production (Kristensen & Petersen, 2016 ; Horghagen og Kristensen, 2019).

The discipline of occupational science arose in 1989, and can be defined as:

> *Occupational science is an emerging field/social science that informs a variety of fields, including occupational therapy, through generating knowledge regarding the meaning of everyday doing (occupations) of humans as occupational beings. Occupational science addresses the phenomena of occupation, the experience of occupation, how occupation is situated locally to globally, and implications of occupation at societal to individual levels. Occupational science involves on-going reflexivity and is evolving differently within diverse geographical places.(Laliberte Rudman, 2019 – personal communication).*

The construct of *occupation* comes from the Latin *occupatio*, which means to be occupied or to seize (Christiansen & Townsend, 2014, p. 2). Human occupation is a complex phenomenon, and is defined as

> *A fundamental basic human need, referring to everyday activities or tasks people do to occupy themselves; including looking after themselves, enjoying life and contributing to social life. (Townsend and Polatajko, 2007)*

Norwegian uses the word *aktivitet* for occupation.

The main assumption in occupational science is that humans are active beings and that they are the main actor in their life and in dynamic interactions with other people, objects, tasks and environments. Engaging in occupations in diverse contexts enables personal growth and learning. Dewey (1957) expressed occupational engagement as the “process of engaging with the world" (Dewey, 1957) which can strengthen or undermine health and well-being. Occupational science takes a holistic view of health, to include physical, mental and social dimensions, and recognises that occupations will change during the life course and in different contexts, sometimes including social interaction, sometimes solitude. Personal routines, habits and preferences will affect occupational choices, performances and degree of engagement, according to age, gender, interests, values, preferences and capacities, as well as cultural and social, and maybe religious, contexts or belonging (Townsend & Polatajko, 2007). Thus, engaging in occupations is a dynamic process that shapes our subjectivities, identities and practices for how we want to appear, that is, how we choose to practise our self regardless of age, gender or disability (Laliberte Rudman & Hout, 2013).

A major assumption in occupational science is that meaningful occupation is significant for health and well-being and vice versa (Townsend & Polatajko, 2007), and that inclusion, diversity and justice are three important values (Whiteford & Hocking, 2012). Occupational science is based on the four components of doing, being, becoming and belonging, that equally influence each other and contribute to health and well-being:

> *Doing* – underpins that humans are active beings, and is what people do to experience meaningful occupations, social development and interaction, and potential for personal growth and satisfaction. An impact on doing will have consequences for health and well-being;
> *Being* is existing in the world, and is a part of doing that concerns the degree of quality of life;
> *Becoming* refers to the change and the potential for development and utilisation of one's own resources to contribute to our health and well-being;
> B*elonging* refers to being a part of a community or group, and to sharing values through participating in occupations and common interests (Lindahl-Jacobsen & Jessen-Winge, 2017; Wilcock, 2007; Wilcock & Hocking, 2015).

Occupational science is in this thesis a basis for understanding and reasoning about everyday living in an assistive living environment and about possible threats to a resident's occupation and participation, and how assistive technology could foster or hinder occupation and participation.

## 4.1 Transactionalism

Occupational science seeks to understand human occupation within a dynamic and evolving interrelationship with the environment (people, places, things, situations and cultures) in diverse contextual settings. This interrelationship entails the person's continuous selection of actions that shape their environment, at the same time as the environment reciprocally shapes them (Boger et al., 2016). This is called *transactionalism*, first introduced by Dewey (Dewey, 1957) and is also described as a relational theory (Laliberte Rudman & Hout, 2013). In other words, transactionalism is the ongoing negotiation between person, activity, object and context, which is illustrated by the Human–Activity–Assistive Technology (HAAT) model, as described in section 4.2.

A transactional perspective on human occupation offers an insight into ways of human "doing and being" in different contexts. Transactionalism enables exploration of phenomena such as meaning, learning, growth, morals, social improvement and power relations linked to each of these (M. Cutchin & Dickie, 2013) and:

> *can support knowledge development and translational research targeted toward entities such as political systems, populations and environmental concerns at the same time that it problematizes concepts and theories of occupation that do not account for more than the individual actor. (Cutchin & Dickie, 2013, p. 27)*

Understanding human doing and being may illuminate how older citizens negotiate everyday living with technology, within the context of an assisted living facility. One fruitful model for exploring and understanding the transactional dynamic between resident and technology in the context of an assisted living facility is the HAAT model introduced by Cook and Polgar (Cook & Polgar, 2012), as used in Paper III.

## 4.2 Human–Activity–Assistive Technology Model

The HAAT model was applied to analyse, understand, explain and discuss the human–machine interaction in the feasibility installation (Paper III). The HAAT model defines an assistive technology system as "consisting of an assistive device, a human operator who has a disability, and an environment in which the functional activity is to be carried out" (Cook & Polgar, 2012, p. 20). Thus, four components are included in model: the human, the activity (occupation), the assistive technology and the context. These components are always in a dynamic interrelation (i.e. the transaction must be considered with respect to characteristics and interactions, see Figure 4.1), and subsequently, a “change in any aspect of the occupational situation will result in changes in all other aspects and in how all aspects relate to one another” (Humphry & Wakeford, 2013, p. 219).

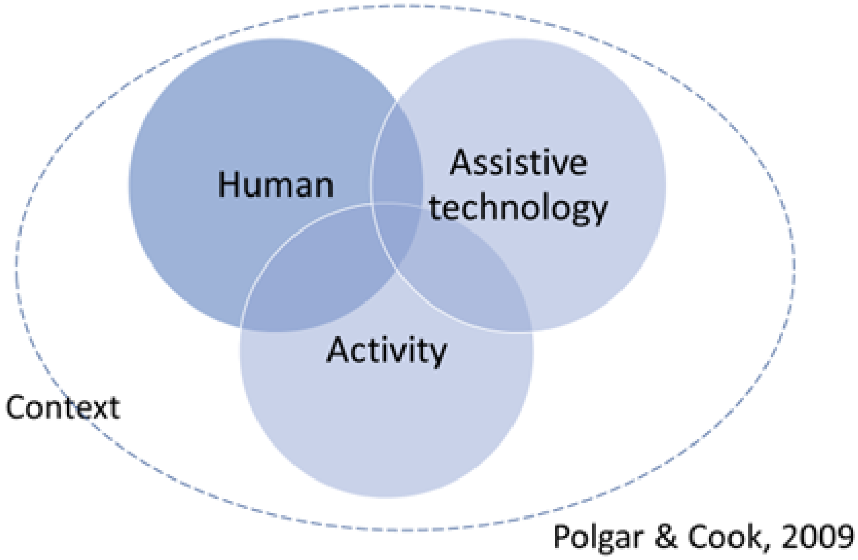

FIGURE 4.1 THE HAAT MODEL

## 4.3 Occupational Justice

A central concept in this thesis is *occupational justice.* Occupational justice expands on the concept of social justice for all (Rawls, 2001), and is based on three ideas; justice, occupation and enablement (Morville & Enemark Larsen, 2017). Its focus is on what people actually do within social relations and under certain living conditions. The evolving theory of occupational justice concerns a justice that recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class or other difference (Nilsson & Townsend, 2010).

Occupational justice sees “humans as occupational beings who need and want to participate in occupations to develop and thrive” (Stadnyk, Townsend, & Wilcock, 2014, p. 326). Human occupation is thus seen as a determinant for health – as are the contextual factors of personal characteristics, social network and health capital (Hocking, 2017). Occupational justice may be restored through occupations that enable people to make choices that are in line with their preferences and what they find meaningful (Hocking, 2017). It has been defined as

> *equitable, or fair opportunities and resources to do, be, belong and become what people have the potential to be and the absence of avoidable harm (Wilcock & Hocking, 2015, p. 414).*

In contrast, occupational *injustice* can influence health negatively, and restricting occupation and participation is a restriction of citizenship (Fransen, Pollard, Kantartzis, & Viana-Moldes, 2015). Occupational justice can be explained as a moral right to take part in an occupation and is closely connected to human rights. The World Federation of Occupational Therapists define how occupational justice requires occupational rights for all to:

> *• Participate in a range of occupations that support survival, health and well-being so that populations, communities, families and individuals can flourish and realise their potential, consistent with the Ottawa Charter 1 (WHO, 1986)*
>
> *• Choose occupations without pressure, force, coercion, or threats but with acknowledgement that with choice comes responsibility for other people, lifeforms and the planet*
>
> *• Freely engage in necessary and chosen occupations without risk to safety, human dignity or equity (WFOT, 2019b).*

In this thesis, occupational justice is a highly relevant term as older citizens are often excluded from societal events and research on the assumption that they are too frail, too technologically illiterate, or impossible to recruit. These assumptions result in actions that marginalise and discriminate on the basis of age.

## 4.4 Occupational Performance

Occupational performance is defined as a:

> *result of a dynamic, interwoven relationship between persons, environment and occupation over a person's lifespan; the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life and contributing to the social and economic fabric of a community. (Townsend & Polatajko, 2007, p. 371).*

This thesis was an opportunity to explore whether access to assistive technology could influence a resident's occupational performance. For instance, if a technology interface was easy to use, it would empower the older citizen to cope better with the technology and therefore, sustain occupation and participation in everyday living. In one example, access to a simple remote TV control with an adapted user interface enabled a person with D to turn on and off TV, as well as choose one of four channels independently. This device enabled the person to perform a meaningful occupation – watching TV (Holthe, 2015).

## 4.4 Quality of Life and Human Dignity

These are complex concepts. Quality of life is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns" (The Whoqol Group, 1995). From an occupational perspective, quality of life refers to the ability to

> *choose and participate in occupations that foster hope, generate motivation, offer meaning and satisfaction, create a driving vision of life, promote health, enable empowerment and otherwise address the quality of life (Townsend & Polatajko, 2007, p. 373)*

The literature, occupational science included, seems to agree that the experience of quality of life is subjective. In occupational science, quality of life entails participation in subjectively meaningful occupation as important for health and well-being. As previously mentioned, *being* is a core word in occupational science, and refers to a part of doing; occupational balance and meaningfulness in life decide quality of life and well-being (Lindahl-Jacobsen & Jessen-Winge, 2017).

In Paper I the concept of human dignity was defined as "the intrinsic dignity that belongs to every human being" (Heggestad, 2014), it is thus closely related to human identity. The UN Declaration of Human Rights clearly states in Article 1 that "All human beings are born free and equal in dignity and rights" (UN, 2020). A study from 2015 found that persons with dementia (N=11) related human dignity to three main factors: access to love and confirmation; experience of social inclusion and fellowship; and being met as an equal with warmth and understanding (Tranvag, Petersen, & Naden, 2015). In occupational science terminology, this would refer to occupational justice, that is, equitable or fair opportunities and resources to do, be, belong and become what people have the potential to be (Whiteford & Hocking, 2012).

## 4.5 User Inclusion

Research on technology development with older citizens usually includes such stakeholders as healthcare workers and family caregivers as well as the care recipients themselves. The different opinions about needs, preferences and requirements for usable and acceptable technologies are pivotal. Users can be cast in different roles: as sources of data (i.e. informants); as research partners; as independent investigators in relation to researchers as mentors (Hulatt & Lowes, 2005).

Several terms are used to describe *user inclusion* in research and health service innovation, but they all refer to a participatory approach that involves end users in:

- defining their needs and challenges;
- prioritising their values and goals;
- developing solutions to their problems;
- making decisions about user requirements;
- implementing and using the product or design in practice (Moser, 2019).

User inclusion may thus help to prioritise health research goals by taking into account those issues that matter most to people in their everyday lives.

In occupational science, this means the social inclusion of older citizens as valued citizens on equal terms, who share and uphold equality and respect (Whiteford & Pereira, 2012). Further, the process of engaging with the world is a core interest together with social inclusion and participation (Hocking, 2017; Whiteford & Pereira, 2012). This study interprets it as the process of engaging with the world of technology, including: the moral right to be included and to participate in the community or society, and having a voice (Whiteford & Townsend, 2011); and the transactional relations between person, occupation and technology within a specific context (Cutchin & Dickie, 2013). The occupational science perspective on ageing is in line with WHO and EU policies on active and healthy ageing (WHO, 2016; EU Commission, 2018), which imply that older citizens with and without MCI/D are rightful, autonomous citizens with obligations and privileges on a par with other citizens (Cahill, 2018).

In this PhD, user inclusion was conceived as a partnership with assisted living residents (Clarke & Keady, 2002), in line with the occupational science view that partnership with users is necessary for knowledge co-production (Hocking 2012). Such partnerships enable a user inclusion that can fulfil the aim of “society talking back to science” (Askheim, 2016, Hoddinott et al., 2018) and avoid a tokenistic user inclusion. Tokenism gives a false appearance of inclusiveness since users have little influence (Romsland, Milosavljevic, & Andreassen, 2019). Not listening to users’ voices on issues that matter to them just perpetuates the gap between practice and policy.

User inclusion aligns with the concept of *social inclusion* and the importance of maintaining or enhancing democratic rights, occupational justice, emancipation and co-determination, as well as adapting and enhancing health services to better address users’ needs (Whiteford & Pereira, 2012).

In study III and IV, the assisted living residents were invited to take part in diverse research occupations over time. Their participation provided a broader understanding of their perspectives on everyday living, as well as an ongoing responsive dialogue about how technology influenced the course of the intervention according to their needs and opinions.

## 4.6 Ontology and Epistemology

My ontological position (assumptions of reality) is in line with occupational science, which perceives humans as active beings searching for meaning and belonging, whatever their age, gender or health status, which includes physical, mental and social dimensions. Human occupation is about “people acting in the world”, and their choice of occupation changes during their lifetime. Nevertheless, occupation always matters to people and is closely connected to health and well-being (Whiteford & Hocking, 2012). Epistemology refers to a “paradigm of knowledge” and what constitutes the current knowledge base (Creswell, 2014). Occupational science is based on epistemological pluralism, which means a synthesis of transdisciplinary research that, rather than being mutually exclusive, offers multiple ways of enriching the study of occupation (Kinsella, 2012, p. 78).

**Occupational Science**

EPISTEMOLOGY

Human occupation is related to health and well-being

Transactionalism: Seeks to understand occupation between persons, occupations, objects and contexts

Critical occupational perspective

Occupational justice

ONTOLOGY

Humans are active by nature

Human occupation and participation are vital for health and well-being

Meaningful occupation

HAAT is one model to analyse transactionalism

TABLE 4.1 INTERRELATION BETWEEN EPISTEMOLOGY AND ONTOLOGY IN OCCUPATIONAL SCIENCE

# 5 Method

As previously stated, this thesis is a part of the ALP. As a PhD candidate in ALP, I worked independently on some research tasks and collaborated with the ALP team on other tasks (as presented in Table 5.0).

| Work Package | ALP tasks | PhD tasks |
|---|---|---|
| **Aim** | To use machine learning technology to assist older adults with cognitive impairments to cope with everyday living and to stay longer at home | To explore user engagement in technology development in the ALP together with older adults in assisted living |
| WP1 Mapping use of technology | Information meeting with residents, next of kin and staff in the ALP | Participated |
| WP1 | State of the art of technology | Systematic literature review (Paper I) |
| WP1 | ALP research group meetings (interdisciplinary) | Participated |
| WP1 | Focus group discussion with multi-professional community healthcare workers | Moderated one of the focus groups, transcribed, led the analysis work and wrote the first draft (Paper II) |
| WP1 | Survey of home-dwelling older citizens using standardised questionnaires | Participated. Interviewed ten persons in one assisted living |
| WP2 Develop technological solution | Dialogue cafés 1, 2, 3 and 4 to investigate user needs and to develop a technological solution | Group leader, planned and prepared group work, wrote summaries |
| WP2 | Recruitment to intervention with environmental sensors | – |
| WP1 Mapping | | Individual interviews with eight participants |
| WP2 Developing | Modelling intervention | Feasibility study on environmental sensors with one resident, in |

| | | |
|---|---|---|
| | | collaboration with commercial partner. Present at installation and in follow-up visit. Took the lead on the process evaluation and wrote first draft and final version (Paper III) |
| WP2 Developing WP3 Evaluation of technology | Modelling intervention | Deployment of environmental sensors with seven other residents, in collaboration with commercial IT partner. Made all appointments for installations, re-installations and follow-up visits (Paper IV) |
| WP2 and 3 | | Follow-ups with technology, observations and conversations about the sensors over 7 months (Paper IV) |
| WP2 | Dialogue cafés 5 and 6 | Participated as group leader and wrote summaries of the group work |
| WP2 | | Focus group discussion with residents having environmental sensors installed 14 March 2018. Led the group, transcribed half the interview, led the analysis process, wrote first draft and all versions until final version (Paper IV) |
| WP4 Create a wider dialogue | Organise ProjectSTEP meeting with advisory group (twice a year) | Participated, and presented status of my work at some meetings |
| WP4 | Organise consortium meetings with international partners (twice a year) | Participated, and presented findings of my work for discussion |

| | | |
|---|---|---|
| WP4 | Foresight conference (November 2019) | Participated in the expert group preparing the work meeting and took part in the conference |
| WP4 | Closing ALP national conference 29 October 2019 | Made 20-minute speech. Took part in conference preparation |
| WP4 | Final project report (January 2020) | Contributed to final project report |

Table 5.0 Overview of PhD research occupations within the ALP

## 5.1 The Medical Research Council Framework - MRC

The MRC framework guided the methodological approach to planning and analysing an intervention, enabling us to understand its transactions/dynamics and to explore and reflect on practices. The MRC framework  has four steps with subthemes: (1) development; (2) feasibility/piloting; (3) evaluation; and (4) implementation (Craig et al., 2008) (Figure 5.1).

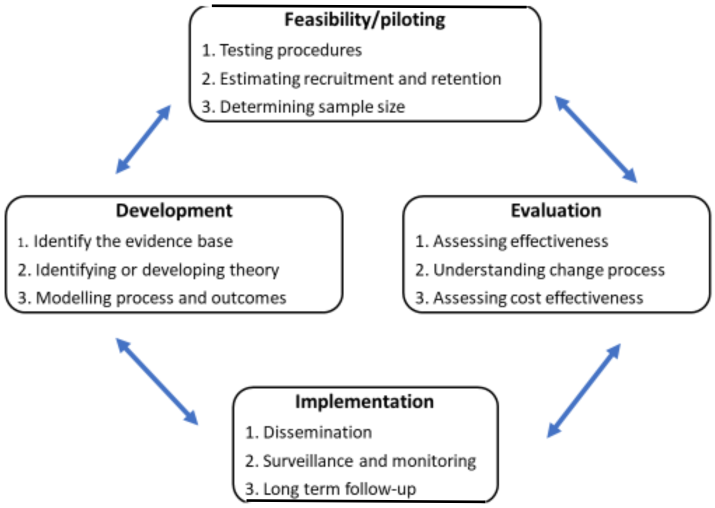

Figure 5.1 The MRC framework (Craig et al 2008)

The framework was developed in the UK to guide how to carefully approach the development and implementation of complex interventions, which seldom is a linear process. MRC underscores the value of evaluating both outcomes and processes in complex interventions in order to assess “feasibility and quality of the implementation, clarify causal mechanisms, and identify contextual factors associated with variations in outcome”(Moore et al., 2015) (Craig et al., 2008, p. 223).

## 5.2. Methods Across the Four Studies in Relation to MRC

Table 5.1 shows an overview of the four studies, their design, participants, data collection methods and analyses. (An overview of the four studies in relation to the thesis' research questions is in Table 3.1)

| | **Study I** | **Study II** | **Study III** | **Study IV** |
|---|---|---|---|---|
| Aim | Obtain an overview of types of technology that have been explored with home-dwelling older adults with MCI/D | Explore how community healthcare workers use "welfare technology" to care recipients with MCI/D in the home-based services | Explore how a feasibility study on an environmental sensor installation could inform an intervention study | Explore user inclusion in technology research and in an intervention study |
| Design | Systematic literature review | Qualitative study | Feasibility study | Qualitative study |
| Participants | 29 studies were eligible for review | 24 community healthcare workers | 1 resident without MCI/D | 8 residents with undocumented MCI/D |
| Data collection methods | Systematic literature review | Five focus group discussions | Observation and interview | Individual interviews, and focus group discussion |
| Tools | Different databases<br>MMAT | Semi-structured interview guide | Process evaluation | Semi-structured interview guide<br>Sociodemographic<br>Rand 12<br>KFI<br>HADS<br>COPM*<br>ETUQ* |
| MRC step | **Development**<br>Identifying evidence base | **Evaluation**<br>Assessing effectiveness<br>Understanding change process | **Feasibility**<br>Testing procedures | **Implementation**<br>Surveillance and monitoring<br>Long-term follow-up<br><br>**Development**<br>Modelling |

| | | | | |
|---|---|---|---|---|
| | | | | **Evaluation** Assessing effectiveness |
| Primary data analysis | Describing, comparing and contrasting data | Thematic inductive analysis according to Braun & Clarke | Process evaluation | Inductive meaning condensation (Braun & Clarke) |

TABLE 5.1 OVERVIEW OF THE FOUR STUDIES (*Tools are licensed and not publicly available)

## 5.3 Method in the Systematic Literature Review: Paper I

It is necessary to study the current state of research when entering a new field. We hired a research librarian to assist with a professional search in this complex field. There were many search words that changed according to the MeSH terms (Medical Subject Headings terms) for each database. One example of a search using MeSH terms in PsychINFO is provided in Paper 1 and the Appendix 2).

The search of five databases resulted in 362 papers. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2009) shows how papers were selected (Figure 5.2).

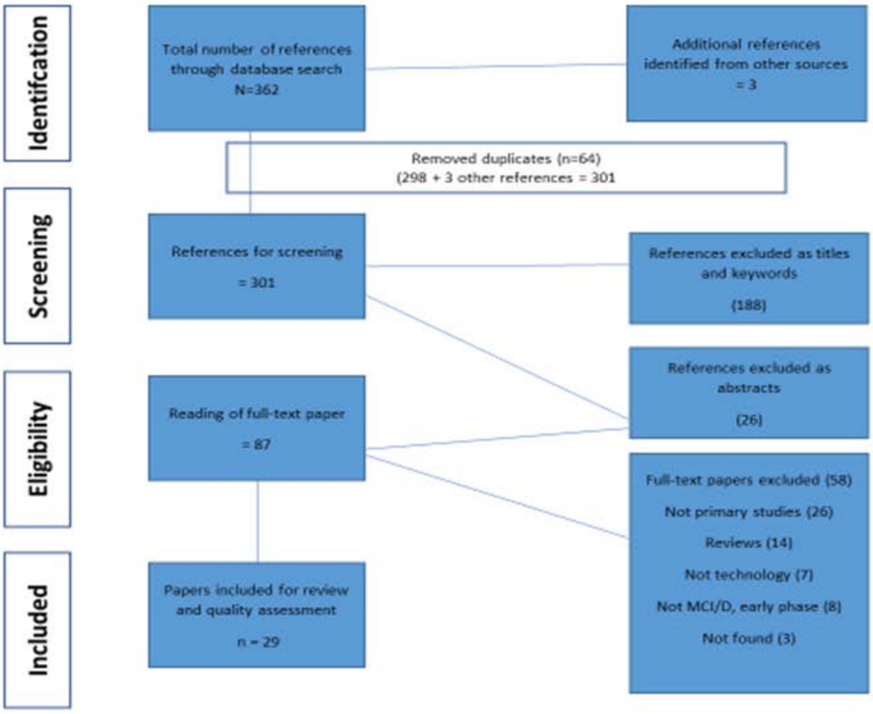

FIGURE 5.2 SELECTION OF PAPERS FOR THE LITERATURE REVIEW

The 29 selected papers were assessed for their quality using the Mixed-Method Appraisal Tool (MMAT) (Pluye et al., 2011), which was selected since the study was expected to be mixed-method. MMAT is designed for the critical appraisal of systematic mixed studies reviews, that is, reviews that include qualitative, quantitative and mixed-method studies. It appraises their methodological quality in five categories: qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive studies and mixed-method studies (Pluye et al., 2011). The MMAT tool was first published in 2009, which is the version we used for our review in 2016–2017. Since then, it has been validated in several studies testing its interrater reliability, usability and content validity. The MMAT was updated in 2019 (Hong et al., 2019).

Two researchers each read all 29 eligible papers and filled in a checklist. They then met and compared their checklists. Where they disagreed, we discussed and re-scored the paper. The MMAT checklist provided four questions for each design (except for mixed methods, which had three questions). Six of the 29 papers were assessed with 4 stars (i.e. high quality), 11 received 3 stars (they met 75% of the criteria), 7 received 2 stars (they met 50% of the criteria) and 5 received 1 star (they met 25% of the criteria). No study was excluded due to its low quality, since we wanted a broad overview of current research.

The data was collected and systematised using an *xls* matrix that allocated the following data characteristics to each paper: author, year, country, title, type of technology, purpose of technology, number of participants (MCI/D + family caregivers/staff), MMAT score and study design according to MMAT, duration of intervention, usability/acceptability, impact on quality of life, occupational performance, human dignity, and implications for clinical practice. Methods reported in the systematic literature review (Paper I) were focus groups (4 studies); workshops (2); experimental trials/field trials (17); and observation (3). These were often evaluated through individual interviews. We also found that the voices of persons with MCI/D were reported in fewer than half the papers and therefore were not explicit (Paper I).

## 5.4 Focus Group Interviews as Method: Paper II and IV

Focus groups were used in Studies II and IV. A focus group contains a group of people who have a common issue to discuss. Not only can the participants explore what they think about an issue, but also why they think as they do (Bowling, 2014). The moderators should facilitate the conversation so that all members participate and respond to each other (Rubin & Rubin, 2012).

The focus group interviews (Bowling, 2014) with community healthcare workers (Paper II) had 24 participants from different backgrounds, divided into five groups.

| | |
|---|---|
| nurses | 11 |
| physiotherapists | 4 |
| occupational therapists | 2 |
| home helps | 4 |
| home trainers | 2 |
| assisted living host | 1 |

TABLE 5.2 PARTICIPANTS IN STUDY II

All group interviews lasted for 45–60 minutes and had two ALP researchers as moderators. An interview guide (Appendix 3) ensured that groups discussed the same questions. All meetings were audio-recorded and transcribed verbatim for inductive analyses.

The focus group interview with assisted living residents (Paper IV) was conducted with seven assisted living residents. It was scheduled for a limited time (45 minutes) in a separate room at the assisted living facility. I led the discussion with Erik Thorstensen, PhD candidate, as co-leader. The interview guide concentrated on three topics and had open-ended questions (Appendix 7). All participants were encouraged to share their opinions on the topics presented. The focus group was audio-recorded and transcribed verbatim. The results from the focus groups are presented in Paper II and paper IV.

## 5.5 Method in the Feasibility Study: Paper III

The implementation of environmental sensors is characterised as a complex intervention (Craig et al., 2008; Richards, 2015). Therefore, we chose to conduct a feasibility study on a proposed study design prior to a main trial, “to inform the development and conduct of a planned research project” (Giangregorio & Thabane, 2015, p. 129).

The process evaluation took place one week after installation (Moore et al., 2015) (Paper III). Ten key questions were designed to provide an understanding of the collaborative installation process, to explore the uncertainties of the intervention and to reveal any strengths and pitfalls in the implementation plan:

1. How should we introduce sensor technology to the residents?
2. How is the resident’s reaction upon the installation and the visit?
3. Who will be present during installation?
4. How long does the installation take?

5. How is the installation carried out, practically?
6. How does the resident take part in the installation process?
7. Did we meet any unexpected barriers? What were they?
8. Technical reliability—are the data transferred as intended?
9. Information needs in the resident/family/staff?
10. How long should a resident have the technology installed before being interviewed about his/her experiences?

### 5.5.1 Description of the Technology Solution for ALP: Papers III and IV

The technology was chosen after the participants' user needs and what types of technology the participants would wish for were identified. This was the topic for the first four dialogue cafés. In turn, the choice of technology would be restricted to, or limited by, the commercial partner's product range and expertise. Together with the participants and the commercial partner, we chose environmental sensors that would monitor the environment and remind the resident of issues they rated as important before they left their apartment (i.e. stove or coffee-machine left on or open windows). This solution was to be tried out with 10-15 residents.

In May/June 2017, eight residents were positive about trying out two solutions that the commercial partner could provide: a voice reminder; and a remote light control connected to environmental sensors in a home-monitoring security system.

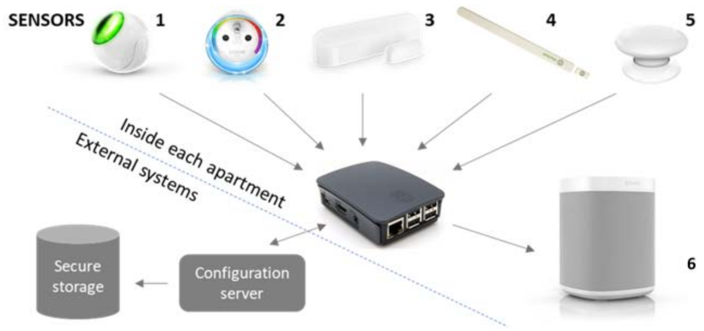

FIGURE 5.3 TOPOLOGICAL MAP SENSORS AND TRANSMISSION OF SIGNAL (1 = MOTION SENSOR; 2 = POWER METER; 3 = MAGNET SENSOR; 4 = SLIM MAGNET SENSOR; 5 = PUSH BUTTON; 6 = LOUD SPEAKER)

The environmental sensors had to be mounted in the apartment so they would cover separate zones, be connected through a controller that transmits signals to the server.

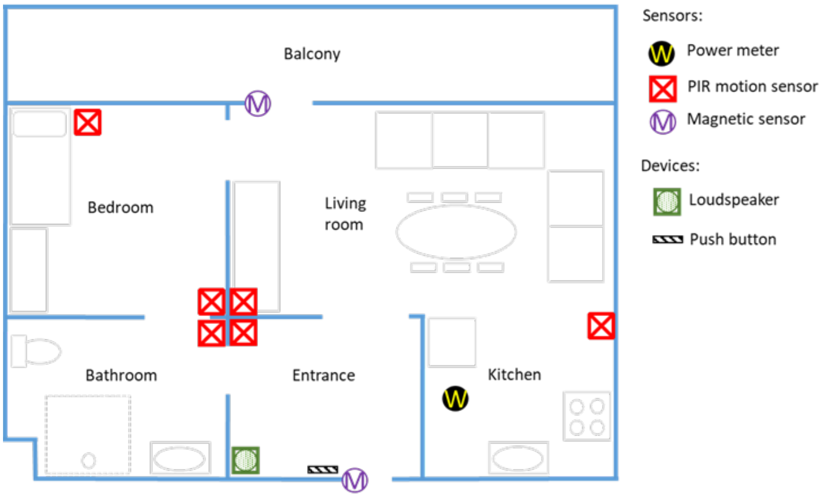

FIGURE 5.4 PLACEMENT OF SENSORS IN APARTMENT (reproduced with permission from Flavia Dias Casagrande, 2019)

#### 5.5.1.1 Voice Reminder

The voice reminder consisted of one switch (push button) and a loudspeaker by the main door. When leaving the apartment, the person could push the button and await a verbal message, for example: “Everything is OK in your apartment” or “The coffee-machine is on. Please turn if off before you leave the apartment”.

The button was to be connected wirelessly to the environmental sensors, the loudspeaker and a control box (ethernet). The wireless sensors could be magnetic on doors and windows, powered on the stove, coffee-machine, TV and radio, and motion sensors in most rooms (Figure 5.3).

The idea was that residents who wanted to leave the apartment easily could check whether any electrical equipment was on by pressing the push button and receiving a response. Several residents really wanted this solution because they were afraid of alerting the fire department. The push button could also be an app (icon) on a tablet provided by the commercial partner, or it could be configured as an automatic response to opening the door (without using the push button).

#### 5.5.1.2 Remote Light Control

This solution was to prevent residents falling at night and to support navigation. The technology was a portable switch place on the bedside table that would operate lights when the resident was in bed. This could be a light in the bathroom or the kitchen. The switch could also be integrated in the tablet, but this solution was later rejected by the all but one of the participants.

## 5.6 Individual Structured Interviews in Paper IV

During May and June 2017, as part of the intervention with environmental sensors, we carried out individual interviews with eight residents, using standardised tools. Although they had already consented to taking part in the intervention study (Appendix 6), they were asked to renew their consent before each interview. Although the consent process could be seen as extended and bothersome, ALP's policy was to ensure that all participants understood the consequences of consenting, and to remind them what project participation was about. Further, since we planned for a longitudinal intervention, a participant's condition could change over time. Thus, we needed to be sure that each participant was able to consent throughout the project.

During individual interviews, we collected sociodemographic data and mapped self-rated scores on health, cognitive functioning, anxiety and depression, using the following standardised tools:

### *Sociodemographics*

Sociodemographic data were collected as a standard inquiry made by the ALP team. Only age is presented in this thesis (Table 6.1), due to GDPR (General Data Protection Regulation). The survey data will be reported in a separate paper by Halvorsrud et al. (in progress).

### *RAND-12*

(Nasjonalt kunnskapssenter for helsetjenesten, n/a)

RAND-12 is a Norwegian short-version of the American 116-item, self-scoring tool developed by the Medical Outcome Study. It is a core set of measures of functioning and health (year of publication not provided), distributed by the non-profit and non-partisan US organisation RAND (Research And Development) Corporation (Appendix 5). https://www.rand.org/content/dam/rand/www/external/health/surveys_tools/mos/mos_core_survey.pdf

### *MCFSI – Mail-In Cognitive Function Screening Instrument [KFI – Kognitiv funksjonsinstrument]*

(Michelet et al., 2018)

KFI is the Norwegian validated (Michelet et al 2018) version of the MCFSI (Mail-In Cognitive Function Screening Instrument) (Walsh, Raman, Jones, Aisen, & Alzheimer Disease & Associated Disorders, 2006). It was translated by Knut Engedal, Anne Brækhus, Karin Persson, Anne Brita Knapskog, Susan Juel and Geir Selbæk. KFI is a self-rating, 14-item questionnaire about how the person perceives their own cognitive abilities on that day, compared to one year ago. There are three answer alternatives: Yes, No, Perhaps (Appendix 5).

### *HADS – Hospital Anxiety and Depression Scale*

(Zigmond & Snaith, 1983)

HADS is a self-assessment scale for detecting states of depression and anxiety. The scale consists of two subscales (anxiety and depression). The sum scores range from 1 to 21, with 21 as the highest level (Appendix 5).

The second round of individual interviews contained two other questionnaires:

### *COPM – Canadian Occupational Performance Measure*

Mary Law, Sue Baptiste, Anne Carswell, Mary Ann McColl, Helene Polatajko, Nancy Pollock, (1991, 1994, 1998, 2005 and fifth version 2014.)

The purpose of COPM is to measure self-reported occupational performance, to identify the significance of certain everyday occupations to the person, and to invite them to evaluate their own performance and satisfaction with their occupational performance. COPM is a semi-structured interview and is used for clients over 7 years of age. When using COPM for persons with cognitive impairment, it is recommended that a supporting person or family carer is present.

The interview has three main areas, with sub-questions: personal care; work; and leisure and social activities. The instrument contains a 10-point numeric scale for the person to evaluate the significance of the activities, and to rate their ability to perform and their satisfaction with the performance. Ten points represent optimal performance or satisfaction. These points can be summarised and display changes, in line with a participant's own evaluation.

COPM was developed in Canada and translated into Norwegian by Ingvild Kjeken in 2001 (Law et al., 2014). The instrument is well known to occupational therapists. A training course is recommended, but not mandatory.

### *ETUQ – Everyday Technology Use Questionnaire*

Professor Louise Nygård, KI, Sweden (Rosenberg, Kottorp, Winblad, & Nygård, 2009)

ETUQ was developed in 2002 by occupational therapists in Sweden, led by Professor Louise Nygård. It evaluates people's perceptions of the relevance of everyday technology and their ability to use technology at home and in society. The ETUQ offers a systematic method for capturing individuals' and groups' perceived difficulties in using everyday technology. The instrument is sensitive to detecting difficulties and changes in ADL. It is validated for research on mapping and evaluating levels of occupational difficulties in handling everyday technology and may generate individual ability measures that can be used in statistical analyses (Nygård et al., 2015).

ETUQ has seven items: technologies connected to household, information and communication; personal care; maintenance in the home; accessibility; economy; shopping; and travel.

The scoring alternatives are: Is the technology in question relevant? If not, move to the next item on the list. If yes, the next question is, do you use it? There are four alternatives under this question. If the technology is not used, it may either be because the person has stopped using it, or never used it although it was in their home.

ETUQ has been translated into Norwegian, but evaluators must attend a one-day course in order to use it.

The ETUQ scores informed my understanding of residents' technology use in the assisted living facility.

### 5.7 User Inclusion Occupations: Paper III and IV

Several methods were used in engaging the assisted living residents for three years. Individual interviews (Bowling, 2014) with standardised tools, first as part of a survey (called the survey) (Halvorsrud et al. in progress), and second as a background data on the participants (called individual interviews, two of which took place at different times, see Figure 5.5).

Project participants were also invited to attend dialogue cafés with structured group discussions, inspired by the concept of world cafés (Brown & Isaacs, 2005). The first café explored older citizens' user needs, the second asked for their opinions of different solutions to address those needs (presented in cartoon form by the ALP team), and the third sought their opinions on mock-up versions of the selected solutions after hands-on demonstrations (Lund et al. – in progress). In total, six dialogue cafés took place between October 2016 and October 2019. The residents were invited to take part in the environmental sensor installation intervention after the fourth café. The sensors were deployed between the end of August 2017 and December 2017. After the trial was closed in February 2018, the participants were invited to a focus group interview (Bowling, 2014) on 14 March 2018  to give their opinions on the installed technology and on taking part in the project. See timeline Figure 5.5.

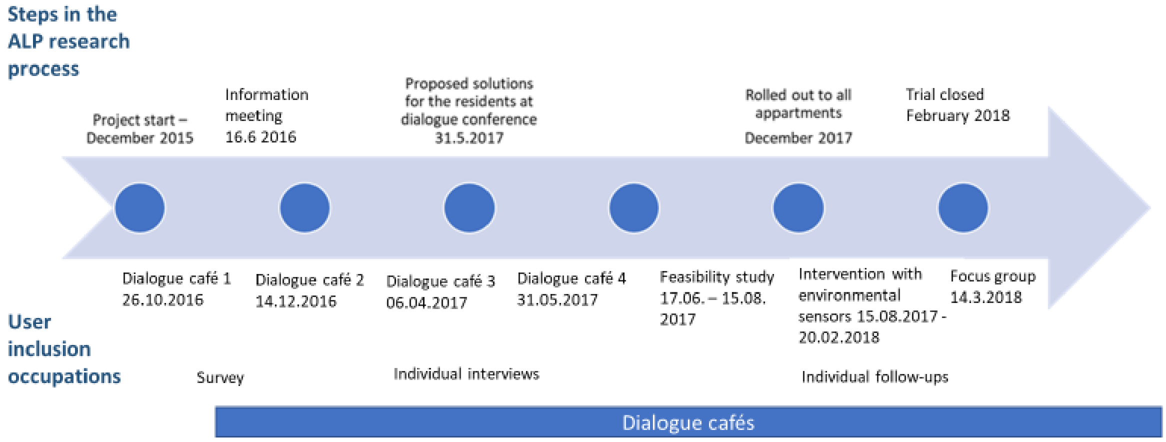

FIGURE 5.5 TIMELINE OF PROJECT TASKS AND RESIDENTS' PARTICIPATION

## 5.8 Recruitment of Participants: Study III and IV

In the ALP, as in this study, the inclusion criteria were being older than 67 and being a resident in the assisted living facility. The housekeeper assisted with the recruitment by telling selected residents (those able to provide informed consent) and encouraging them to volunteer to take part in the project.

### 5.8.1 A Stepwise Recruitment Process: Paper III and IV

The ALP applied a stepwise process to inviting, recruiting and retaining participants to the study.

Step 1: Meeting the management leader and the housekeepers in the assisted living facility to anchor the project and to discuss the recruitment process. The researchers were continually in dialogue with the housekeeper regarding recruitment, who always considered a resident's ability to provide informed consent, in line with Kennedy's recommendations (Kennedy, 2016).

Step 2: ALP researchers were invited to present the ALP at a regular “house meeting” in the assisted living facility on 16 June 2016. The meeting was announced as usual to all 60 residents, who were introduced to the ALP via the agenda. The housekeepers encouraged and reminded many residents to attend by phone or by home visits. During the meeting the research team presented the aims and tasks of the ALP through PowerPoint slides and asked for questions. Invitations to take part in a survey were presented at the end of the meeting.

Step 3: Some residents immediately consented to take part in semi-structured interviews, with questionnaires about technology, perception of health, memory and quality of life. A few were recruited later through the housekeeper. (These interviews were part of a bigger survey that was to be conducted in several Oslo districts).

Step 4: Researchers visited the assisted living facility 2–3 times a week in the beginning. They met people in the canteen, had informal conversations and talked about the project to create interest in it and positive perceptions of it.

Steps 5, 6, 7: Open invitation to all the residents to participate in four dialogue cafés, which were organised as group discussions following user scenarios, and a peer exchange led by a moderator. The aim was to create a forum for exchanging opinions and to co-create knowledge on different topics, including user needs, user perceptions of technologies, user requirements and technology requirements.

Step 8: After the fourth dialogue café, all residents were invited to take part in the intervention with environmental sensors. Those who wanted to take part had to fill in a separate consent form.

## 5.9 Analysis and Rationale for Applying a Critical Occupational Perspective: Paper IV

After first doing an inductive thematic analysis of the focus group interview, I did a second analysis inspired by the critical occupational perspective, using Njelesani’s framework (Njelesani, Gibson, Nixon, Cameron, & Polatajko, 2013) to explore the research findings and possibly identify injustices and question taken-for-granted assumptions (Gerlach, Teachman, Laliberte-Rudman, Aldrich, & Huot, 2018; Laliberte Rudman & Aldrich, 2016; Njelesani et al., 2013). This approach takes a more critical stance by investigating mechanisms that perpetuate injustices and that could inform a policy for social change (Hocking 2012) and is motivated by participation in an ongoing debate (Sayer 2011), rather than judging something as good or bad.

By applying Njelesani's framework, which provides a rationale for using a critical occupational perspective on my empirical material, enabled me to analyse my findings in a broader sociocultural sense. A critical occupational approach challenges power relation and looks for innovative or transformative ways to provide healthcare. In preparing Paper IV, I selected the four questions marked with an asterisk (*), because they seemed the most relevant at the time, and to address the paper's word limit.

The framework contains the following questions:

- What are the relevant sociocultural structures and processes that may mediate and constrain participants' perspectives? *
- Which occupations are seen as being preferable? How are they discussed or represented in the data? *
- What appears to be understood as the preferred way to engage in occupations?
- What assumptions underpin the ongoing valorisation of some occupations and the rejection of others?
- What power relations are at play? *
- Whose interests do the occupations serve? *
- Who is privileged as participants in the occupations? (Njelesani et al., 2013)

## 5.10 Ethical Considerations

This study has strived to consider all ethical aspects during the research. First, the ALP protocol was submitted to the Regional Ethical Committee (REK) in 2015. REK replied that the project fell outside research on health and diseases, and that the research institution (Oslo Metropolitan University) would be responsible for carrying out the project subject to rules on duty of confidentiality, privacy and local approvals (Appendix 9). The ALP therefore applied to the Norwegian Centre for Data Research (NSD), and changes in the project plan meant a new "message and change" submission regarding the intervention study was sent and answered (Appendix 10).

The target group of community healthcare workers were promised anonymity and confidentiality. No names or characteristics were to be revealed, except for professions. In transcripts the participants were allocated numbers (R1, R2 etc.). The assisted living residents were given a coded number, which was attached to their survey data to a secure server (TSD). The code list and questionnaire answers were stored in a locked cupboard in the researcher's office at OsloMet. The residents were given aliases (A, B, C etc.) in the published papers and in this thesis, in line with GDPR. The older adults in assisted living were asked for written consent before each research occupation (Appendix 10, example of consent form).

The intervention study may have been perceived as intrusive, since deploying environmental sensors required drilling holes in the walls to mount the sensors and repeated home visits were required to check the sensors' ability to transmit signals. Surely, the many follow-up visits to fix or check the technology were also intrusive. Such interventions can disrupt other daily occupations and invade the life of the participant (Creswell, 2014, p. 208). Further, unequal power relations may create a sense of powerlessness in the research participant. The researcher has a mission to complete their work within a certain time, and the power to decide where and when to ask, and to take the lead in an interview or observation. Nevertheless, the participants' privacy, rights, needs, values and desires must be respected (Creswell, 2014). I tried to address the inequality of power by always arranging visits that fitted into their day. I always made an appointment prior to each visit. And, if a visit had to be cancelled, I called to let them know. The residents could also call the researchers if they needed any clarification. This mutual contract contributed to a feeling of collaboration and to equalising power relations to some extent.

Technology development studies need technology trials with the participants. This raises several ethical considerations because a current technological push may impact the researchers' values and actions, as well as the yearning for effective results and glory. Further, taking part in a technology trial may be experienced as burdensome and out of control, for example if a light turns on or an alert rings unnecessarily. In the ALP, the older citizens were first invited into the investigation of user needs and user requirements. By carrying out this interactive and participatory evaluation, we supplemented traditional ethical reflections based on ethical principles (Hofmann, 2019). This participatory approach can include residents' values and what is important for them to lead a good life. This is interesting, since a major ethical consideration is whether and how older citizens will benefit from the technologies. However, technology must benefit the user directly or indirectly to be deemed usable and acceptable, and it must contribute to quality of life, occupational performance and human dignity.

# 6 Results

The aim of this thesis was to explore and describe how assistive technology as a complex intervention with home-dwelling older adults, *with and without* mild cognitive impairment (MCI) and dementia (D), to facilitate occupation and participation in everyday life. Paper I explores the types of technology tried out with older adults with MCI/D over the last decade; Paper II looks at how community healthcare workers implemented the technology with care recipients with MCI/D; and Papers III and IV present how the older adults with and without documented MCI/D can be engaged by and take part in a technology intervention.

This chapter presents the four papers' objectives and main results (Table 6.0).

| | **Objectives** | **Main results** |
|---|---|---|
| **Paper I** | To explore the usability and acceptability of assistive technologies – focusing on the consequences for occupational performance, quality of life and human dignity – by carrying out a systematic literature review on technology trials with older adults with MCI/D and their family carers | A wide range of technologies had been tried out in the 29 reviewed studies, as presented in Table 2.1. Assistive technologies to support older adults with MCI/D at home and their family carers seemed optimistic. The importance of including users with MCI/D and their family carers to ensure the usability and acceptability of the technology was emphasised. However, in many studies the users' voices were not reported. |

|  |  |  |
|---|---|---|
| **Paper II** | To explore and describe how community healthcare workers worked with technology for home-dwelling care recipients and how they talked about it to citizens with MCI/D | Results revealed the complexity of implementing policy aims to provide technology for citizens with MCI/D and how community healthcare workers were situated between policies and the everyday lives of citizens with MCI/D. The workers' lack of knowledge and practical experience influenced their exercise of professional discretion in enacting policy on technology in community healthcare services. Overall, addressing systematic technology approaches was not part of routine care, which may contribute to inequitable provision of technologies to enhance occupational possibilities and meaningful activities in the everyday lives of citizens with MCI/D. |
| **Paper III** | To carry out a feasibility study with one resident without MCI/D in his/her apartment, to pilot environmental sensors for the ALP | A feasibility study can inform the development and conduct of a main trial, not only through the practicalities of installation and collaboration with the vendor, but also through the process and thereby avoid the pitfalls, added expense and wasting time. The MRC framework was useful for the process evaluation to assess the feasibility and quality of implementation, to clarify causal mechanisms and to identify contextual factors associated with variations in outcome. |

| | | |
|---|---|---|
| **Paper IV** | To evaluate participants' opinions on participation in a technology development project and their opinions on the environmental sensors they tested in their apartment? | Older adults in an assisted living, with some kind of impairment: could meaningfully contribute opinions about their needs; appreciated being asked to participate; perceived it as an opportunity to learn about a technology they might need in future.<br>A critical occupational perspective was applied in a second analysis. This raised awareness of sociocultural assumptions that older adults in assisted living were frail and unable to participate. These assumptions reinforce ageist and ableist stereotypes, and they promote occupational injustice. |

TABLE 6.0 OVERVIEW OF THE FOUR PAPERS' OBJECTIVES AND MAIN RESULTS

## 6.1 Paper I

The search terms for this review were designed to extract: current knowledge on assistive technology to support home-dwelling older adults with MCI/D; what types of assistive technologies had been tried out at home with this group; and current knowledge on usability and acceptability of assistive technology.

All the 29 papers emphasised the importance of user inclusion; In total, 665 people with dementia and 83 people with MCI, as well as 248 family carers, and 55 healthcare workers, plus 23 others (older adults without MCI/D, dementia experts and volunteers) took part in the 29 studies. Despite this, less than half of the 22 trials reported opinions from people with MCI/D on the technology tested at home. Rather, family carers and staff were asked for their opinions.

The types of technologies used in the trials are described in table 2.1. Eight of the 29 reviewed papers explicitly evaluated usability of technology, other explored user-friendliness or effectiveness of technology. Usability may increase the chance for the device to be found acceptable.

## 6.2 Paper II

The research questions for this study concerned: healthcare workers' experiences with assistive technology for care recipients with MCI/D; how they worked with and talked about technology; and how they enacted current policy that encouraged more extensive use of technology for clients in home care services. Paper II found that some health care workers feared that technology might substitute human contact, and that its use was motivated only by economic reasons. Quite many of the healthcare workers referred to lack of education and training in assessing user needs and implementation of assistive technology. Despite being offered training, healthcare workers seldom got to use this knowledge, often because the care recipients had not been provided with the technology. Procurement of assistive technology to home care recipients with MCI/D was not yet a routine care. Rather, the healthcare workers expected the next-of-kin to be responsible for buying technological devices and install them.

## 6.3 Paper III

One resident (without documented MCI/D) agreed to participate in the feasibility study. She volunteered to try the sensor solution at home for four weeks and give her opinions on the usability and acceptability of the technology, and on how we could modify and improve the solution.

The sensors were carefully planned by the engineering partners in collaboration with the commercial partner. For example, it was important that the detection areas of the motion sensors did not overlap, or the registration of movement would be unreliable.

This study included a process evaluation to inform the main technology intervention. The results were negative, as mentioned, since the assistive technology did not work as intended during the trial, for several reasons:

- Batteries were depleted earlier than expected or specified
- Network and disc communication errors with the controller
- The need to relocate movement sensors to secure detection areas
- IP address limitations
- Thick brick-walls hindered transmission of signals from x-Comfort power meter
- Voice message not working due to network issues, even though a widely available smart speaker was used
- The large amount of data that needed to be sent to a secure server limited the ability to control the network through, for instance, mobile data routers
- Logistic challenges, such as procuring or replacing equipment that was out of stock when needed

- Too few power outlets in the apartments
- Installation took much longer than expected and went on between 28 August 2017 and 21 February 2018 – appointments with residents had to be rescheduled due to the time-consuming reconfiguration of sensors

The non-functioning of the environmental sensor system led to delays and extra costs. We also feared that participants would lose faith in the project and withdraw and/or that the malfunctions would cause them to adopt or nurture an attitude of "technology being sophisticated and impossible to use".

Despite malfunctioning of the technology, the work that was done was useful in several ways:

- Several teething problems of the sensor setup were removed
- We learnt there was a need for a dedicated a test-and-fix period after installation, even though widely available sensors were used
- Tools for monitoring the system should be used after installing the sensors. The system in this project was monitored in an arbitrary way by the organisation running the assisted living facility

These lessons offer an insight into the complexity of all details that must work. A responsible person must be appointed who has access to the installation and can configure and fix what is not working properly. There should be automatic surveillance of the system, to ensure proper functioning.

## 6.4 Paper IV

The questions for the fourth study concerned how the participants evaluated both their project involvement over three years, and the assisted technology (sensors) they tried out. The project participants and findings from the individual interviews will be presented:

### 6.4.1 Participants

Six women and two men consented to take part in the intervention study, aged between 81 and 92. Table 6.1 presents their scores on the self-rated standardised instruments used as part of the survey in the ALP. This information is included here to better understand the results. The participants are anonymised in line with GDPR.

| Participant and age in 2017 | RAND-12[*] self-rated health | KFI[**] self-rated cognitive functioning | HADS[†] self-rated anxiety | HADS[†] self-rated depression |
|---|---|---|---|---|
| A 85 | Good | 3.5 | 0 | 6 |
| B 83 | Very good | 4.5 | 2 | 3 |
| C 92 | Very good | 4 | 1 | 0 |
| D 82 | Fairly good | 2 | 1 | 0 |
| E 86 | Good | 1 | 0 | 0 |
| F 88 | Poor | 3.5 | 3 | 0 |
| G 81 | Good | 3.5 | 1 | 6 |
| H 88 | Fairly good | 6 | 3 | 0 |

[*] RAND-12: 1 = *excellent*, 2 = *very good*, 3 = *good*, 4 = *fairly good*, 5 = *poor*
[**] KFI: 1= *yes*, 0.5 = *maybe*, 0 = *no*. According to a Norwegian validation study, the limit for recommending an assessment of cognitive functioning is 5 for self-scored responses and 7 for scores given by next of kin.
[†] HADS: The instrument has scores for each item under Anxiety (A) and Depression (D) respectively**.** Number of scores: 0–7 = *normal (no anxiety/depression),* 8–10 = *borderline abnormal* (i.e. borderline case), 11–21 = abnormal (i.e. case)
Norwegian versions of the scoring sheets are in the appendices.

TABLE 6.1 OVERVIEW OF PARTICIPANTS' SELF-SCORED HEALTH STATUS IN STUDY IV

The participants had been residents at the assisted living facility for between 6 months and 16 years at the beginning of the study (2016). Despite having some physical, mental and/or cognitive impairments, for which they received community care services, they considered themselves autonomous citizens. They were all mobile, although half of them used mobility aids.

### 6.4.2 Summary of the Structured Individual Interviews

All participants scored between 0 and 7 for their own perception of anxiety and depression on the HADS scoring sheet, which means normal/no anxiety/depression (Appendix 3). However, two residents seemed to experience more depressive symptoms (scores of 6), while there were lower scores on anxiety (Table 6.1). This may indicate that anxiety was less frequent in this sample. However, one can feel lonely and depressed even in safe surroundings.

In the self-reported cognitive functioning questionnaire (KFI) (Appendix 4), all but one reported a score lower than 5, which is the score for recommending a cognitive assessment by a specialist (Michelet et al., 2018). The mean score for the eight residents was 3.5 and the median 3.5, which is associated with good to fairly good cognitive health.

Only one of eight residents scored *poor* on perceived health condition on the self-rating instrument of health, RAND-12 (Appendix 5). The other seven rated their health as good, fairly good or very good. The participants clearly stated that they were not patients, but autonomous citizens, who decided for themselves, despite having various limitations and impairments.

Later in the study, two standardised tools were used in individual interviews, COPM (Law et al., 2014) and ETUQ (Nygård et al., 2015)[2]. The three most meaningful activities for the eight residents, reported by COPM, were:

1. getting around outside of the assisted living facility, either to go for walks in the neighbourhood or to the grocery store, or to do errands or visit family, hairdresser, GP and so on.
2. reading
3. socialising with family and friends outside the assisted living facility.

Getting around was the most challenging, due to poor mobility and no public transport close to the assisted living facility. Many were dependent on taxi services or on family. Transportation issues were a major concern discussed at the dialogue cafés.

According to ETUQ, all eight participants seemed to have and to use a wide range of technologies. However, the most frequent everyday technology was the TV, and four residents stated that it was the most significant technology in their lives. TV was important for keeping up to date with the news, for entertainment and for company when alone at home. One participant admitted to struggling to use the TV independently (we learnt from the housekeeper that all residents had received new decoder boxes for the TV, and that many were finding them difficult to use).

The second most important technology was the mobile phone. Six of eight participants had a mobile phone and the other two missed having one. One said, “I get very helpless if this doesn’t work!” Another said, “I miss having a mobile phone! Everyone has one nowadays!” The telephone was important to reach family and friends and to be socially connected to other people. The two residents who did not have a mobile phone wanted one, to be like the other residents.

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[2] Both instruments are licensed and scoring sheets are not available as attachments in this thesis.

We also learnt that all the residents had been equipped with a tablet as part of the assisted living facility services. The tablet provided daily information about internal meetings, activities and the day’s menu. They could book an appointment at the hairdresser or pedicurist, as well as use apps, such as YouTube or Facebook. Only a couple of our participants used the tablet and took great pleasure in the entertainment, the papers available and more. The others claimed that they never used it, and that it sat in the charger all the time, sometimes on a shelf or a table just out of reach. This non-use of tablets could reflect participants’ attitudes towards technology in general.

Summing up the ETUQ questionnaires, we found that the TV and the telephone were the most important everyday technology for the residents. Only one stated that the computer was the most important technology, since it provided a connection to the rest of the world. They had all heard of someone who struggled to switch the TV on and off, due to having to use two remote controls. Some asked the housekeeper for help during the day. In the evening, after the housekeeper had left, they eventually had to ask the ambulant nursing team, which they were hesitant to do. One participant said that she’d had a black screen one evening, but had not asked for help and sat without watching TV the whole evening, “That was dull!”

# 7 Discussion

This thesis explores how current assistive technology – as a complex intervention with home-dwelling older adults, both *with* and *without* MCI/D –facilitates occupation and participation in everyday life. The main findings across the four papers will be discussed;

i. user inclusion and older citizens as stakeholders in a technology development project,
ii. enacting assistive technology and health care workers as stakeholders, and
iii. discrepancies in assistive technology procurement
iv. discussion of the relationship between the four studies

## 7.1. User Inclusion and Older Citizens as Stakeholders

Another central aspect is *user inclusion*, both in research and in collaborative work during the implementation of technology. Paper I concluded that user participation is necessary to identify user interface characteristics and to try out technology in a real-life settings with older adults with MCI/D. Paper II concluded that community healthcare workers, as a user group, are not systematic in their use of technology with home care recipients with MCI/D. Paper III concluded that user participation led to an awareness of the complexity of implementation and revealed important factors that informed the intervention. Paper IV concluded that user participation over three years revealed their point of view on technology in everyday living and co-created knowledge about user needs, requirements, usability and acceptability of assistive technology. The conclusion is that user inclusion is important and, although it is time consuming, it enhances our knowledge and can be fun. We could never have learnt what we did without the older adult participants, which underscores how this study contributed to the knowledge acquired.

The claim for user inclusion in research is based on democratic rights (those who are concerned by the research have the right to participate), ethical rights (to have a voice in matters of personal concern), for improving the research quality (quality increases by user participation) and to increase its accuracy (useful research outcomes) (O. P. Askheim, Lid, & Østensjø, 2019). Further, user inclusion aims to balance the power relations from the academic monopoly towards empowerment of marginalized groups, to enable knowledge production and social transformation. User inclusion in research is known to be challenging in more than one respect: it is time consuming and it challenges a researcher’s authority and knowledge and therefore well worth the effort (Creswell, 2014). In this thesis, user inclusion was regarded as a *partnership* with the residents in the assisted living facility (Clarke & Keady, 2002), perceiving the older adults as capable co-creators with specific expertise (Askheim, 2012; Romsland et al., 2019), rather than being frail, passive recipients of care unable to voice their opinions.

However, user inclusion is not a straightforward process and it has been critiqued as being symbolic, used first and foremost to legitimise the research, which in practice is controlled by the researchers. Users are often invited into a project that already has clear aims and objectives, and therefore only participate as informants to represent the research results, without any control over them (Askheim & Høiseth, 2019). In study III and IV, user inclusion was practised through different methods (interviews, dialogue cafés, intervention with sensor technology and focus group discussions) to co-create knowledge about how technology can benefit older citizens. Despite our intention about partnership in research, a co-researcher does need to understand: the research's goals and methods; what they are expected to contribute; and what their role is as a co-researcher. The participants' knowledge, motivation, skills and familiarity with technology, influenced the research in different ways; for example, in defining own needs for technological support and in the selection of technological solutions they found interesting and as responding to their user needs.

Assisted living older citizens are often seen as frail, less competent and disabled, particularly if they have a health issue or need a rollator or wheelchair. Further, if being slow to adopt new technology risk exacerbating the potentially serious social problem known as the *digital divide* (van Dijk, 2006). Thus, they are at risk of being stigmatised and treated as a homogeneous group and discriminated against, due to not taking part in the digital world. Such assumptions can prevent older citizens from being treated as equal participants in our society, and sustain ageism, ableism and occupational injustice.

Another issue regarding occupational (in)justice is older citizens' non-use of technological devices, which can contribute to a digital divide in our society. Older citizens are more often non-users of technology and thereby lose access to services and goods (Batt-Rawden et al., 2017; Lee & Coughlin, 2015; Peek et al., 2014; Pols, 2017), and are victimised by the digital divide (van Dijk, 2006). Poorly adapted user interfaces for older citizens, such as lack of contrast colours, button sizes and the number of steps in a procedure, as well as calibration requirements, may prevent older citizens from mastering or benefiting from a device. When devices are too complicated or clumsy to operate, they will be rejected, which puts older citizens at risk of occupational injustice and exclusion.

Furthermore, externally imposed barriers can prevent older citizens from participating in meaningful occupations. This is referred to as *occupational deprivation* (Hocking, 2017) and has recently sparked an interest in developing ‘age-friendly environments’ (WHO, 2020). The risk of occupational deprivation is that persons who are deprived of occupational participation can lose their abilities and capabilities, leading to reduced health and well-being, as well as social exclusion. This is a negative spiral. However, if such passivity is understood as *normal* for citizens in old age, it may reproduce assumptions of older citizens as disabled with lost skills and vitality. Further, the term “normalcy” is an ideological, social construct, defined by those who have power in society. The definition of normalcy can frame our attitudes as normative and legitimise discrimination, or ageism (Townsend & Polatajko, 2007).

An opinion found frequently among older citizens during this PhD study, is that “technology is for those who are frailer than me”, which illustrates an attitude of ableism. However, study IV found that, despite the eight residents stating that they did not currently need technology, they were interested in learning about developments to prepare for the future and to participate in society. They agreed that it did not matter that the technology in the ALP had failed. They found that the most important aspect of the project was that visits from the researchers broke up a dull day.

## 7.2 Enacting Assistive Technology and Health Care Workers as Stakeholders

Community healthcare workers are an important stakeholder group when it comes to technology adoption (Dugstad et al., 2019; Nilsen et al., 2016). Pols (2017) argued that end users (nurses and patients) must establish a relationship with technology, although they often do not recognise its purpose or function (Pols, 2017). A current change of attitude towards assistive technology can be seen among health care workers as evidence for efficiency is provided, for example with electronic medicine dispensers or GPS. Despite this increased acceptance of technology in some health care services, several studies have found a resistance to assistive technology use in home care services and in nursing homes, as Paper II also concludes. This resistance is caused by such factors as a community health care worker feeling uncertain about their responsibilities, or poor technology competence explaining non-procurement. Further, some research found that slow technology adoption in healthcare services is equally due to little knowledge of, or competence in, technological possibilities and how it can be handled by staff, as well as a lack of technological immaturity (Lapierre et al., 2018), and technological integration in community healthcare services (Batt-Rawden et al., 2017; Dugstad et al., 2019; Nilsen et al., 2016; Peek, et al., 2016). This points towards the need for innovative leadership that understands how the technology works, that perceives assistive technology as an integrated part of their service, that trains all employees and that will update the current routines of home care services.

There is also a need to improve the technology and infrastructure of digital services. Malfunctioning decreases faith in technology as a trustworthy assistance to home care recipients and can be taken as a sign of not taking recipients seriously and will lead to slower adoption rates. The translation of knowledge from evidence-based health research into clinical practice, is known to take 17 years on average (Balas & Boren, 2000). This demonstrates how challenging it can be to embed new knowledge into existing services. User inclusion in research is therefore important for both evaluating effectiveness and for speeding up the adoption of technology. This way it might lead to change of healthcare practices sooner. Although many healthcare workers were encouraged to volunteer for education and training, few asked for such training courses (Iplos, 2018). One reflection is that there is obviously a gap between the healthcare policy encouraging use of technology in home care services versus the everyday work situation of healthcare workers and the actual procurement of assistive technology. Section 7.3 elaborates on this discrepancy.

## 7.3 Discrepancies in Technology Procurement

All the four studies were occupied with *assistive technology*. The literature review highlighted the many possibilities for supporting assistive technology to older adults with MCI/D. Papers III and IV underpinned that older citizens, as residents of an assisted living facility, want to participate in projects and learn about and utilise technology. What is interesting is that, although it is often available and citizens want it, the technology is not yet mature, and that healthcare workers are not yet implementing technology for care recipients as part of routine care (Paper II). Also, the digital infrastructure is unreliable and needs to be improved. The consequence is that technology that could support older citizens with or without MCI/D has yet to become a reality or part of the routine.

The use of assistive technology is a strategy governed by health authorities in Norway, and all community healthcare workers must adopt this policy that states municipalities should integrate technology into their healthcare services by 2020. The aim is to minimise costs and maximise efficiency, user choice and quality of service (KS, 2019). Despite this top-down push, the adoption of technology in community health services is still low (Dugstad et al., 2019; Ipsos, 2018; Nilsen et al., 2016; Pols, 2017), as set out in Chapter 2.2 and 7.2.

Local democracy enables municipalities to vary in how eager they are to implement technologies, since the individual local authority is best qualified to determine the most accommodating and cost-effective long-term care solutions (Vabo, 2012). This means that each municipality is responsible for adjusting its services to be in line with the law and regulations, and to address user needs. Each one can structure its community healthcare services so that health care workers fulfil their duty according to laws, regulations, ethical conduct and local discretion. The lack of systematic procurement of technology for older citizens with and without MCI/D is a system-level weakness, which is related to *how* the municipality interprets and mediates current policy for integrating assistive technology into community care services. If care recipients are not informed about their rights, they may suffer from social injustice (Whiteford & Pereira, 2012).

Technology can be perceived as enabling continuing autonomous everyday living and independent living at home. Thus, seen through an occupational science lens, technology represents occupational possibilities that empower older people with respect to citizenship, inclusion and participation. However, older citizens with MCI/D may need support to learn how to relate to the many details that have to work in order to create a responsible solution, which is referred to as the *care arrangement* (Thygesen, 2009). The care arrangement requires different stakeholders (older citizens, next of kin and community healthcare workers) to make an effort to ensure that the technology works as intended. However, sometimes the technology fails to demonstrate its potential to support older citizens with and without MCI/D, due to being immature and not sufficiently robust or user-friendly. This discrepancy between technological possibilities and older adults’ interest versus accessibility could be referred to as occupational injustice, ageism and ableism (Paper IV).

## 7.4 Discussion of the Relationship Between the Four Studies

Moreover, all four studies are concerned with the *complex interventions* in equipping older adults with assistive technology. The first two studies focus on assistive technology for older adults with MCI/D and the last two address user inclusion to develop knowledge about technology to enable occupation and participation, during a technology trial with assisted living residents. The common issue to the four papers is that any intervention using assistive technology with older citizens in need of care is complex. For it to result in a successful and trustworthy community healthcare service, many stakeholders must engage in the intervention. For example, if healthcare workers do not engage in the procurement of assistive technology, then older citizens may experience occupational injustice due to not being found eligible to have their needs assessed. This also perpetuates the digital divide in society if older citizens’ non-use of technology is taken for granted. A denial of enabling technology threatens their meaningful occupation and participation.

Implementing assistive technology with older adults in real-life settings is, as previously mentioned, a complex intervention based upon two major components: existing data on similar or comparable interventions; and a coherent idea of the theory behind it (Richards, 2018). This idea of complexity was upheld by:

- descriptions in the primary studies from the systematic literature study (Paper 1) of interventions with assistive technology to older adults with MCI/D and their next of kin;
- the exploration of healthcare workers’ practice with assistive technology to recipients of home care services with MCI/D (Paper II), as many were uncertain about their responsibilities and how to procure assistive technology;
- the process of the intervention study with assistive technology in the assisted living facility (Paper IV), which required a feasibility study and evaluation (Paper III), as recommended by the MRC (Craig et al 2008), before deploying the technology in all the participants’ apartments (Paper IV);
- the time taken to install and follow up on the sensor technology with all eight residents (Paper IV).

Throughout the three-year intervention (Paper IV), a process of dialogue and reflexivity was important for user inclusion. The eight participants took part regularly in other research activities, such as individual interviews, dialogue cafés and a focus group through. This showed that many older adults want to learn about technology to be part of society. Therefore, healthcare workers have a responsibility to help clients of home care services make use of technology to enhance their occupation and participation.

# 8 Methodological Considerations

This thesis intended to explore how current assistive technology – as a complex intervention with home-dwelling older adults, both *with* and *without* MCI/D –facilitates occupation and participation in everyday life. It was constructed on the assumption that assistive technology has the potential to support older adults at home and enable taking part in activities at home and in society.

Including older adults in assisted living in several research occupations over three years, helped the development of knowledge that could be used in practice at a later stage. In line with the MRC framework (Craig et al., 2008) the process of knowledge development moved back and forth between the three phases of discovery, evaluation and implementation (Hallberg, 2015). First, the *discovery phase* was to identify the problem, the resources or what was interfering with the phenomenon of interest, namely, how assistive technology can to support user needs of older adults in an assisted living. Participants and researchers met several times (both at dialogue cafés and home visits) during the discovery phase. The participants were asked open questions about everyday life in the assisted living facility and possible challenges and user needs. By using cartoon scenarios, the researchers showed how technology could be used to address the issues they were occupied with, such as: needs for safe navigation at night and automatic light control; falls that activated immediate alert to next of kin; forgetting a key or wallet. Participants were encouraged to voice their opinions.

In the *evaluation* phase, older residents and researchers established requirements for supporting user needs, validated the scenarios and ran hands-on demonstrations of possible assistive technology (mock-ups). Together, participants and researchers first agreed on what scenarios would be of interest, based on the user needs expressed earlier, second on what solutions to test at home.

The *implementation phase* was to take place in a real-life context, which is very different from a laboratory setting, and offers vital knowledge for clinical practice. In this study, a feasibility study and a process evaluation were carried out with the home-monitor security system in one resident’s apartment that was thoroughly evaluated before installing this solution in the other seven apartments.

## 8.1 Possibilities and Challenges with Conducting this Research

Doing this multidisciplinary research entail several possibilities;

i. an arena for multidisciplinary work and mutual learning;
ii. access to real users living in a real-life context, having real user needs that must be explored
iii. funding
iv. getting published to a greater audience

Challenges when conducting such research were connected to two major issues;

i. recruitment
ii. consent procedures
iii. anonymity/privacy of participants
iv. disciplinary terminology between the partners
v. the choice of assistive technology, its installation and the malfunctioning of components and systems
vi. time and resources
vii. installation routines and timely support from commercial partner (vendor), materials, teething problems etc

These challenges take time to solve, and are a threat to the project's timeframe, especially as three PhD students were involved and needed to finish their data collection in order to analyse and write up results in due time. In one of the Bergen-projects (Bjørkfjell et al 2016), the vendor withdrew from the project without providing the solutions as promised because they had UK standards and therefore did not work as intended in Norway. Berge (2018) explains how collaboration between research partners depends upon trust, and that building trust is a dynamic process involving accepting interdependency between partners, to fulfil their obligations to the project and to share responsibility for the process (Berge 2018). For similar future projects, commitment to a partnership agreement should be requested along with a SWOT (strengths, weaknesses, opportunities and threats) analysis.

## 8.2 Needs for Adjustments in this PhD Study

My PhD work turned out not to be straight forward. Two major issues occurred; recruitment of participants with MCI/D and malfunctioning of the environmental sensor technology.

Recruiting participants for research studies can be difficult and time consuming and impact a project's timeframe. The assisted living housekeeper played an important role in motivating residents to volunteer for the project. The sample was a *convenience sample*, as the participants were close to hand since they lived in the assisted living facility (Bowling, 2014).

The aim was to include 10-15 residents with MCI/D in the trial. However, only eight volunteered for the project, despite keeping the project open for new participants till end of 2017. 16 June 2016 was the starting date for recruiting participants. However, we soon realized that MCI/D as an inclusion criterion had to be dropped. First, because those residents who had volunteered for the study (partly by being encouraged by the housekeeper) were eager to contribute, and it would be ethically wrong to dismiss them because we were unable to verify an MCI/D diagnosis. Second, there were 50-60 residents in the assisted living facility, and it would public knowledge who was taking part in the study. Such a criterion could stigmatise project participation, which would be unethical. Thus, all the residents were invited to ALP.

The malfunctioning of the technology resulted in many extra visits to repair the flaws. We feared these extra visits may burden the participants and that they would lose faith in the project. Since the home-monitoring security system did not work as intended it was impossible to evaluate its effect and experienced usefulness. However, the participants contributed to the knowledge development, by their opinions on the implementation process.

## 8.4 Strengths and Limitations

This study's main strength is as a longitudinal study over three years, with a seven-month long technology intervention among the same eight older citizens.

Validity in qualitative research is dependent on the accuracy of findings from all the stakeholders' standpoints. The higher the accuracy, the more likely it is that terms such as trustworthiness, authenticity and credibility are used. One method of checking validity/trustworthiness/credibility is to verify the findings (Creswell & Miller, 2000). The fact that I met with the residents over a period of three years developed social relations, dialogue and the co-creation of knowledge. It also offered several opportunities for verifying their opinions over time. Methods of validation might be triangulation (which we did), member-check (which we only did in Paper III), using rich descriptions (which we did not do in line with GDPR), and to clarify bias (which we did) (Creswell, 2014). We also extended our time in the assisted living facility, but this was due to the technology not working and constantly needing to be fixed.

Reliability also comes from whether another researcher reaches the same result, whether transcripts are checked for mistakes, to prevent codes drifting from the initial meaning, and from cross-checking codes between research partners who code their transcripts separately (Creswell, 2014).

Another strength, as well as a challenge, was the ALP transdisciplinary researcher team that consisted of professionals from technology, engineering, IT, health research, ethics and social research, who collaborated on all the research tasks. Different terminology and different aspirations for project planning and outcomes therefore had to be addressed.

One major limitation was that the technology failed. This led to unexpected delays in the project plan and caused much discussion and frustration.

Another limitation may be that my gender, personal values and socioeconomic background influenced my interpretation of the findings (Creswell, 2014). I therefore wrote down my pre-understanding, in order to be aware of this issue, and I kept a diary throughout the intervention phase. I was actively involved in the study but was aware of maintaining an “active listening” approach and of not interfering as an occupational therapist, which is my profession.

## 8.5 Clinical Implications

This thesis aims to demonstrate the complexity of technology for older adults with and without MCI/D, which has implications for clinical practice. In order to achieve the national aim of integrating technology into community healthcare services to support home-dwelling older citizens with and without MCI/D, several factors must be taken into consideration.

First and foremost, a user needs evaluation must take place. Assessing user needs in older citizens with MCI/D is seldom straightforward and requires skilled healthcare workers. This is important, because access to supportive technology may enable older citizens to enhance their occupational performance, quality of life and human dignity in several ways. These outcomes promote empowerment, occupation and participation. Thus, being neglected or denied such an assessment and the subsequent procurement of technology is an occupational injustice.

The next important factor is that the technology must work as intended and be reliable over time. That includes the infrastructure, which is crucial for transmitting signals to the right recipient. Reliability entails that commercial companies are responsible for the quality and robustness of their products and solutions, while municipalities must be responsible for the digital infrastructure, as long as the technology is part of their healthcare services.

Lastly, and probably the most important factor, is a community healthcare worker's knowledge and skills in recognising the potential of technology and in making the effort to adapt it to a user's needs and preferences. Better routines and more transdisciplinary collaboration are needed for this to succeed.

## 8.7 Future Research

The current policy on integrating technology into community healthcare services is driven by the government's desire for a societal transformation. Future technology is expected to be more usable, acceptable and user-friendly for older citizens, and will probably be based on AI functions that make the technology self-learning and even smarter and more personalised. AI could predict our actions, alert us to risks and dangers, and even detect irregularities that could be a threat to health and safe living (Teknologirådet, 2019). Robot technology is another promising area in research. Robots are expected to monitor psychological and physical well-being, to take over practical routine work in the home, and to serve as therapeutic companions for older citizens with MCI/D (Darragh et al., 2017b). Robot technology is still in its infancy and more research is needed to test usability and acceptability. So, although technology is regarded as difficult to operate and alien today, it has the potential to support those in need of assistance with everyday living, to provide meaningful days and to support safe living.

Another concern is that research and innovation are two separate actions that are not necessarily easy to combine. Innovation may be both a process and a result, but its main goal is to create value for the common good (Willumsen and Ødegård, 2015). Research linked to innovation explores the social aspects of the innovation process, in order to understand, analyse and evaluate its efficiency or consequences (Norwegian Research Council, 2015). I suggest we need more transdisciplinary RRI, which calls for collaboration between research, practice and lay people, different disciplines and organisations. By connecting different types of knowledge (Idsøe, 2019) we could develop sustainable and desired solutions that are found usable and acceptable by older citizens.

In this PhD study, the eight participants in the intervention study were residents in an assisted living facility and thus had the rights and obligations that this entails. However, I wondered how the sociocultural structures and processes within the facility influenced the residents? Was the culture of care based on assumptions of the residents being disabled and frail, without seeing their resources or unique identities? And were the residents adopting this disabled and frail role? In 1951, Talcott Parson described the sick role as one that must be earned, in the sense that one must want to get well and heed professional help and cooperate in the healing process, to gain the privilege of being exempted from normal work and responsibilities in return (Blaxter, 2010). However, it is a different matter if people become chronically ill. The patient is not then expected to become well, but to be dependent on assistance, physical help and may even generate costs for society.

In study interviews, the residents clearly stated that they were absolutely not patients, but autonomous citizens, who decided for themselves, despite having various limitations and impairments. This perspective also led to calling the older adults in this study citizens, since I want to reflect my understanding of older adults in assisted living as equal members of society, as autonomous citizens.

Several studies have reported on the low reliability of technology (Dugstad et al., 2019; Røhne et al., 2016; Ørjasæter & Kistorp, 2016). This was also found in the intervention study (Paper IV), and the residents were very patient regarding the functionality of the technology, because they assumed it was complicated.

Low quality and reliability in technology is one thing, the other is user acceptability, and technology must be incorporated as a part of a citizen’s daily life (Arntzen, Holthe, & Jentoft, 2016). If the technology disturbs or interferes with daily habits in unwanted ways (such as making strange sounds or giving verbal messages that are not understood, by blinking lights or having a user interface that is too complicated), it can be a barrier to occupational performance, and is no longer usable or acceptable. I argue that technology that does not work is discriminatory and can have severe implications. Older citizens with and without MCI/D, as recipients of community home care services, must receive follow-up from community healthcare workers who ensure that the technology always supports the citizen in leading their life with dignity.

# 9 Conclusion

This thesis demonstrates that implementing assistive technology with older citizens is still a complex intervention that needs many stakeholders to collaborate to obtain safe and trustworthy solutions. Despite technological advantages working well in some contexts, the intervention in this PhD study showed that technology may not be reliable, and thus not suitable as part of a responsible community healthcare services.

Finding in this study enlighten the need to collaborate with future end users, that is, the older citizen. In this study, older assisted living residents have proven that they, as autonomous citizens, wanted to take part in society and to share their opinions on technologies as a means of daily support for independence, safety and meaningful days.

The main conclusion is that exploration of the assistive technology field regarding older adults in need of care, is broad and versatile, and of increasing interest to research and development. This work recommends health care workers' enactment of AT to older adults' various needs and preferences for technology, request knowledge and competence about AT in order to facilitate occupation and participation. However, including older adults in designing and deciding what technology research projects should concentrate on is both possible and necessary to create a future that avoids exclusion and occupational injustice.

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# List of appendices

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Appendix 1. Overview of references in new literature search 2020.

| **Author & year** | **Number of references** | **Time period** | **Type of technology** | **Results** |
|---|---|---|---|---|
| Klimova et al. 2018 (Klimova, Valis, & Kuca, 2018) | 10 | 2009-2017 | Technology for daily living: reminders for memory orientation, i.e. calendars and clocks; and communication, i.e. easy to use phones.<br>Technology for safety: automatic shut-off devices, water-tap controls, sensors for flooding and falls | The most common technology are devices for daily living and for safety. Benefits are to feel independent, and to be confident of execute ADL, which leads to QoL, and reduction of psychological and behavioural symptoms. |
| Bateman 2017 (Bateman et al., 2017) | 24 | 2012-2016 | mHealth app on a tablet, mobile phone, a personal digital assistant or computer | Lack of consensus as to which health outcomes were used. Limited evidence that mHealth app improves Qol for people with MCI/D. |
| Ienca 2018 (Ienca, Wangmo, Jotterand, Kressig, & Elger, 2018), | 571 | 2000-2016 | Intelligent assistive technology – IAT GPS, personal care/companion robots, handheld devices, video-monitoring, brain-computer interface | The majority of IAT are designed in the absence of ethical values and considerations. User value sensitive design should be prioritized, to avoid the top-down approaches in technology design. |
| Tyacks and Camic, 2017 (Tyack & Camic, 2017) | 16 | 1996-2015 | Touch screens | Touch screen-based interventions can benefit well-being in persons with dementia. |

Appendix 1. Overview of references in new literature search 2020.

| | | | | |
|---|---|---|---|---|
| Liapi, 2017 (Liapis & Harding, 2017) | 9 | from the earliest time to 2015 | personal computers as therapeutic benefit for people living with dementia, or at risk of dementia | Findings are promising, however more studies are needed to examine the computer use and potential to improve outcomes. |
| Pinto-Bruno 2017 (Pinto-Bruno, García-Casal, Csipke, Jenaro-Río, & Franco-Martín, 2017) | 6 | 2006-2013 | ICT-based applications; sensors, web interface, hub and cognitive assistant, touch screen, 29 different devices, TV, radio and telephone, and everyday technology. | Limited evidence for effect on outcome measures but shows promising results. |
| Liu 2019 (Liu et al., 2019) | 9 | 2011-2018 | virtual reality (VR) technology | VR technology is a very effective tool for cognitive assessment and recovery, however, may still be improved. Low sample in the studies, this should be increased in future studies. |
| Lussier (2019) (Lussier et al.) | 17<br>(13 real-life and 4 lab-based) | From earliest till Nov 2017 | Real-life monitoring of people with MCI by several sensors in private homes and lab apartments. | Such monitoring may provide ecological assessments over long periods of time, as part of follow-up for people with MCI. |
| Ganesan 2019 | n/a | n/a | Ambient Assisted Living (AAL) tools for 1) physical 2) cognitive impairment, 3) | There are many barriers in using AAL with older adults with cognitive impairments. Further research |

Appendix 1. Overview of references in new literature search 2020.

| | | | | |
|---|---|---|---|---|
| (Ganesan et al., 2019) | | | smart-home technologies, 4) for social participation and communication, and to reduce caregiver burden. | is needed to evaluate the clinical effectiveness of AAL to support physical, cognitive and social impairments |
| Koumakis 2019 (Koumakis, Chatzaki, Kazantzaki, Maniadi, & Tsiknakis, 2019) | 14 former EU-research projects related to dementia | 2014 – current date | Mobile phone, wearables and home-based systems for dementia care | Current lack of, and urgent need for comprehensive and cost-effective solution that will incorporate technology in integrated care for people with dementia. |
| Sanders 2020 (Sanders & Scott, 2020) | 38 | 1994 – 2019 Greater priority on papers published after 2010 | Clock/calendars, motion sensor lighting, pill dispensers, boil alerts, reminder displays, Smoke alarm, modified telephones, Talking Mats, games and entertainment apps, multimedia reminiscence apps, Old-fashioned TV/radio, alarms and sensors, GPS, fall detectors, water/gas monitoring control, geofence alarm | Use of technology to persons with D is increasing and is likely to increase individuals' trust and familiarity with them. Technology research should include people with dementia to a greater extent. They will require highly targeted and individual approaches if technology should enhance QoL. |
| Thordadottir 2019 (Thordardottir, | 30 | 2007-2017 | IAT – innovative assistive technology; sensor-based surveillance and | IAT-based interventions |

| | | | | |
|---|---|---|---|---|
| Malmgren Fänge, Lethin, Rodriguez Gatta, & Chiatti, 2019) | | | monitoring systems, mobile technology such as wearable fall detectors, and activity bracelets as well as tablets with health information or alarm functions. | can be accepted and used by people with CI and their caregivers. Therefore, they have the potential to compensate for functional decline, i.e., to facilitate everyday activities for several months, despite steady progression of the disease. |
| Song 2019 (Song & van der Cammen, 2019) | 16 | 2007-2019 | EAT – electronic assistive technology; wearables, AAL and telecare | Little evidence that EAT can improve physical and mental well-being of older adults |
| Moyle 2017 (Moyle, Arnautovska, Ownsworth, & Jones, 2017) | 4 | 2012-2014 | Videoconferencing through socially assistive robots (SAR) | Preliminary evidence from 4 studies shows that SAR are generally feasible for supporting interactions between people with D and their carers. |
| D’Onofrio 2017 (D'Onofrio et al., 2017) | 26 | 2000 - 2015 | 1) technologies used by patients with dementia, 2) technologies used by caregivers, 3) monitoring systems, 4) ambient assistive living with ICTs, and 5) tracking and wayfinding | There is a potential for ICTs to support dementia care at home and to improve quality of life for caregivers, reducing healthcare costs and premature institutional care for these patients. |

OVERVIEW OF REVIEWS AND FINDINGS, LITERATURE SEARCH 2017-2020

Appendix 2 Overview of MeSH-terms used in the literature search 2016

Table 1 Databases and search words for identifying literature for review per 14.09.2016:

| | | |
|---|---|---|
| Medline | AAL, ai, aid*, alzheimer disease, alzheimer*, ambient, ambient assisted living, artificial, artificial intelligence, assisted, assisted living facilities, assistive, automation, autonom*, body, cognitive, consumer participation, daily, daily living, dement*, dementia, dementia friendly, dementia, multi-infarct dementia, vascular, device*, digni*, diseas*, disorder*, everyday, friendly, frontotemporal lobar degeneration, health, health related quality of life, home, home automation, hrqol, impair*, intelligence, lewy, lewy body diseas*, lewy body disease, life, living, man-machine systems, mci, memory, memory disorder*, memory disorders, memory impair*, mild, mild cognitive impair*, mild cognitive impairment, of participat*, patient satisfaction, personal autonomy, personhood, principle-based ethics, qol, quality, quality of life, related, residential facilities, satisf*, self-help, self-help devices, sensor, sensor technology, sensor-based, sensor-based technology, smart-home, technology, welfare, well-being, wellbeing | 235 text results |
| PsychINFO | AAL, AI, aid*, alzheimer's disease, alzheimer*, ambient, ambient assisted living, artificial, artificial intelligence, assisted, assistive, assistive technology, automation, autonom*, autonomy, body, client participation, cognitive, cognitive impairment, daily, daily living, dement*, dementia, dementia friendly, dementia with lewy bodies, device*, digni*, dignity, diseas*, disorder*, everyday, friendly, health, health related quality of life, home, home automation, hrqol, human computer interaction, human machine systems, impair*, independence (personality), intelligence, involvement, lewy, lewy body diseas*, life, life satisfaction, living, mci, memory, memory disorder*, memory disorders, memory impair*, mild, mild cognitive impair*, of participat*, qol, quality, quality of life, related, respect, satisf*, satisfaction, self-help, sensor, sensor technology, sensor-based, sensor-based technology, smart- | 93 text results |

Appendix 2 Overview of MeSH-terms used in the literature search 2016

| | | |
|---|---|---|
| | home, social behavior, technology, vascular dementia, welfare, well being, well-being, wellbeing, | |
| Embase | alzheimer disease, artificial intelligence, dementia, mild cognitive impairment, quality of life | 18 text results |
| Ahmed | alzheimers disease, assistive devices, dementia, disability aids, mild cognitive impairment | 1 text result |
| Cinahl | AAL, ai, aid*, ambient assisted living, IN artificial, artificial intelligence, TC assistive, AF automation, assisted living, cogn*, cognition disorders, cognitive device*, disorders, home, home automation, man-machine systems, mci, mild cognitive impairment, self-help, self-help devices, sensor, sensor technology, sensor-based, DH sensor-based technology, smart-home, technology, technolog*, welfare | 15 text results |
| | | Total 362 |

Appendix 3

# Interview guide focus groups

## Intervjuguide til helsepersonell-fokusgruppe

*Innledning*

-Tusen takk for at dere vil bidra inn i dette prosjektet!

-Orientere om hensikten med studien som er å undersøke:

1) hvordan dere arbeider med velferdsteknologi i arbeid med *brukere med lette hukommelsesvansker*

2) hvordan dere vurderer behov og møter brukeres behov for teknologi som støtte i brukers hverdag

3) hvordan dere samarbeider med andre (f.eks.: den eldre, pårørende, utviklere eller andre) relatert til bruk av velferdsteknologi

-Dette er utgangspunkt for en frivillig samtale og dere deler det dere ønsker. Dersom dere vil avbryte samtalen kan dere gjøre det uten å oppgi noen grunn.

-Vi har en tidsramme på cirka time

-Vi ønsker å komme inn på følgende tema:

- *Velferdsteknologi som støtte for brukere med hukommelsesvansker i å mestre hverdagen*
- *Velferdsteknologi som en del av tjenestetilbudet*
- *Verdier og holdninger til velferdsteknologi*

-Kort presentasjonsrunde av deltakerne og med deres fagbakgrunn

-Da starter vi og evt sette på lydopptaker her.

*Velferdsteknologi som støtte for brukere med hukommelsesvansker i å mestre hverdagen*

- Har dere eksempler på teknologi som brukere med hukommelsesvansker anvender
    - Støttespørsmål:
        - Hvordan virker den inn på livskvalitet, verdighet, trivsel, selvstendighet, autonomi, privatliv etc.
        - Eksempler på teknologi som er særlig egnet for personer med hukommelsesvansker?
        - Suksesshistorie?
        - Hvordan vurderer dere behov for teknologi?
        - Hva er hensikten med teknologien?

        - Hva kan hemme eller fremme at en bruker anvender teknologi?
        - Får du spørsmål om å assistere brukere i bruk av teknologi?
        - Hvordan samarbeider dere om teknologi hvis dere jobber i team?
        - Hvis bruker har vært fraværende en periode(sykehus, reise eller lignende) hvordan bruker hun/han da teknologien?

*Velferdsteknologi som en del av tjenestetilbudet*

- Har dere eksempler på velferdsteknologi dere anvender i arbeid med brukere med hukommelsesvansker? (mobil, kalender, ipad etc.)

    - Støttespørsmål:
        - Hvordan hjelper denne teknologien dere med å gjøre jobben deres?
        - Er det noen ganger den hindrer dere i å gjøre jobben?
        - Er det noe teknologi dere drømmer om i fremtiden som kan assistere dere i deres arbeid?

*Verdier og holdninger til velferdsteknologi*

- Hvordan innvirker holdninger (egne holdninger, brukers holdninger, kollegaers holdninger) til bruk av teknologi?
- Hva synes dere om opplæringen dere får i bruk av teknologier?
    - Støttespørsmål:
        - Hvilken betydning har kompetanse om teknologi?

*Er det noe mer dere ønsker å dele?*

TUSEN TAKK FOR DERES BIDRAG!!!

**Invitasjon til fokusgruppeintervju; ansatte i kommunehelsetjenesten**

FOKUSGRUPPEINTERVJU I FORSKNINGSPROSJEKTET 'ANSVARLIG INNOVASJON INNEN VELFERDSTEKNOLOGI FOR ELDRE MED LETTE HUKOMMELSESVANSKER. (ASSISTED LIVING PROSJEKTET)

Dette er en forespørsel til deg om du vil delta i et forskningsprosjekt om velferdsteknologi. Prosjektet er rettet mot eldre med lette hukommelsesvansker og deres bruk av og forhold til teknologiske løsninger i hverdagen. Vi er interesserte i hvordan eldre bruker teknologi i hverdagen og hvilke behov for teknologiske løsninger de har. Vi inkluderer både de eldre selv, pårørende og helsepersonell i prosjektet, fordi disse gruppene vil ha ulike, men interessante perspektiver. Prosjektleder er OsloMet. Se for øvrig prosjektets nettsider: https://assistedlivingweb.wordpress.com/

For å få bedre innsikt i helsepersonells oppfatninger om brukes av og behovet for velferdsteknologi vil vi gjennomføre fokusgruppeintervjuer i Oslo kommune. Hvert intervju vil ta ca 1 time. Hovedfokus for intervjuet er:

- Å undersøke hvordan helsepersonell erfarer eldre med lette hukommelsesvansker og deres bruk av og behov for teknologi i hverdagen
- Å undersøke helsepersonells erfaringer av hvordan behov for velferdsteknologi kartlegges og hvordan behovet dekkes
- Å få innsikt i helsepersonells interaksjoner med andre relatert til bruken av teknologien (det kan være den eldre, pårørende, helsepersonell eller andre)

Det gjøres lydopptak av intervjuene som vil slettes senest i løpet av 2025.

Det er frivillig å delta i intervjuet. Alle forskere som er tilknyttet studien har taushetsplikt. Informantene kan be om få intervjuet til gjennomsyn. Dersom du har spørsmål kan du kontakte

Liv Halvorsrud, tel xxxxxxx e-post yyyyy

Anne Lund, tel zzzzzzxz e-post vvvvv

Prosjektet er vurdert av Norsk senter for samfunnsdata (NSD), Personvernombudet for forskning og tilrår at prosjektet gjennomføres.

**Jeg er villig til å delta i intervjuet**

Sted og dato Deltakers signatur

130916

# RAND-12 Din helse

Spørsmålene under handler om hvordan du oppfatter helsen din. Disse opplysningene vil hjelpe oss til å forstå hvordan du føler deg og hvor godt du er istand til å utføre dine vanlige aktiviteter. Hvert spørsmål skal besvares ved å sette ett kryss (x) i den boksen som passer best for deg.

- **1. Stort sett, vil du si at helsen din er:**

○ Utmerket

○ Veldig god

○ God

○ Nokså god

○ Dårlig

**2. De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er helsen din slik at den begrenser deg i utførelsen av disse aktivitetene nå? Hvis ja, hvor mye? [Kryss X (en boks på hver linje)]**

| | **Ja, begrenser meg mye** | **Ja, begrenser meg litt** | **Nei, begrenser meg ikke i det hele tatt** |
|---|---|---|---|
| a. Moderate aktiviteter som å flytte bord, støvsuge, gå en spasertur eller drive med hagearbeid | ○ | ○ | ○ |
| b. Gå opp trappen flere etasjer | ○ | ○ | ○ |

**3. I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av din fysiske helse?**

| | **Ja** | **Nei** |
|---|---|---|
| a. Fått gjort mindre enn du ønsket | ○ | ○ |
| b. Vært begrenset i type arbeidsoppgaver eller andre aktiviteter | ○ | ○ |

**4. I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av følelsesmessige problemer (som å føle seg engstelig eller deprimert)?**

| | **Ja** | **Nei** |
|---|---|---|
| a. Fått gjort mindre enn du ønsket | ○ | ○ |
| b. Utført arbeid eller andre aktiviteter mindre grundig enn vanlig | ○ | ○ |

- **5. I løpet av de siste fire ukene, hvor mye har smerter påvirket det vanlige arbeidet ditt (gjelder både arbeid utenfor hjemmet og husarbeid)?**

○ Ikke i det hele tatt

○ Litt

○ Moderat

○ Ganske mye

○ Ekstremt mye

**6. De neste spørsmålene handler om hvordan du føler deg og hvordan du har hatt det i løpet av de siste fire ukene. For hvert spørsmål, ber vi deg velge det svaret som best beskriver hvordan du har følt deg**

| | **Hele tiden** | **Mesteparten av tiden** | **En god del av tiden** | **Noe av tiden** | **Litt av tiden** | **Aldri** |
|---|---|---|---|---|---|---|
| a. Har du følt deg rolig og avslappet? | ○ | ○ | ○ | ○ | ○ | ○ |
| b. Har du hatt mye overskudd? | ○ | ○ | ○ | ○ | ○ | ○ |
| c. Har du følt deg nedfor og deprimert? | ○ | ○ | ○ | ○ | ○ | ○ |

- **7. I løpet av de siste fireukene, hvor mye av tiden har den fysiske helsen din eller følelsesmessige problemer påvirket dine sosiale aktiviteter?**

○ Hele tiden

○ Mesteparten av tiden

○ En god del av tiden

○ Noe av tiden

○ Litt av tiden

○ Aldri

# De neste spørsmålene handler om din hukommelse.
# Kognitiv funksjonsinstrument (KFI) - selvrapportert

| | Ja | Nei | Kanskje | For spørsmål 7 om bilkjøring: Ikke aktuelt |
|---|---|---|---|---|
| 1. Synes du hukommelsen din er blitt vesentlig dårligere sammenlignet med for ett år siden? | ○ | ○ | ○ | ○ |
| 2. Forteller andre deg at du ofte gjentar de samme spørsmålene? | ○ | ○ | ○ | ○ |
| 3. Hender det oftere at du legger fra deg ting på feil sted (hvor de ikke pleier å ligge)? | ○ | ○ | ○ | ○ |
| 4. Er du mer avhengig av skriftlige påminnelser (f.eks. handlelister, kalendere)? | ○ | ○ | ○ | ○ |
| 5. Trenger du mer hjelp fra andre for å huske avtaler, familietilstelninger eller ferier? | ○ | ○ | ○ | ○ |
| 6. Er det blitt vanskeligere å huske navn, finne riktige ord eller fullføre setninger? | ○ | ○ | ○ | ○ |
| 7. Er det blitt vanskeligere å kjøre bil (f.eks. kjører saktere, vansker med å kjøre når det er mørkt, kjører deg lettere bort, involvert i ulykker, eller nesten ulykker)? | ○ | ○ | ○ | ○ |
| 8. Sammenlignet med for ett år siden, er det blitt vanskeligere å håndtere din personlige økonomi (f.eks. betale regninger, regne ut vekslepenger, fylle ut selvangivelse)? | ○ | ○ | ○ | ○ |
| 9. Deltar du mindre i sosiale aktiviteter? | ○ | ○ | ○ | ○ |
| 10. Er din arbeidskapasitet blitt redusert det siste året (både betalt og ubetalt arbeid)? | ○ | ○ | ○ | ○ |
| 11. Er det blitt vanskeligere å følge med på nyheter, handlingen i bøker, filmer eller TV-program sammenlignet med for ett år siden? | ○ | ○ | ○ | ○ |
| 12. Er det noen aktiviteter (f.eks. hobbyer som kortspill eller håndarbeid) som er blitt vesentlig vanskeligere sammenlignet med for ett år siden? | ○ | ○ | ○ | ○ |
| 13. Har du fått redusert evne til å orientere deg i omgivelsen eller går du deg lettere bort f.eks. når du kommer til et nytt sted? | ○ | ○ | ○ | ○ |
| 14. Er det blitt vanskeligere å bruke husholdningsapparater (som vaskemaskin, DVD-spiller eller datamaskin)? | ○ | ○ | ○ | ○ |

Sideskift

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# HAD

Her kommer noen spørsmål om hvorledes du føler deg. For hvert spørsmål setter du kryss for ett av de fire svarene som best beskriver dine følelser **den siste uken.** Ikke tenk for lenge på svaret - de spontane svarene er best

- **1. Jeg føler meg nervøs og urolig**

  ○ 3 - Mesteparten av tiden

  ○ 2 - Mye av tiden

  ○ 1- Fra tid til annen

  ○ 0 - Ikke i det hele tatt

- **2. Jeg gleder meg fortsatt over tingene slik jeg pleide før**

  ○ 0 - Avgjort like mye

  ○ 1 - Ikke fullt så mye

  ○ 2- Bare lite grann

  ○ 3 - Ikke i det hele tatt

- **3. Jeg har en uroføelse som om noe forferdelig vil skje**

  ○ 3 - Ja, og noe svært ille

  ○ 2 - Ja, ikke så veldig ille

  ○ 1- Litt, bekymrer meg lite

  ○ 0 - Ikke i det hele tatt

- **4. Jeg kan le og se det morsomme i situasjoner**

○ 0 - Like mye nå som før

○ 1 - Ikke like mye nå som før

○ 2- Avgjort ikke som før

○ 3 - Ikke i det hele tatt

- **5. Jeg har hodet fullt av bekymringer**

○ 3 - Veldig ofte

○ 2 - Ganske ofte

○ 1- Av og til

○ 0 - En gang i blant

- **6. Jeg er i godt humør**

○ 3 - Aldri

○ 2 - Noen ganger

○ 1- Ganske ofte

○ 0 - Vanligvis

- **7. Jeg kan sitte i fred og ro og kjenne meg avslappet**

○ 3 - Ja, helt klart

○ 2 - Vanligvis

○ 1- Ikke så ofte

○ 0 - Ikke i det hele tatt

- **8. Jeg føler meg som om alt går langsommere**

  ○ 3 - Nesten hele tiden

  ○ 2 - Svært ofte

  ○ 1 - Fra tid til annen

  ○ 0 - Ikke i det hele tatt

- **9. Jeg føler meg urolig som om jeg har sommerfugler i magen**

  ○ 0 - Ikke i det hele tatt

  ○ 1 - Fra tid til annen

  ○ 2 - Ganske ofte

  ○ 3 - Svært ofte

- **10. Jeg bryr meg ikke lenger om hvordan jeg ser ut**

  ○ 3 - Ja, jeg har sluttet å bry meg

  ○ 2 - Ikke som jeg burde

  ○ 1- Kan hende ikke nok

  ○ 0 - Bryr meg som før

- **11. Jeg er rastløs som om jeg stadig må være aktiv**

  ○ 3 - Uten tvil svært mye

  ○ 2 - Ganske mye

  ○ 1- Ikke så veld mye

  ○ 0 - Ikke i det hele tatt

- **12. Jeg ser med glede frem til hendelser og ting**
  - ○ 0 - Like mye som før
  - ○ 1 - Heller mindre enn før
  - ○ 2 - Avgjort mindre enn før
  - ○ 3 - Nesten ikke i det hele tatt
- **13. Jeg kan plutselig få en følelse av panikk**
  - ○ 3 - Uten tvil svært mye
  - ○ 1 - Ganske ofte
  - ○ 2 - Ikke så veldig ofte
  - ○ 3 - Ikke i det hele tatt
- **14. Jeg kan glede meg over gode bøker, radio og TV**
  - ○ 0 - Ofte
  - ○ 1 - Fra tid til annen
  - ○ 2 - Ikke ofte
  - ○ 3 - Svært sjelden

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HØGSKOLEN I OSLO
OG AKERSHUS

Invitasjon brukere i hjemmetjenesten.

# FORESPØRSEL OM Å VÆRE MED I FORSKNINGSPROSJEKTET 'ANSVARLIG INNOVASJON INNEN VELFERDSTEKNOLOGI FOR HJEMMEBOENDE ELDRE MED LETTE HUKOMMELSESVANSKER (ASSISTED LIVING-PROSJEKTET)'

## *DEL 1*

## BAKGRUNN OG HENSIKT

Dette er en forespørsel til deg om du vil delta i et forskningsprosjekt om velferdsteknologi. Prosjektet er rettet mot hjemmeboende eldre med mild hukommelsessvikt og deres bruk av og forhold til teknologiske løsninger i hverdagen, såkalt *velferdsteknologi*. Velferdsteknologi er teknologi i hverdagen som kan gi økt trygghet, sikkerhet og selvstendighet, og samtidig muliggjøre aktivitet og deltakelse i sosialt liv. Vi er interesserte i hvordan eldre bruker teknologi i hverdagen og hvilke behov for teknologiske løsninger de har. Vi inkluderer både de eldre selv, pårørende og helsepersonell i studien, fordi disse gruppene vil ha ulike, men interessante, perspektiver på problemstillingen.

Vi henvender oss til deg fordi du mottar hjemmetjeneste der du bor, og den som er ansvarlig for deg i hjemmesykepleien har angitt at du er i prosjektets målgruppe og at du har sagt deg villig til å bli kontaktet.

Prosjektet gjennomføres av forskere fra Høgskolen i Oslo og Akershus. Forskerne er knyttet til forskningsområder innen Informasjons- og kommunikasjonsteknologi (IKT), helsevitenskap, samfunnsvitenskap og etikk. Studenter i sykepleie og ergoterapi vil assistere i å innhente data. Prosjektet samarbeider også med Teknologirådet, Sensio AS, University of Bristol, University of Exeter og Karlsruhe Institute of Technology. Se mer om prosjektet på www.hioa.no/... [webside kommer]

## HVA INNEBÆRER DET Å VÆRE MED I STUDIEN?

Dersom du ønsker å delta i studien ber vi deg fylle ut et spørreskjema oppdelt i ulike tema. Spørreskjemaene vil gi oss informasjon om din bruk av teknologi, dine behov for teknologi og om andre forhold som kan påvirke din teknologibruk.

Spørreskjemaene vil inneholde spørsmål vedrørende din hukommelse, dagliglivets aktiviteter, livskvalitet og psykiske helse. Vi vil innhente data om alder, kjønn, utdannelse, om du bor sammen med noen, personlig økonomi, mottagelse av hjelp, opphold på korttidsplass og sykehusinnleggelse. Det vil også innhentes data om andre sykdommer, røyking, alkoholbruk og fysisk aktivitet. Vi ber også om å få innhente informasjon om kognitiv funksjon, sykehusopphold, vedtak og medisiner fra din journal i hjemmesykepleien/Gerica.

Vi vil anta at utfylling av spørreskjemaene vil ta ca 30 minutter, og vi vil gjerne assistere deg i dette.

## MULIGE FORDELER OG ULEMPER

Du vil ikke ha noen spesielle fordeler av studien, men erfaringer fra studien vil senere kunne hjelpe andre eldre til å leve lenger hjemme med god livskvalitet. Om du har behov for teknologi kan vi videreformidle dette til tjenesteapparatet, men vi kan ikke garantere at disse ønskene vil oppfylles.

Noen synes det er slitsomt å fylle ut spørreskjemaer. Om du skulle oppleve det slik kan du ta en pause eller avslutte din deltagelse i studien.

Enkelte av spørsmålene i spørreskjemapakken kan være vanskelig å svare på, og kan vekke tanker og følelser du kan ha behov for å snakke om i ettertid. I så fall kan du gjerne snakke om dette med helsepersonell i hjemmetjenesten i etterkant av spørreundersøkelsen.

## OPPFØLGINGSPROSJEKT

Noen av dere som deltar i denne studien vil bli forespurt om å delta i en oppfølging av prosjektet på et noe senere tidspunkt. Du vil få mer utfyllende skriftlig og muntlig informasjon i forkant, slik at du kan bestemme deg for om det er noe du vil være med på. Vi vil i så fall også be om din tillatelse til å intervjue en av dine pårørende om deres erfaringer med din bruk av teknologi i hverdagen.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte

- Liv Halvorsrud, mob. 979 52 187, Liv.Halvorsrud@hioa.no.

Dersom du trekker deg, får det ingen konsekvenser for deg eller den helsehjelpen du mottar.

## HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle personopplysninger vil bli behandlet **konfidensielt** og kun informasjon som er nødvendig for studien vil bli innhentet. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Det vil ikke være mulig å gjenkjenne enkeltpersoner når resultatene av studien presenteres. En kode knytter deg til dine opplysninger gjennom en navneliste. Navnelisten med koden er forsvarlig nedlåst på Høgskolen i Oslo og Akershus. Det er kun forskerne i dette prosjektet som har adgang til navnelisten. Alle personer tilknyttet studien har taushetsplikt.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Personidentifiserende data vil slettes senest fem år etter prosjektslutt.

Prosjektet er meldt til Regional komite for medisinsk og helsefaglig forskningsetikk, [saksnr. 2015/2413] og Norsk senter for samfunnsdata (NSD), Personvernombudet for forskning.

# JEG ER VILLIG TIL Å DELTA I PROSJEKTET

**Jeg er villig til å delta i prosjektet**

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

**Jeg tillater at prosjektets forskere innhenter data fra min journal (Gerica):**

Sted og dato

Deltakers signatur

**Jeg tillater at prosjektets forskere kontakter meg for mulig fremtidig oppfølging av studien**

Sted og dato

Deltakers signatur

# Fokusgruppeintervju 14. mars 2018, kl 14 – 15.30

| | |
|---|---|
| 14.00<br>Velkommen<br>Bordplassering<br>Kaffe og kake<br>Presentasjon av Erik og Torhild + deltakerne | |
| 14.15<br>Hvem har vært med på hvilke kafeer? | DC1 26.10.16 Brukerbehov<br>DC2 09.12.16 Diskusjon om ulike løsninger<br>DC3 06.04.17 Prototyper av løsningene<br>DC4 31.05. 17 Invitasjon til å delta i del 1<br>DC5 11.01.18 Presentasjon av RoomMate og invitasjon til å delta i del 2 |
| 14.25<br>Intro<br>Om prosjektet – | hensikten med prosjektet<br>hensikten med fokusgruppa |
| 14.30<br>Tema 1 Om teknologien (sensorene) | Hva tenker dere om å ha sensorer i leiligheten? Hvilke erfaringer har dere gjort dere?<br>Hva tenker dere sensorer kan gjøre for oss i hverdagen?<br>Hvilken verdi skulle dere ønske at de hadde? Tror dere det kommer til å skje? |
| 14.50<br>Tema 2 Om installasjonen | Hva synes dere om arbeidet med å sette inn alle sensorene? |
| 14.55<br>Tema 3 Brukerinvolvering /medforsker-rollen | Vi spurte alle om delta i prosjektet – og du sa ja – Hva var det som gjorde at du sa ja?<br>Hva tenkte du når du fikk invitasjonen til den første dialogkafeen? Hvordan forsto du dette?<br>Hva tenker dere om å være med på prosjektet?<br>Hvorfor ble dere med?<br>Og hvorfor fortsatte dere?<br>Har noen hatt lyst til å trekke seg? Fortell om det!<br>Hva tror dere er grunnen til at noen ikke vil være med?<br>Hvordan snakker dere om prosjektet til andre?<br>Når vi sier at dere er «Medforskere» - hva tenker dere om det?<br>Hva legger dere i det å være «medforsker»?<br>Hva tenker dere om informasjonen dere har fått? |

| | |
|---|---|
| | Hva tenkte du da fikk informasjon om den første dialogkafeen?<br>Er det noen andre erfaringer fra dialogkafeene?<br>Har dere sagt noe til oss som vi ikke har gjort noe med?<br>Er det skapt nye relasjoner –<br>«Hva har dere snakket om sammen i forbindelse med dette prosjektet?»<br>Noe vi kunne gjort annerledes |
| 15.20<br>Avslutning | Tusen takk for at dere stilte opp på dette intervjuet.<br>Dere er viktige personer for oss i prosjektet, og vi lærer mye av dere.<br>Del 2 av prosjektet starter i disse dager, og vi få ønske hverandre lykke til med neste fase av prosjektet.<br>Takk for frammøtet! |

HØGSKOLEN I OSLO
OG AKERSHUS

ASSISTED LIVING

Invitasjon til

# FOKUSGRUPPE-INTERVJU

**ONSDAG 14. MARS KL 14 – 15.30**

PÅ SENIORSENTERET, SKØYEN TERRASSE

Enkel servering

Denne invitasjonen går til deg som har deltatt i fase 1 av prosjektet. Du inviteres herved til et fokusgruppe-intervju sammen med syv andre beboere her på Skøyen, og som også har deltatt i prosjektet.

Intervjuet tar ca 1,5 timer, og det er frivillig å delta. Alle som deltar må fylle ut et samtykkeskjema før intervjuet starter.

**Hva er en fokusgruppe?**

En fokusgruppe er en type gruppeintervju der alle deltakerne har erfaring og kompetanse på et spesielt område, i dette tilfelle om sensorteknologi som er installert i regi av Assisted Living. Vi som arbeider i prosjektet ønsker å lære om dine erfaringer med teknologien som du har fått installert, og om hvordan det har vært å delta i prosjektet.

Vi ønsker å gjøre lydopptak av intervjuet, slik at vi kan gå tilbake og lytte, dersom det er behov for dette. Ingen deltakere blir nevnt ved eget navn, og informasjon om deg blir anonymisert.

Vi som vil lede fokusgruppen heter Erik Thorstensen og Torhild Holthe. Begge er doktorgradsstudenter ved OsloMet – Storbyuniversitetet, tidligere Høgskolen i Oslo og Akershus (HIOA).

**Hjertelig velkommen!**

## SAMTYKKE

Fokusgruppeintervjuet er en del av Assisted Living-prosjektet, og vi trenger å få ditt skriftlige samtykke.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i fokusgruppeintervjuet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte;

- Anne Lund, mob. xxxx.

Dersom du trekker deg, får det ingen konsekvenser for deg eller den helsehjelpen du mottar.

## HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle personopplysninger vil bli behandlet **konfidensielt** og kun informasjon som er nødvendig for studien vil bli innhentet.

Alle personer tilknyttet studien har taushetsplikt.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert og lydopptak og personidentifiserende data vil slettes senest i løpet av 2025.

Prosjektet er meldt til Regional komite for medisinsk og helsefaglig forskningsetikk, [saksnr. 2015/2413] og Norsk senter for samfunnsdata (NSD), Personvernombudet for forskning [saksnr. 47996].

# JEG ER VILLIG TIL Å DELTA I FOKUSGRUPPEINTERVJU

**Jeg samtykker til å delta i fokusgruppe-intervjuet 14. mars 2018.**

| | |
|---|---|
| Skøyen, 14. mars 2018 | Deltakers signatur |
| | Deltakers navn med trykte bokstaver |

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

| Region: | Saksbehandler: | Telefon: | Vår dato: | Vår referanse: |
|---|---|---|---|---|
| REK sør-øst | Silje U. Lauvrak | 22845520 | 10.02.2016 | 2015/2413<br>REK sør-øst D |
|  |  |  | Deres dato: | Deres referanse: |
|  |  |  | 08.12.2015 |  |

Vår referanse må oppgis ved alle henvendelser

Ellen-Marie Forsberg
Høgskolen i Oslo og Akershus

**2015/2413 Ansvarlig innovasjon innen velferdsteknologi for hjemmeboende eldre med lette hukommelsesvansker (Assisted Living-prosjektet)**

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 20.01.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

**Forskningsansvarlig:** Høgskolen i Oslo og Akershus
**Prosjektleder:** Ellen-Marie Forsberg

### Prosjektleders prosjektbeskrivelse

*Prosjektet forsker på bruk av velferdsteknologi hos hjemmeboende personer med mild kognitiv svikt (MCI/D). Prosjektet er tverrfaglig og knyttet til forskningsområder innen teknologi, helsevitenskap, samfunnsvitenskap og etikk. Prosjektet vil bidra i utviklingen av teknologiske løsninger for eldre med MCI/D, bl.a. basert på behov definert av gruppen selv gjennom en involveringsprosess spesielt utviklet for målgruppen. Denne REK-søknaden omhandler helseforskningen i prosjektet. Hovedelementene i denne er: i) spørreundersøkelse rettet mot ca 300 eldre med MCI/D som er inkludert i Oslo Kommunes hjemmetjeneste; ii) intervjuer med 20-25 eldre i målgruppen og 20-25 av deres pårørende; iii) personell innen hjemmetjenesten; iv) installasjon av sensorbaserte løsninger i 20-25 boliger i Skøyen Omsorg + og involvering av disse beboerne i diskusjoner om utvikling av teknologien, samt evaluering av teknologien.*

### Vurdering

Formålet med prosjektet er å undersøke eldres bruk og opplevelser av teknologi i hverdagen. Komiteen vurderer at prosjektet, slik det er presentert i søknad og protokoll, ikke vil gi ny kunnskap om helse og sykdom som sådan. Prosjektet faller derfor utenfor REKs mandat etter helseforskningsloven, som forutsetter at formålet med prosjektet er å skaffe til veie "ny kunnskap om helse og sykdom", se lovens § 2 og § 4 bokstav a).

Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet. Det er institusjonens ansvar å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern samt innhenting av stedlige godkjenninger.

### Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2 og § 4 bokstav a). Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre

til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Silje U. Lauvrak
Rådgiver

**Kopi til:** Arild Steen: Arild-Henrik.Steen@afi.hioa.no
Høgskolen i Oslo og Akershus ved øverste administrative ledelse: postmottak@hioa.no

Ellen-Marie Forsberg
Arbeidsforskningsinstituttet Høgskolen i Oslo og Akershus
Postboks 4 St. Olavs plass
0130 OSLO

*Vår dato: 09.06.2017* *Vår ref.: 47996/5/ASF/RH* *Deres dato:* *Deres ref.:*

## BEKREFTELSE PÅ ENDRING

Vi viser til endringsmelding mottatt 10.05.2017, for prosjektet;

*47996* *Ansvarlig innovasjon innen velferdsteknologi for hjemmeboende eldre med lette hukommelsesvansker (Assisted Living-prosjektet)*

Endringsmeldingen gjelder for delstudie 5 i prosjektet hvor deltagerne i delstudien (beboere på et senter) får installert ulike sensorbaserte teknologiløsninger i sin bolig.

### TEKNOLOGILØSNINGER

På bakgrunn av dialogkafeer med beboerne, har forskergruppen utforsket deltagernes utfordringer i hverdagen og forskjellige typer teknologiske løsninger som kan passe til disse. Resultatet er at beboerne på Skøyen er positive til to typer løsninger som Sensio (som er partner i prosjektet) kan levere:

a) En bryter ved utgangsdøren som de trykker på når de forlater huset. Denne er knyttet til magnetiske sensorer på verandadøren og på vinduer, og på kaffetrakter. Dersom kaffetrakter er på eller noen vinduer eller dør åpne, vil det komme et talevarsel gjennom en høyttaler. I tillegg til bryteren ved utgangsdøren vil de ha en tilsvarende 'bryter' i en 'app' på et nettbrett (som de allerede har og som Sensio har programvare på).
b) En bryter ved nattbordet som kan slå på lys på badet, slik at de unngår å falle i mørket på vei til badet om natten. Denne kan også opereres via et program på nettbrettet.

I tillegg vil det settes inn fire bevegelsessensorer i leilighetene til dem som ønsker å være i prosjektet.

Sensorløsningen vil bli installert av elektrikere og vil stå på ca 10 uker (avhengig av om beboerne er borte i løpet av sommeren, osv.). Prosjektets forskere vil intervjue deltagerne før løsningen installeres, mens den er i drift og etter den er slått av. Beboernes svar vil også kobles til svar på delstudie 1.

I endringsmeldingen opplyser forsker at det vil bli mindre justeringer av antall sensorer og plasseringen av dem avhengig av preferansene til de beboerne som blir med i prosjektet (f.eks. hvilke dører/vinduer/apparater de vil ha med i varselsystemet, og ut fra hensyn til deres møblering).

### INFORMASJONSSIKKERHET

Hendelser/sensordata sendes fra Skøyen til Sensios server hvor de mellomlagres i en uke før de slettes. Dataene vil sendes videre fra Sensio til Tjenester for sensitive data (TSD). Dataene blir lastet opp til TSD via deres nettskjema, og nettskjema krypterer dataene før de sendes til TSD. Det er på TSD dataene vil behandles.

Dataene mellomlagres hos Sensio fordi Sensio må kunne sjekke om det skulle være feil på sensorene eller gateway'en slik at de kan gjøre nødvendig vedlikehold. Det vil ikke gjøres forskning på disse datafilene hos Sensio. For å kunne identifisere eventuelle sensorer som ikke virker, vil Sensio ha en kodeliste på en kryptert minnepinne som oppbevares i et låst arkivskap. Denne kodelisten vil gjøre dem i stand til å koble informasjon fra enkeltsensorer til den aktuelle sensoren i den aktuelle leiligheten. Det lagres kun avidentifiserte persondata på server hos Sensio. All lagring av data over en uke skjer på TSD, og det er disse dataene som vil bli brukt til forskning.

I nettskjema vil sensordataene kobles til intervjudata gjennom en kodeliste. Dataene vil bli lagret og behandlet uten navn, fødselsnummer eller andre personidentifiserbare opplysninger. Det vil kun være en kode knyttet til hver bruker. Koblingsnøkkelen vil oppbevares nedlåst i eget skap hvor kun prosjektets forskningsansvarlige ved HiOA har tilgang. Koblingsnøkkelen vil oppbevares på en kryptert minnepenn eller fil. Kun prosjektets forskere har adgang til prosjektets område på TSD.

Forskningsteamet vil studere «events» registrert av sensorene. En «event» er f.eks. at en bevegelsessensor er aktivert fordi en person har gått forbi, at et vindu blir åpnet/lukket eller at en bryter blir slått på. Forskerne vil se etter sammenhenger mellom «events» fra ulike sensorer; f.eks. at beboeren trykker på lysstyringsbryteren og aktiverer bevegelsessensoren under sengen ved at de står opp.

VURDERING
Prosjektets formål er å bidra med kunnskap innen forskning rettet mot bruken av velferdsteknologiske løsninger, som teknologisk assistanse i hjemmet. Ved å installere de nevnte teknologiløsningene og sensorer kan forskergruppen forstå brukernes opplevelser av teknologien bedre. På denne måten vil forskergruppen kunne utvikle et mer intelligent smarthussystem som forstår når beboeren er på vei ut og kan varsle om sikkerhetsrisikoer, og som forstår når beboeren er på vei ut av sengen om natten og kan slå på lyset på badet - uten at de trenger å trykke på en bryter eller operere et nettbrett. Systemet skal også kunne tilpasse seg brukerens handlingsmønster.

Vi vurderer at deltakernes personvern er godt ivaretatt, og at nytteverdien av installeringen av teknologiløsningene overstiger personvernulempen til den enkelte deltaker. I vår vurdering har vi blant annet lagt vekt på at deltakerne skal samtykke til deltakelsen. Videre rekrutteres kun beboere med mild kognitiv svikt. Informantene har behov for assistanse, men er generelt godt fungerende. Forskergruppen på Høgskolen i Oslo og Akershus har et nært samarbeid med husvertene på senteret hvor deltakerne bor, og disse kjenner beboerne godt og treffer dem daglig. Disse vil gjøre en skjønnsmessig vurdering av beboernes samtykkekompetanse. Vi vurderer også at informasjonsskrivet er godt utformet.

Prosjektet vektlegger også brukermedvirkning, og aktuelle brukere av løsningene har selv vært med på å bestemme hvilke typer løsninger som blir relevant å installere. På denne måten er deltakernes behov og ønsker imøtekommet, noe som kan føre til at installeringen kommer den enkelte deltaker til gode.

Videre vurderer vi at det er valgt teknologiløsninger som er mindre inngripende, og mye av teknologien som installeres er brukerstyrt (brytere). I tillegg vil løsningene underveis kunne tilpasses hver enkelt brukers behov, da forskergruppen er tilgjengelig igjennom hele perioden dersom det oppstår tekniske problemer, eller deltakerne har bekymringer om løsningene eller forskningen. På bakgrunn av dette mener vi at deltakerne i prosjektet har god kontroll over løsningen og hva som registreres. Dette reduserer personvernulempen med å delta i prosjektet.

Personvernombudet vurderer også at mengden data som lagres er begrenset til det som er relevant for formålet, og at data oppbevares og sendes på en sikker måte.

Til slutt vurderer vi at samfunnsnytten med delprosjektet er stor. Prosjektet vil føre til økt kunnskap på feltet og vil kunne bidra i den generelle utviklingen av teknologiske løsninger for eldre med mild kognitiv svikt eller demens.

Personvernombudet legger til grunn at prosjektopplegget for øvrig er uendret.

Personvernombudet vil ved prosjektslutt rette en henvendelse vedrørende status for behandling av personopplysninger.

Ta gjerne kontakt dersom noe er uklart.

Vennlig hilsen

Kjersti Haugstvedt
Kjersti Haugstvedt

Amalie Statland Fantoft
Amalie Statland Fantoft

## Paper I

Torhild Holthe, Liv Halvorsrud, Dag Karterud, Kari-Anne Hoel, Anne Lund (2018). **Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review.** Published May 4, 2018 Open Access DOVE medical press: Clinical Interventions in Ageing. Accepted Jan 22, 2018. DOI: **https://dx.doi.org/10.2147/CIA.S154717**

Clinical Interventions in Aging

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REVIEW

# Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review

Torhild Holthe
Liv Halvorsrud
Dag Karterud
Kari-Anne Hoel
Anne Lund

Faculty of Health, Oslo Metropolitan University, Oslo, Norway

**Background:** The objective of this review was to obtain an overview of the technologies that have been explored with older adults with mild cognitive impairment and dementia (MCI/D), current knowledge on the usability and acceptability of such technologies, and how people with MCI/D and their family carers (FCs) were involved in these studies.

**Materials and methods:** Primary studies published between 2007 and 2017 that explored the use of technologies for community-dwelling people with MCI/D were identified through five databases: MEDLINE, PsycINFO, Embase, AMED, and CINAHL. Twenty-nine out of 359 papers met the criteria for eligibility. We used the Mixed Methods Appraisal Tool for quality assessment.

**Results:** A wide range of technologies was presented in the 29 studies, sorted into four domains: 1) safe walking indoors and outdoors; 2) safe living; 3) independent living; and 4) entertainment and social communication. The current state of knowledge regarding usability and acceptability reveals that even if researchers are aware of these concepts and intend to measure usability and acceptability, they seem difficult to assess. Terms such as "user friendliness" and "acceptance" were used frequently. User participation in the 29 studies was high. Persons with MCI/D, FCs, and staff/other older adults were involved in focus groups, workshops, and interviews as part of the preimplementation process.

**Conclusion:** Research regarding technologies to support people with MCI/D seems optimistic, and a wide range of technologies has been evaluated in homes with people with MCI/D and their FCs. A major finding was the importance of including people with MCI/D and their FCs in research, in order to learn about required design features to enhance usability and acceptability. Surprisingly, very few studies reported on the consequences of technology use with regard to quality of life, occupational performance, or human dignity.

**Keywords:** technology, Alzheimer's disease, coping, aging in place, safety, quality of life, dignity

## Introduction

The aging society is described as a grand societal challenge,[1] and access to technology is one important strategy in future health-care services.[2] Older people often have multiple and chronic diseases, often requiring extensive care services. The prevalence of Alzheimer's disease or related dementias extends to nearly 44 million people worldwide and is most common in Western Europe.[3] Dementia is a neurodegenerative condition due to disease of the brain, of a chronic or progressive

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nature, that influences cognitive, psychological, behavioral, and motor skills, having consequences for quality of life (QoL) and everyday living competency.[4] The ICD-10 presents four criteria for dementia: 1) impaired memory; 2) clear consciousness; 3) impaired emotional control, motivation or social behavior; and 4) the condition must have lasted for at least 6 months. Dementia is divided into mild, moderate, and severe stages, depending on the extent to which the condition influences everyday living.[5]

Mild cognitive impairment (MCI) encompasses attention, concentration, memory, comprehension, reasoning, and problem solving. According to Winblad et al (2004), MCI is a useful term as both a clinical and a research entity[6] and is usually perceived as the preclinical stage of dementia. However, MCI may be stable and occasionally reversible.[7] The risk of mortality seems to be high for all types. Hedman et al (2013) studied patterns of functioning in older adults with MCI and found that they exhibited different patterns: stable, fluctuating, descending, or ascending. The patterns may change over time, and thus individual support is needed.[8]

Technologies, such as digital calendars, speaking watches, and Global Positioning System (GPS), have been shown to support time orientation, memory, and safety in people with mild cognitive impairment/dementia (MCI/D).[9–12] Technology may have the potential to support a person's occupational performance, meaning helping out "the actual execution or carrying out of an occupation" (p. 26),[13] and facilitate a good and dignified life, reducing the pressure on family carers (FCs) and the need for community care services. Dignified lives for older adults, defined by Heggestad[14] refers to Jacobson's definition (2009) of human dignity as "the intrinsic dignity that belongs to every human being,"[14] are increasingly discussed in health-care services. Human dignity is closely related to human identity. Being a technology user has implications for identity.[15] If a person finds the technology ugly, not user friendly, or not compatible with his or her lifestyle, the device will hardly be accepted.

Access to technology that addresses a need is anticipated to have an impact on QoL, which may be defined as:

> an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns.[16]

However, it is a prerequisite that the technology matches the needs of the user and is accepted as an aid and incorporated into everyday living.

Eicher et al (2017) claimed that good usability and user acceptability encourage patients to engage in the training and coping with the new technology. Therefore, it is interesting to investigate usability and acceptability in technology studies.[17] "Usability" is defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use,"[18] while "acceptability" is defined as "the degree of primary users' predisposition to carry out daily activities using the intended device" (p. 73).[19] Arthur (2009, p. 29) defined acceptability for technology as being a "means to fulfill a human purpose,"[20] and stated that technology may be a method, process, or device.

It has been argued that technology mainly has been provided to safeguard older people with MCI/D at home, with less attention given to technology for assisting people in living a good life.[21] Kenigsberg et al (2016) state that assistive technology such as information and communication technologies can provide useful information for assisting older adults with dementia, if tailored to the end users' capacities. However, there is still a need to educate health staff to assess users' capacities, preferences, and motivation for using technology and to evaluate the information and communication technologies to better inform technology developers as to user needs and performance styles.[22] In addition, an important factor concerns creating a supportive network for the user as part of the technology implementation.[23]

The criteria for successfully matching technology to a person's needs and capacities are various. They include health staff's assessment skills in revealing the needs, resources, challenges, and capacities of the user, their ability to successfully individualize the technology to the user's needs and context, and the user's acceptance of technology. An additional issue is the usability of the chosen technology: its maturity, robustness, and predictability as a sustainable solution for the user. The organization of community services and access to proper technology support are also important.[24]

Several pilot projects (Enable,[64] Safe@home,[65] ACTION,[66] COGKNOW,[67] Rosetta,[27] Casas,[68] and NOCTURNAL[69]) have focused on the usability of different types of technologies for older people with dementia and MCI in test laboratories or at home, and found that such technology may be of benefit for both the person with MCI/D and their FC. However, all of these projects concluded that further research is needed, in particular studies that include the users' perspectives on usability and acceptability.

This systematic review aims to investigate primary studies that include people with MCI/D in technology trials.

As recommended for systematic reviews, we outlined three research questions for our literature search:[25]

- What types of technologies have been explored with home-dwelling older adults with MCI/D?
- What is the current knowledge about the usability and acceptability of such technologies with regard to occupational performance, QoL, and human dignity for independent living?
- How are users involved in the reviewed technology studies?

## Material and methods

This systematic review was prospectively registered in PROSPERO (reg 42017058789, May 7, 2017).

### Data sources and search strategy

We searched PROSPERO (www.prospero.org) to check whether others had performed a recent literature review on this topic, before starting the literature search. However, we did not find any earlier or ongoing reviews on this topic.

### Eligibility criteria

The review aimed to identify peer-reviewed primary studies concerning technologies that had been developed and/or explored with home-dwelling older adults with MCI/D above 65 years of age. The search included studies from January 2007 to June 2017. Papers in the English language were included.

#### Inclusion criteria

- Primary studies on technology for older people with MCI/D.
- The title and/or keywords included a type or types of technology; this could be the name of a device or technology mentioned as a system, eg, smart-home system, ambient assistive living (AAL), or artificial intelligence (AI).
- The title and/or keywords included the population (mild) cognitive impairment, dementia, or early phase of dementia, or Alzheimer's disease.

#### Exclusion criteria

- Not target population (MCI/D)
- Not primary study
- Laboratory studies
- Not technology for support of everyday living
- Long-term care/nursing home
- Conference paper, editorial, protocol
- Review articles/meta-analyses
- Books, book chapters.

### Information sources

Five databases were searched for studies: MEDLINE, PsycINFO, Embase, AMED, and CINAHL (Table 1). A systematic literature search must make use of search words that are valid in the thesaurus of each database, eg, Medical Subject Headings terms.[25]

### Search strategy

The strategy was to use the Medical Subject Headings terms related to each database. Table 2 shows an example of the search strategy from the CINAHL database.

### Study selection

Altogether, 359 titles were identified in this literature search. After checking for duplicates, the number decreased to 298. Ovid Auto Updates were checked for relevant titles after the search date June 20, 2016 and until June 17, 2017. One more paper was of interest; however, the full text was not found. Another two papers were detected through other sources; one was sent to us from an earlier project colleague[34] and the other was found in the first author's personal archive of papers on technology and dementia.[32] Thus, the review consisted of 301 papers to be appraised by all five authors, three nurses, and two occupational therapists. Four of the authors completed Steps 1 and 2 in the review process before the fifth author (a nurse) took part from Step 3 onward.

## Review process

The review process had four steps:

- Step 1. Screening titles: The pile with 301 titles was divided into two piles. Two teams, each consisting of one nurse and one occupational therapist, screened titles and keywords for relevance separately. Then, the two authors from each team met and compared their screening results and agreed upon which titles to include and exclude. Thereafter, the two teams met and presented their screening results and elaborated an overview of which titles to include for the next step. In this first screening step, 188 titles were excluded.
- Step 2. Reading abstracts: The two teams read the abstracts of the selected papers and excluded papers not relevant to the research questions. An additional 26 titles were excluded owing to being reviews, editorials, conference papers, nonintervention studies, studies not involving MCI/D, nursing home studies, or books and book chapters. At the end of this step, 87 titles remained.
- Step 3. Reading full-text articles: The first author transferred the 87 titles eligible for full-text review into an

**Table 1** Databases and search words for identifying literature for review, June 20, 2016

| Database | Search terms | No of text results |
|---|---|---|
| MEDLINE | AAL, ai, aid,* alzheimer disease, alzheimer,* ambient, ambient assisted living, artificial, artificial intelligence, assisted, assisted living facilities, assistive, automation, autonom,* body, cognitive, consumer participation, daily, daily living, dement,* dementia, dementia friendly, dementia, multi-infarct dementia, vascular, device,* digni,* diseas,* disorder,* everyday, friendly, frontotemporal lobar degeneration, health, health related quality of life, home, home automation, hrqol, impair,* intelligence, lewy, lewy body diseas,* lewy body disease, life, living, man-machine systems, mci, memory, memory disorder,* memory disorders, memory impair,* mild, mild cognitive impair,* mild cognitive impairment, of participat,* patient satisfaction, personal autonomy, personhood, principle-based ethics, qol, quality, quality of life, related, residential facilities, satisf,* self-help, self-help devices, sensor, sensor technology, sensor-based, sensor-based technology, smart-home, technology, welfare, well-being, wellbeing | 235 |
| PsycINFO | AAL, AI, aid,* alzheimer's disease, alzheimer,* ambient, ambient assisted living, artificial, artificial intelligence, assisted, assistive, assistive technology, automation, autonom,* autonomy, body, client participation, cognitive, cognitive impairment, daily, daily living, dement,* dementia, dementia friendly, dementia with lewy bodies, device,* digni,* dignity, diseas,* disorder,* everyday, friendly, health, health related quality of life, home, home automation, hrqol, human computer interaction, human machine systems, impair,* independence (personality), intelligence, involvement, lewy, lewy body diseas,* life, life satisfaction, living, mci, memory, memory disorder,* memory disorders, memory impair,* mild, mild cognitive impair,* of participat,* qol, quality, quality of life, related, respect, satisf,* satisfaction, self-help, sensor, sensor technology, sensor-based, sensor-based technology, smart-home, social behavior, technology, vascular dementia, welfare, well being, well-being, wellbeing | 93 |
| Embase | Alzheimer disease, artificial intelligence, dementia, mild cognitive impairment, quality of life | 18 |
| AMED | Alzheimers disease, assistive devices, dementia, disability aids, mild cognitive impairment | 1 |
| CINAHL‡ | AAL, ai, aid,* ambient assisted living, IN artificial, artificial intelligence, TC assistive, AF automation, assisted living, cogn,* cognition disorders, cognitive device,* disorders, home, home automation, man-machine systems, mci, mild cognitive impairment, self-help, self-help devices, sensor, sensor technology, sensor-based, DH sensor-based technology, smart-home, technology, technolog,* welfare | 15 |
| Total | | 362 |

**Note:** ‡Search date: September 27, 2016.

Excel file, with columns for data about the aim of studies, number of participants and sample characteristics, study design, types of technologies, and findings regarding usability, effectiveness of technology, and acceptability reported by people with MCI/D and their FCs. The five authors individually read on-fifth of the articles and filled in the data abstraction Excel file. At this step, another 58 papers were excluded for reasons of: not being primary studies (26 studies), being reviews (14 studies), not focusing on technology usability and acceptance (seven studies), participants not having MCI/D (eight studies), and being unable to find the full text of a paper (three studies) (Figure 1). The full-text review ended up with 29 papers.

**Table 2** Example of search strategy

| Search ID | Search terms | Results |
|---|---|---|
| S1 | mci OR mild cognitive impairment | 2,601 |
| S2 | (MH "Assisted Living") | 2,146 |
| S3 | S1 AND S2 | 10 |
| S4 | (MH "Cognition Disorders") OR "cognitive disorders" | 14,274 |
| S5 | S2 AND S4 | 31 |
| S6 | (MH "Technology") OR "technology*" | 81,053 |
| S7 | S5 AND S6 | 1 |
| S8 | S2 AND S6 | 70 |
| S9 | cogn* | 73,515 |
| S10 | S8 AND S9 | 6 |
| S11 | S3 OR S10 | 15 |

- Step 4. Out of the pool of five authors, two and two read the same half of the 29 papers. The first author read all the selected papers. We conducted a quality assessment of papers using the Mixed Methods Appraisal Tool (MMAT)[26] for systematic mixed methods review. Only papers that clearly stated having a mixed method design were sorted under mixed methods.

## Quality assessment of papers

The MMAT for systematic mixed methods review was used to assess the quality of the papers selected for this review. The MMAT has five categories of study design: 1) qualitative; 2) quantitative randomized controlled trials; 3) quantitative nonrandomized; 4) quantitative descriptive; and 5) mixed methods. The MMAT permits the researcher to concomitantly appraise and describe the methodological quality for qualitative, quantitative, and mixed method studies, defined using specific methodological quality criteria.[26] Six of the

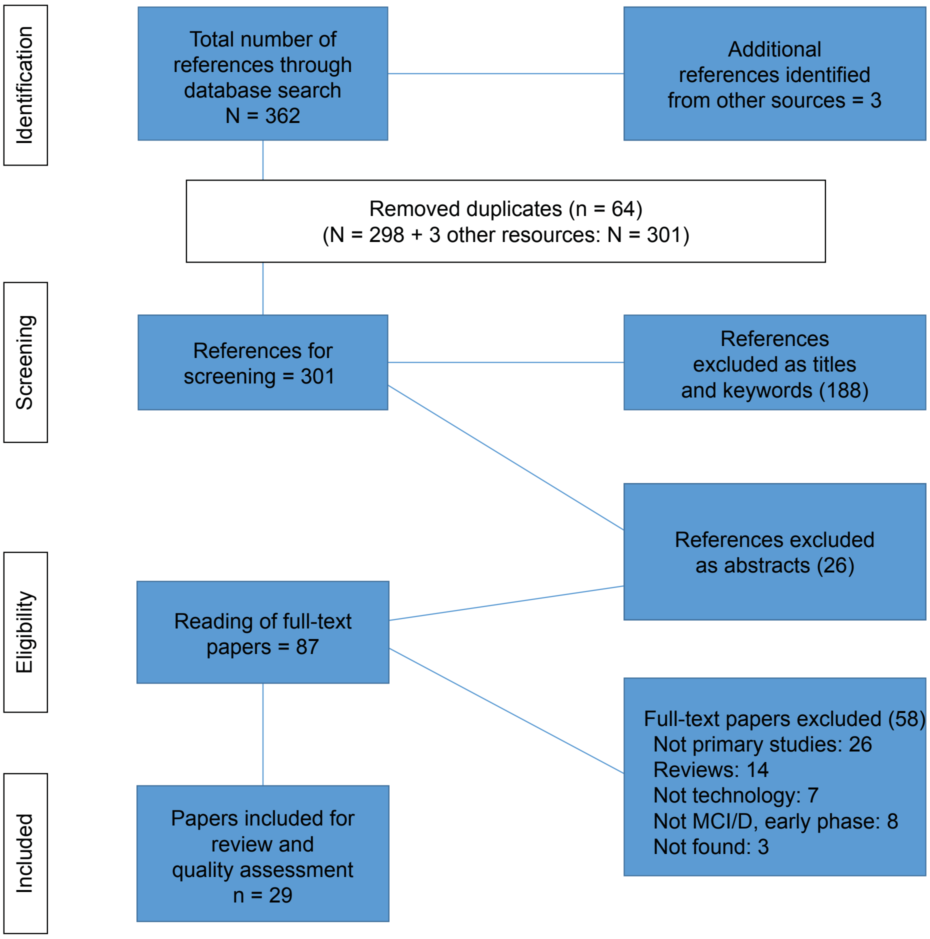

**Figure 1** PRISMA flowchart for selection of papers.

**Note:** Adapted from Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Reprint—Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA statement. *Phys Ther*. 2009;89(9):873–880. Creative Commons license and disclaimer available from: http://creativecommons.org/licenses/by/4.0/legalcode.[25]

**Abbreviations:** PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; MCI/D, mild cognitive impairment/dementia.

29 reviewed papers were rated as high-quality studies, meeting all the quality criteria (four stars); 11 were rated with three stars (meeting 75% of the quality criteria); seven with two stars (meeting half of the quality criteria); and five with one star (meeting 25% of the quality criteria) (Table 3). This allowed us to overview by the quality of the selected studies and provided the opportunity to exclude studies with the lowest quality from the review, or to contrast high-quality studies with low-quality studies. However, in our review, the aim was to obtain an overview of what technologies have been explored among people with MCI/D and their FCs. Therefore, no studies were excluded because of a lack of quality.

## Preparing data abstraction findings for presentation

The following data characteristics were recorded in the Excel files: author, year, country, MMAT score, title; type of technology, purpose of technology; number of participants (MCI/D + FCs/staff); design according to MMAT, duration of intervention, usability/acceptability; impact on QoL, occupational performance, and human dignity; and implications for clinical practice.

According to the template for this paper, data abstraction is presented in three steps: quantitative synthesis, qualitative synthesis, and study designs for user involvement in the 29 reviewed studies.

## Results

The aim of this review was three-fold: to obtain an overview of the kind of technologies that were evaluated with people with MCI/D and FCs in the past decade (2007–2017), and how these users rated the usability and acceptability of such technologies. Further, we wanted to learn about how people with MCI/D and FCs had been involved in the studies reviewed.

**Table 3** Data abstraction sheet

| Author, year, country, MMAT score, title | Type of technology | Purpose of technology | Number of participants (MCI/D + FCs/staff) | Design according to MMAT‡ | Duration of intervention | Usability/acceptability | Impact on QoL, occupational performance, and human dignity | Implications for practice |
|---|---|---|---|---|---|---|---|---|
| **Domain 1: safe walking indoors or outdoors** | | | | | | | | |
| Faucounau et al, 2009, France ** Electronic tracking system and wandering in Alzheimer's disease: a case study[32] | GPS | To promote safe walking; to reduce feelings of anxiety in MCI/D and FCs. Possibility to locate a person | 1 + 1 | 1 | 1 day | The patient's view is essential to understand usability and acceptability. However, it may be difficult to understand owing to progression of disease and language problems. User acceptance: MCI/D found the GPS ugly and unattractive and felt it limited his life. He only agreed to carry it to reassure his wife. The dyad abandoned the trial after 1 day | Walking reduced anxiety in the MCI/D. However, the user saw the GPS as a limitation. The GPS had no impact on the MCI/D because it was rejected | Coordinates were inaccurate and battery quickly discharged. FC expected GPS to increase freedom. However, MCI/D left it everywhere and FC had to search for it. FC wanted to administer the GPS. The end user must be at the center of the codesign process |
| Pot et al, 2012, The Netherlands ** A pilot study on the use of tracking technology: feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers[33] | GPS | For FCs to experience fewer worries and MCI/D more freedom, by use of GPS. Possibility to locate a lost person | 28 + 28 | 4 | Experimental, 3-month trial | 25% MCI/Ds were more often outside independently; 50% MCI/Ds were less worried when going outside alone. 60% FCs said GPS provided more freedom for MCI/Ds. User acceptance: 4 MCI/Ds and 7 FCs experienced less conflict about going out alone. 30% FCs reported more time for other things | QoL is not used as outcome measure as the disease progresses. MCI/D may feel controlled with GPS. GPS will primarily support FCs in caring for the MCI/D | Track and trace technology seem to be promising for MCI/D early stages and FCs. The specific problem for each MCI/D and FC must be defined to identify the most appropriate solution |
| Røhne et al, 2017, Norway ** Wearable and mobile technology for safe and active living[34] | Mobile safety alarm with GPS | Mobile safety alarm with GPS for safety indoors and safe walking outdoors. Possibility to locate a lost person indoors or outdoors | 46 + 46 | 4 | Experimental, 2–9-month trial | 52% MCI/Ds experienced more freedom. The device increased the activity level for already active persons. For inactive persons, a mobile safety alarm is not sufficient to change the activity pattern. User acceptance: MCI/Ds and FCs expressed increased confidence and sense of security | Mobile safety alarm addressed the users' expectations regarding safety and freedom, and this may be interpreted in favor of improved QoL. Occupational performance and human dignity N/A | Easy to use. Easier to press the alarm button and talk with spouse than to bother staff at work. MCI/D can stay longer at home. FC wanted to be part of response team, but not 24 hours a day |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Lanza et al, 2014, Germany **** Autonomous spatial orientation in patients with mild to moderate Alzheimer's disease by using mobile assistive devices: a pilot study[36] | Navigation technology | Navigation technology with photos for wayfinding compared to aerial maps. Prototype based on an HTC smartphone with photo-background of environment and arrows indicating which route to follow. Includes verbal and acoustic prompts. Facilitates autonomous navigation | 14 | 3 | Experimental field trial, 3 routes for each = 42 routes | MCI/Ds managed 20 of 42 routes without other assistance than the navigation device. In 22 routes, MCI/Ds needed assistance for wayfinding. User acceptance N/A | N/A | Autonomous wayfinding is crucial for maintaining living in domestic surroundings |
| Chang et al, 2010, Taiwan ** Autonomous indoor wayfinding for individuals with cognitive impairments[35] | RFID tags and readers, PDA for safe navigation | Indoor wayfinding. PDA with prompts and photos facilitates indoor navigation | 6 | 4 | Experimental pretest 10–20 minutes, 5 trials per person | Successful wayfinding was 93%. 15 of 30 trials were successful without detours, 13 trials were successful with detours. User acceptance N/A | N/A | Successful trials due to effectiveness of PDA user interface and navigation cues |
| McCabe and Innes, 2013, UK *** Supporting safe walking for people with dementia: user participation in the development of new technolology[37] | User requirements and design of a GPS device | User participation in development of GPS to develop a device to promote safe walking. User views on product design and design requirements to commercial partner | 12 + 8 | 1 | Focus groups | MCI/Ds can provide clear opinions about the design and usability of GPS devices. GPS devices are considered helpful by older adults, MCI/Ds, and FCs to support independence and increase self-confidence | The participants perceived being "tagged" with a GPS as a benefit to their QoL and independent living. Occupational performance and human dignity N/A | This was a preintervention focus group and not a trial. Participants were clear that devices should be discrete and not add any stigma |
| **Domain 2: safe living** | | | | | | | | |
| Robinson et al, 2009, UK *** Keeping in Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence[41] | Armband with GPS and electronic notepad | UDC process to develop technologies to create acceptable and effective prototype technologies to facilitate independent living | 10 + 11 and 2 + 1 | 1 | 10 + 4 workshops | Three stages of UCD to secure a user participation process. MCI/Ds are capable of providing valuable feedback in the design process | N/A | Involving people with dementia in the process of participatory design is feasible and could lead to devices that are more acceptable and relevant to their needs |

(*Continued*)

**Table 3** (*Continued*)

| Author, year, country, MMAT score, title | Type of technology | Purpose of technology | Number of participants (MCI/D + FCs/staff) | Design according to MMAT‡ | Duration of intervention | Usability/acceptability | Impact on QoL, occupational performance, and human dignity | Implications for practice |
|---|---|---|---|---|---|---|---|---|
| Augusto et al, 2014, UK * Night optimised care technology for users needing assisted lifestyles[38] | Night-optimized care technology: audio and images by bedside, and sequenced lights to bathroom to reduce levels of arousal during nighttime | To promote safety at home by monitoring and assisting MCI/D with use of different technologies: light, music, visual activity | 4 + 5 | 1 | Experimental, 12 days in 5 households | This system worked very satisfactorily for MCI/Ds and FCs and was found appropriate for older people and MCI/Ds. Most useful functions were light management, pictures, and music. User acceptability N/A | AAL systems aim to increase QoL for older people. Occupational performance and human dignity N/A | Managing risk factors with technology may be a key factor in sustaining living at home. Further end-user validation is needed to assess benefits of system |
| Cavallo et al, 2015, Italy *** An ambient assisted living approach in designing domiciliary service combined with innovative technologies for patients with Alzheimer's disease: a case study[19] | Domiciliary multi-functional smart sensor system (Zigbee) | Network with bed and chair cushion, door monitoring, localization outdoors, personal posture, and cognitive stimulation, to continuously monitor health status, safety, and daily activities in MCI/D at home. Promote safety at home | 14 + 15 staff | 1 | Experimental field test, duration N/A | Usability was evaluated as quite positive, with potential to improve quality of care for MCI/Ds. The technological systems were effective and reliable in monitoring MCI/Ds. Several MCI/Ds, FCs, and staff were skeptical of installation and use of technologies. Regarding the technology, FCs judged the environmental modules positively because they were almost invisible and easy to integrate in the homes. Control interfaces were simple to use | Aims to maintain or enhance QoL. Occupational performance and human dignity N/A | Improved care performance led to QoL for MCI/D, FC, and staff. Involvement of MCI/D and FC in design of technologies was fundamental for participating in the trial |
| Meiland et al, 2012, The Netherlands ** Usability of a new electronic assistive device for community-dwelling persons with mild dementia[28] | Touch screen with sensors and actuators, eg, clock, calendar, radio, lamp control, picture dialing, reminders, | To evaluate user friendliness of a prototype touch screen, for support in memory, social contact, daily activities, and feelings of safety. | 12 + 12 | 1 | Experimental field test, 3–8 weeks | MCI/Ds and FCs rated usability positively; size and sensitivity of screen, and number of buttons were appropriate. Easy to use, except for dialing, which had too many steps. Instability | System may serve as a comfort or well-being service, supporting MCI/Ds to perform enjoyable activities. Human dignity N/A | Authors recommend a user participatory design for future studies, with direct involvement of MCI/Ds and FCs from the start of the development |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | task stepwise prompting, emergency call, outdoor navigation, and safety warnings | Promote coping with everyday living and safety at home | | | | of the technical system was unsatisfying. User acceptance N/A | | |
| Meiland et al, 2014, The Netherlands *** Participation of end users in the design of assistive technology for people with mild to severe cognitive problems: the European Rosetta project[29] | User participation in developing a modular home system for monitoring nutrition, sleep, medication, etc (Rosetta) | To support independence in MCI/D at home | 14 + 36 | 1 | Workshops, semi-structured interviews and expert consultations during three phases: initial development phase, design phase (with mock-up), and fine-tuning phase. Data collection occurred over 15 months | Valuable to investigate different user perspectives (MCI/D, FC, staff) in product development. MCI/Ds and FCs ranked help in case of emergency, navigation support, and calendar highest. Dementia experts ranked monitoring of behaviors to detect changes in functioning highest, in particular nutrition, medicines, toileting, performing activities, and sleep patterns. They assumed that involving users in the development process would add value and increase acceptability of technology | N/A | N/A as this is a preimplementation phase |
| Hattink et al, 2016, The Netherlands *** The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact[27] | Modular home system (Rosetta), day navigator (COGKNOW), Emerge system, and unattended autonomous surveillance system | To monitor and promote safety for MCI/D at home. Relieve burden of care for FC | 20 + 17 | 3 | Explorative evaluation study, with field trials from 2 weeks to 8 months | Testing of usefulness, user friendliness and impact: 10 MCI/Ds and 9 FCs rated Rosetta as very useful in spite of technical problems. 3 FCs felt that Rosetta offered a safer feeling and an extra pair of eyes. User friendliness was rated low owing to technical problems. User acceptability: 5 MCI/Ds find the system too hard to understand. 10 MCI/Ds said the presence of sensors was not stressful at all. Most MCI/D and FC had negative feelings re camera | No significant differences between pre- and postmeasures on QoL, autonomy, and feelings of competence. Occupational performance and human dignity N/A | All participants found Rosetta a useful development for the future. They recommend end users with MCI/D take part in the design of new technologies and evaluation of user friendliness and usefulness. Evaluation of devices should only be performed when the technology meets an acceptable standard of stability and reliability |

(*Continued*)

Table 3 (*Continued*)

| Author, year, country, MMAT score, title | Type of technology | Purpose of technology | Number of participants (MCI/D + FCs/staff) | Design according to MMAT‡ | Duration of intervention | Usability/acceptability | Impact on QoL, occupational performance, and human dignity | Implications for practice |
|---|---|---|---|---|---|---|---|---|
| Riikonen et al, 2010, Finland ** Safety and monitoring technologies for the homes of people with dementia[40] | 29 different safety stand-alone technologies at home, eg, alarms, reminders, memory aids, fall detector, GPS, mobile phone, home surveillance | To prevent risks, assist memory, detect emergencies. Promote safety at home. Relieve burden of care for FC | 25 + 25 | 1 | Preintervention, semi-structured interviews. Participation between 1 and 14 months. Average participation = 7.5 months. Evaluation with interviews and observations | Motion-sensitive light caused confusion in MCI/Ds. MCI/Ds could prolong staying at home, 8 months on average. User acceptability: passive devices that did not require active control or activation by MCI/Ds were preferred | N/A | The technology improved the social care network and reduced stress in FCs |
| Rowe et al, 2009, USA **** Reducing dangerous nighttime events in persons with dementia by using a nighttime monitoring system[39] | Night monitoring system with sensors on bed and exit doors | To prevent nighttime injuries and unattended exits. Sensor provides a text, voice, and alarm when MCI/D leaves bed, and location detection in house | 26 + 26 and control group with 27 + 27 | 2 | Case–control study, 12 months | System was highly reliable. FCs continued to use the system after the project ended. User satisfaction was rated between 4 and 5 on QUEST (0 = not satisfied at all, 5 = very satisfied). User acceptability: high, all chose to keep the system after project conclusion | N/A | Important as FC support. MCI/Ds can stay longer at home if night injuries are avoided. 30% of MCI/Ds with night injuries resulted in nursing home placement |
| Wu et al, 2016, France **** The attitudes and perceptions of older adults with mild cognitive impairment toward an assistive robot[52] | Robot technology to remind MCI/D about events and support daily living | Robots with event and appointment reminder, object-finding, video conferencing, remote surveillance, and companionship. Aims to develop a robot that could support older adults to manage living at home | 5 MCI/D and 15 MCI/D | 1 | Focus group with 5 individuals; interviews with 15 | None of the 20 MCI/Ds considered robots as useful for themselves. They did not consider themselves to need help; 6 emphasized the need for human presence and contact. Some feared that robot use may lead to social isolation | N/A | Older people do not seem ready to embrace robots |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Mehrabian et al, 2015, France *** The perceptions of cognitively impaired patients and their caregivers of a home telecare system[53] | Home telecare technologies to detect emergencies, monitor taking medicines, and provide telecare communication with health professionals | To monitor and support safety at home, plus cognitive stimulation exercises and task reminders | 62 + 30 | I | Interview and questionnaires. Evaluates acceptance of home telecare technologies | MCI/Ds reported the machine to be helpful in emergency cases, but they would not feel safe if left alone in the home with it. They preferred the presence of another person. Many said this machine could be of help if they no longer managed on their own. A common concern was the costs. FCs denied need for help in caring for MCI/D. The results showed some evidence that MCI/Ds and FCs are receptive to the introduction of new telecare technologies | N/A | FCs were more positive toward the machine than MCI/Ds. FCs assumed that a machine could give them spare time and increase their QoL |
| **Domain 3: independent living** | | | | | | | | |
| Lindqvist et al, 2015, Sweden *** Experienced usability of assistive technology for cognitive support with respect to user goals[43] | Assistive technologies for cognitive support, eg, mobile phones, day planner, electronic calendars, item locators, and clock/reminder, which aim to support occupational performance | To support everyday living in general | 14 + 14 | I | Semi-structured interviews, pre- and 3 and 6 months post procurement of technology. 2 periods of 6 months | Constant visible information, in one place, and repetition of messages were useful. Effectiveness of personalized reminders varied a lot and could represent stress. Design and function of buttons could hinder a task. FCs must be active and help run the technologies. Internet and mobile communication must be reliable and ensure contact with manufacturer/support services. User acceptance: technology that easily fits into the user's context increases user's sense of control and thus acceptability | N/A | Increases control of own day. Being in control of assistive technology is important for successful use. Customization to each user must include user's own perceptions on own goals |

(*Continued*)

**Table 3** (*Continued*)

| Author, year, country, MMAT score, title | Type of technology | Purpose of technology | Number of participants (MCI/D + FCs/staff) | Design according to MMAT‡ | Duration of intervention | Usability/acceptability | Impact on QoL, occupational performance, and human dignity | Implications for practice |
|---|---|---|---|---|---|---|---|---|
| Malinowsky et al, 2010, Sweden *** Ability to manage everyday technology: a comparison of persons with dementia or mild cognitive impairment and older adults without cognitive impairment[44] | ETs, eg, coffee machines, microwave ovens, computers, cash machines | To assess and compare the ability to manage ETs among older adults without cognitive impairment and those with MCI/D | 71 and 45 older adults | 4 | Observation and interview with all participants using META assessment tool | MCI/Ds had more challenges to manage ETs compared to older adults, which could imply that they are at risk of being excluded from participation in everyday activities and of losing their independence. User acceptability N/A | N/A | It is important to assess ability to manage ETs, when assessing ability to perform everyday activities. Assessment of ability to perform complex ADLs should be incorporated in the clinical evaluation of MCI and mild dementia |
| Malinowsky et al, 2012, Sweden **** Individual variability and environmental characteristics influence older adults' abilities to manage everyday technology[45] | ETs, which are relevant and somewhat challenging, eg, mobile phone, iron, automatic telephone services | Observation of use and management of a self-chosen ET, to assess quality of occupational performance | 68 and 42 older adults | 4 | Observation of managing at least two ET at home, 1 day for each participant | Intrapersonal capacity varied. Adaptation of environment could simplify management of ETs as support. Familiarity was not found to be significant in the analysis but may be in real life. User acceptability N/A | N/A | The "person–environment fit" is dynamic. Adapting social and physical environment can facilitate MCI/Ds' management of ETs. Motivation is crucial for continued use of ETs |
| Lancioni et al, 2009, Italy *** Persons with mild and moderate Alzheimer's disease use verbal-instruction technology to manage daily activities: effects on performance and mood[30] | Verbal instruction technology, with photo-cells and light-reflecting paper, and an MP3 player | To remind people how to perform daily activities, eg, preparing a snack or shaving | Study I: 6; Study II: 3 | 4 | Observational study. Video films to assess mood | N/A | Improvement of mood can be seen as improved QoL. Indices of happiness were observed in 7 of the MCI/Ds during activity engagement. Verbal instruction technology improved occupational performance by giving MCI/Ds the opportunity to recapture the activity. Human dignity N/A | Data suggested that verbal instruction technology may recapture activity engagement and improve the participants' mood, which can, in turn, influence FCs and social context. This may be a method for people with a mild to moderate degree of Alzheimer's disease |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Lancioni et al, 2010, Italy **** Technology-aided verbal instructions to help persons with mild or moderate Alzheimer's disease perform daily activities[31] | Verbal instruction technology, with photo-cells and light-reflecting paper, and an MP3 player | Same technology for Studies I and II: a control unit, which activated an MP3 player giving an instruction; a photo-cell that registered movement, which activated the next interval instruction. Length of intervals was individually programmed, based on earlier observations of participants | Study I: 7; Study II: 4 | 1 | Experimental, Study I: setting a table or preparing coffee, took place at participants' homes.<br>Study II: making a salad, took place at a day center | N/A | 5 of 7, and 1 of 4, people showed higher indices of happiness during activity trials versus nonactivity periods. Verbal instructions supported by basic technology seem to support MCI/Ds' recapture performance of daily activities. Improved performance was statistically significant for all 7 in study I. Human dignity N/A | Activity engagement improved mood and clear signs of happiness |
| Boman et al, 2014, Sweden **** Users' and professionals' contributions in the process of designing an easy-to-use videophone for people with dementia[42] | Design-stage concept for an easy-to-use videophone; evaluation for product design and demand | To simplify dialing: videophone instead of mobile phone/ landline | 6 + 18 | 1 | 5 focus groups | MCI/D meant it was important to start early with the device. Users did not want it before they really needed it. FCs expressed that videophone should be presented as fun to use instead of an aid | Being able to see each other as well as the surroundings could add meaning to the communication and provide more things to talk about was seen as favorable for QoL. Occupational performance and human dignity N/A | Videophone can be a useful tool for improving communication and add QoL |
| **Domain 4: entertainment and social communication** | | | | | | | | |
| Astell et al, 2010, UK * Using a touch screen computer to support relationships between people with dementia and caregivers[21] | Touch screen with photos, music, and video clips (CIRCA) | To engage in reminiscence experience and to improve communication and relationship between MCI/D and staff. Reminiscence for joy and entertainment | Part I: 40 + 40;<br>Part II: 11 + 14 | 4 | Part I: one-to-one interview, focus group, demonstration with paper/ prototype. Trial: 2 × 20 minutes one-to-one sessions with CIRCA, compared to traditional reminiscence | Tablet could improve MCI/D/staff relationship compared to traditional reminiscence work. It provided new topics, more choices, and supported conversation. User acceptance: an indication of enjoyment was synchronous laughter and singing | N/A | Empowers MCI/D and redresses the status hierarchy during the course of interaction. Staff job satisfaction |

(*Continued*)

**Table 3** (*Continued*)

| Author, year, country, MMAT score, title | Type of technology | Purpose of technology | Number of participants (MCI/D + FCs/staff) | Design according to MMAT[‡] | Duration of intervention | Usability/acceptability | Impact on QoL, occupational performance, and human dignity | Implications for practice |
|---|---|---|---|---|---|---|---|---|
| Lim et al, 2013, Australia * Usability of tablet computers by people with early stage dementia[48] | Tablet for leisure activities, joy, and social contact | To assist in daily living and be a source of leisure activities and social networking. For joy and social contact | 21 + 21 | 4 | 7 day trial; 30 minutes training before bringing the iPad home | Almost half of MCI/Ds (43%) used the tablet independently for more than 10 minutes/day, which proved to be helpful for FCs. 18% of MCI/Ds expressed a clear disinterest. 33% of FCs found the iPad not helpful, whereas 19% found it extremely helpful. The rest rated some degree of helpfulness. Helpful if the MCI/D is able to engage with the applications | N/A | User needs must be considered on a case-by-case basis, along with access to informal support. Authors recommend larger trials to determine usefulness of tablet computers |
| Kerssens et al, 2015, USA ** Personalized technology to support older adults with and without cognitive impairment living at home[46] | Touch screen with personalized photos, music, and messages (Companion) | To provide meaningful engagement. For joy and entertainment | 7 + 7 | 1 | Trial for 24–57 days, median = 31 days | The majority enjoyed the touch-screen shows, which brought back memories and helped relaxation and joy. 2 of 6 MCI/Ds did not use touch screen independently. User acceptance: 5 dyads kept the Companion for 45 days or more. 2 dyads kept it for 33 and 65 weeks, respectively | Results indicate that Companion was easy to use; it facilitated meaningful and positive engagement and simplified FCs' daily lives. This may be interpreted as positive responses for QoL and occupational performance. Human dignity N/A | The Companion may help to manage neuropsychiatric symptoms and offer respite for FCs at home. FCs were positive, and it made helping their spouse with MCI/D easier |
| Leuty et al, 2013, Australia **** Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology[47] | Touch screen for engaging in creative activities (ePAD) | To encourage engagement in painting by artificial intelligence providing prompts when monitoring MCI/D's level of engagement | 6 + 6 | 5 | 1 hour session × 5 weeks for each participant | MCI/D expressed excitement about novelty of the device. Easy to use with practice. Prompts were not noticed by MCI/Ds. ePAD was engaging. Staff remained uncertain as to whether MCI/Ds were truly satisfied with the ePAD | N/A | MCI/Ds enjoyed painting with ePAD, and they were pleased with the art they created. ePAD may foster meaningful art expression |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| de Oliveira Assis et al, 2010, Brazil * Evaluation of cognitive technologies in geriatric rehabilitation: a case study pilot project[50] | Digital activity board, calendar, and routine organizer | For exercises in cognitive rehabilitation programs. For joy and cognitive stimulation | 1 + 1 | 1 | 4 months | 50 minutes sessions twice a week. Specialists rated usability positively. MCI/D and FC opinions not reported. User acceptance N/A | N/A | Increased the points on MMSE after intervention |
| Suijkerbuijk et al, 2015, The Netherlands *** Seeing the first person perspective in dementia: a qualitative personal evaluation game to evaluate assistive technology for people affected by dementia in the home context[51] | Tablet with game/evaluation and dynamic lamp | Personal evaluation game for evaluating a dynamic lamp to improve sleep/wake cycles for 4 participants. iPad for joy and cognitive stimulation | 12 + 12 | 1 | 4 months | None of the MCI/Ds or FCs reported discomfort during the intervention. MCI/Ds and FCs found the game a pleasure. The tablet questionnaire generated only data from FCs. User acceptance: feelings of involvement and motivation appeared | N/A | MCI/Ds may feel reminded of lost abilities or fulfillment due to contribution to well-being of future generations of MCI/Ds |
| Browne et al, 2011, UK ** SenseCam improves memory for recent events and quality of life in a patient with memory retrieval difficulties[49] | Camera that automatically takes photos when present at special events | To jog autobiographical memory of special events. For joy and cognitive stimulation | 1 + 1 | 1 | 10 months | MCI/D's memory for recent events improved, as did psychological well-being (QoL) and her relationship with her husband. User acceptance: enhanced memory, QoL, and relationship with spouse | QoL improved | Memory rehabilitation programs should include methods for improving autobiographical memory |

**Notes:** [‡]MMAT: 1 = qualitative; 2 = quantitative randomized controlled (trials); 3 = quantitative nonrandomized; 4 = quantitative descriptive; 5 = mixed methods. Star ratings: the study met ****all of the quality criteria, ***75% of the quality criteria, **50% of the quality criteria, *25% of the quality criteria.

**Abbreviations:** AAL, ambient assisted living; ADLs, activities of daily living; ETs, everyday technologies; FC, family carer; GPS, Global Positioning System; MCI/D, (person with) mild cognitive impairment/dementia; META, Management of Everyday Technology Assessment; MMAT, Mixed Methods Appraisal Tool for systematic mixed methods review; N/A, not applicable; PDA, personal digital assistant; QoL, quality of life; QUEST, Quebec User Evaluation of Satisfaction with Assistive Technology; RFID, radio frequency identification; UCD, user-centered design.[62]

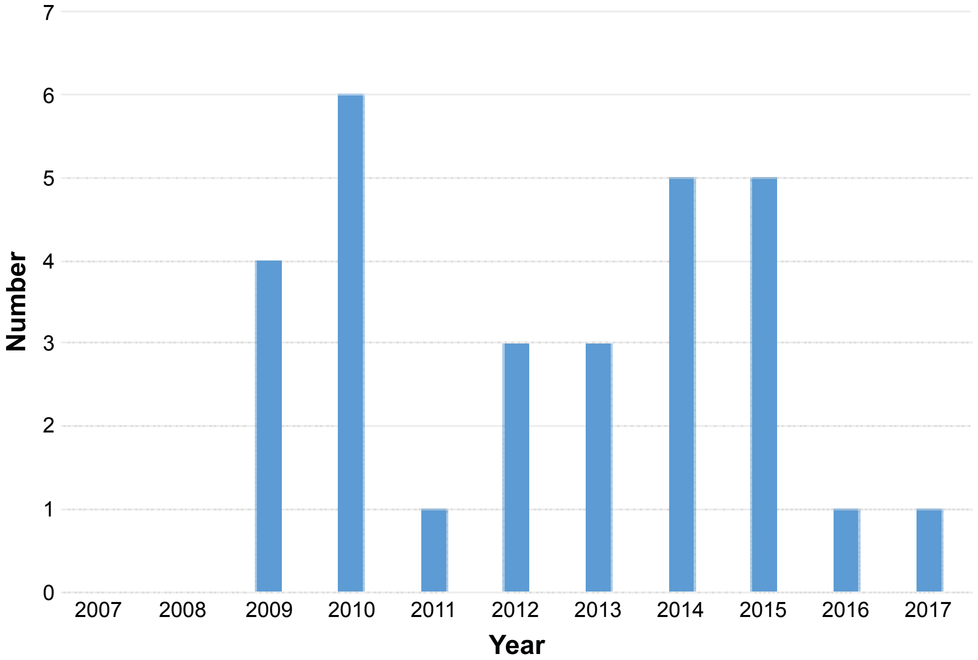

**Figure 2** Number of papers per year.

## Characteristics of included studies

The number of papers published per year varied throughout the past decade and had a peak in 2010 with seven published papers (Figure 2).

The 29 included papers consisted of 17 qualitative studies, one quantitative randomized controlled trial, two quantitative nonrandomized studies, seven quantitative descriptive studies, and two mixed methods studies. The studies mostly took place in Western countries (Figure 3), and three papers were connected to the COGKNOW and Rosetta projects.[27–29] Another author had published more papers on the same technology.[30,31]

The reviewed papers explored several different technologies in conjunction with persons with MCI/D and their FCs. Most of the studies took place in Europe. However, Taiwan, Brazil, the USA, and Canada were also represented, and all these studies contributed to greater knowledge in the field.

## Study participants

The participants in the 29 included papers were older people with MCI or dementia, above 65 years of age. Different terminologies described these participants: older adults with cognitive impairment, Alzheimer's patients, persons

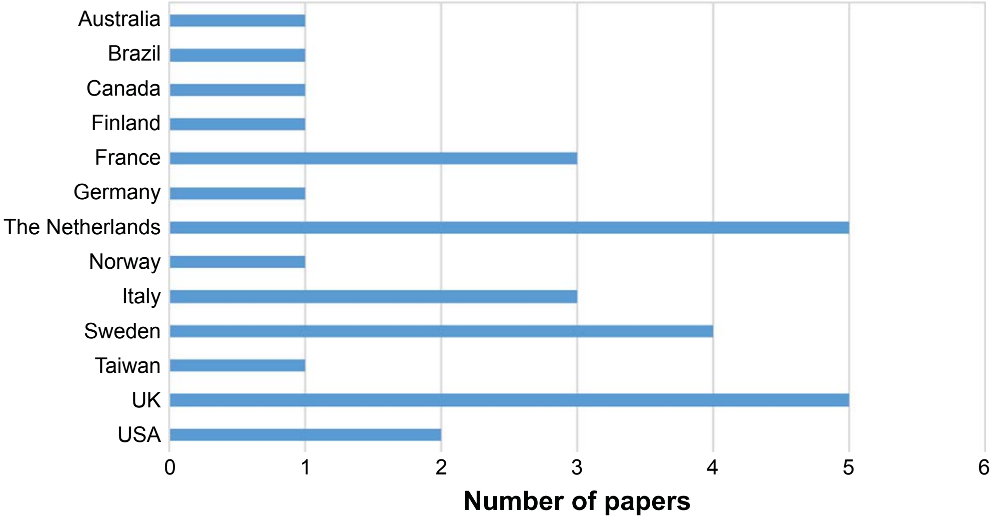

**Figure 3** Overview of papers per country 2007–2017; for papers written in collaboration with authors from other countries, only the first author's country is counted.

with dementia, users, care recipients, etc. In this review, all primary participants in the target group, people with cognitive impairment due to dementia or MCI, are called "people/persons with MCI/D." In total, 665 people with dementia and 83 people with MCI had been involved in the 29 technology studies.

The FCs were named informal carer, spouse, relative, significant other, etc. In this paper, we use the expression FC for all. In total, 248 FCs took part in the 29 studies.

Health workers were named formal carer, nurse, therapist, home-care worker, etc. We chose the term "staff" for all professional health personnel. In total, 55 staff members and 23 others (older adults, dementia experts, volunteers) had taken part in the 29 studies.

## What types of technologies have been explored with older people with MCI/D?

The first research question was to establish an overview of the types of technologies that had been evaluated with older adults with MCI/D and their FCs in everyday life. After listing the technologies studied, we grouped them into four domains according to aims and purposes: 1) safe walking indoors and outdoors; 2) safe living; 3) independent living; and 4) entertainment and social communication.

Columns two and three of Table 3 provide an overview of the types of technology and their purposes, and thus answer the first research question.

Domain 1 presents six papers on technology either for locating persons[32–34] or for supporting navigation,[35,36] or on how to involve users in the product design of devices for location and navigation.[37] Domain 2 presents 10 papers on technologies for enhancing safe living, with five studies focused on monitoring systems,[19,29,38–40] including two papers particularly describing technology for nighttime security.[38,39] Further, one paper investigated "stand-alone" technologies to enhance safe living,[40] and one study investigated user requirements prior to the development of a safety wristband.[41]

Domain 3 presents six studies that explored possibly improved occupational performance with the help of technology.[30,31,42–45]

Domain 4 presents seven studies on technologies for entertainment and leisure. Four papers explored the use of touch-screen tablets (iPads).[21,46–48] One study explored using a camera to document personal events with the intention of reminding the person of (jogging the memory for) recent events,[49] and one study used a digital board with a touch screen for both cognitive stimulation and joy.[50]

In general, some technologies were multifunctional and could therefore belong to more than one domain. Seven studies described user participation with MCI/D and their FC to identify user requirements, as recommendations for development of design of products (see "How users were involved in technology development," later in this section). Only one study compared the user friendliness of two different strategies for indoor navigation for people with MCI/D; namely, a radio frequency identification navigation device (a device communicating with radio frequency signals) compared with an aerial map.[36] Suijkerbuijk et al (2015) asked users with MCI/D to evaluate their use of a dynamic lamp, which aimed to improve sleep/wake rhythms, by answering questions playing a personal evaluation game on an iPad ("Angenaam") (eight couples) or answering a questionnaire using a tablet (four couples).[51]

## Current knowledge about the usability and acceptability of the explored technologies

Our second research question was about the usability and acceptability of the technologies with regard to occupational performance, QoL, and human dignity for independent living. Column seven in Table 3 presents the knowledge on usability and acceptability in the reviewed studies, while column eight presents findings related to QoL, occupational performance, and human dignity.

## Usability and acceptability in the reviewed studies

Many of the studies explicitly aimed to evaluate the usability of the technologies that were explored.[19,28,38,40,43,47,49,51] Cavallo et al (2015) found that perceived usability could improve QoL for people with MCI/D and their FCs.[19] Cavallo et al (2015),[19] Leuty et al (2013),[47] and Lindqvist et al (2015)[43] used the same definition as this review regarding usability. Meiland et al (2012, p. 584) explained usability in terms of "user friendliness" (gratifying, easy to manage), "usefulness" (meeting the needs and desires of people with dementia), and "effectiveness" in promoting autonomy, coping, and QoL.[28] Lindqvist (2015, p. 138) operationalized the concept of usability to include three factors: the user's desired goals, the hindering task according to the user, and the chosen assistive technology.[43] Some researchers used the term "user friendliness" instead of usability.[28,42] Boman et al (2014, p. 170) stated that acceptance of technology has been associated with "the ability to maintain a certain desired self-image of being competent."[42]

None of the studies explicitly evaluated the acceptability of technologies. Some studies reported degrees of acceptance in people with MCI/D and FCs; for example, finding a device ugly could be interpreted as being not accepted,[32] while experiences of fewer worries for the person with MCI/D or spare time for the FC[33] could mean that the device is accepted.

## Usability and acceptability of technology that aims to provide safe walking

Safe walking outdoors refer to the opportunity for people with MCI/D to go for walks alone. Safe walking involves many aspects: strategies for wayfinding, the ability to return to the starting point, physical strength/endurance, balance, judgment of one's own physical capacity, vision, footwear, the surface of the outdoor area, and surrounding characteristics, such as woods, beaches, parks, or cities with heavy traffic, etc. Three papers included the GPS as the subject for technology evaluation.[32–34] The studies from 2009 and 2011 included a GPS localization device, whereas the study from 2017 included a wearable arm–wrist mobile safety alarm with GPS and two-way communication, which can be used both indoors and outdoors, 24 hours a day. GPS is a technology mainly used for the localization of a person. One dyad case study found that the user agreed to carry the GPS only to reassure his wife, and he perceived the GPS as a limitation rather than an instrument of freedom, as his wife did. The couple stressed that the device should not be stigmatizing but rather unnoticeable and support autonomy.[32] FC users of GPS technology expressed fewer worries and reported that the technology was easy to use.[33] Røhne et al (2017) found that people with MCI/D who had a mobile safety alarm were able to stay longer at home.[34] Two other studies explored navigation technologies for indoor wayfinding.[35,36] Chang et al (2010) tested a prototype of near-field radio frequency identification technology, having six people with MCI/D find their way from A to B in a hospital setting,[35] and Lanza et al (2014) compared the use of mobile navigation technology with photographs to ordinary aerial maps for autonomous outdoor wayfinding within a large hospital campus.[36] Both studies found that the participants with MCI/D managed wayfinding in approximately half of the attempts. Therefore, the evaluated technologies seemed promising, given that repeated training sessions are available.

## Usability and acceptability of technology for safe living

Five studies explored integrated monitoring systems, also called AAL, that aim to support independent living and detect risks/events in the home to send alerts in case of accidents.[19,27–29,38,39] The purposes of these technologies varied somewhat, including to "support MCI/D at home,"[27] to create "safe environments and prevent injuries and avoid unattended exits at night,"[39] and to "monitor health status, safety, and activities of daily living".[19] AAL could also imply a strategy to decrease the burden of care for FCs[40] and to postpone the need for transition to a nursing home.[39]

The AAL systems could also offer multimodal assistive services, with cognitive stimulation[38] providing reminders to the person with dementia about events or tasks to carry out, and facilitating communication with family and friends.[28] The AAL systems normally required internet-based computers.[28] None of the papers presented perceptions of these AAL technologies from the perspective of those with MCI/D.

One paper[40] presented user experiences with different "stand-alone" technologies that are not a part of a system but that still aim to contribute to safety at home by preventing risks, detecting emergencies, and assisting the memory of persons with MCI/D. Riikonen et al (2010) found that such technologies contributed to decreased stress in FCs. People with MCI/D seemed to accept best passive devices that did not require active control or activation.[40]

## Usability and acceptability of technology for independent living

Some technologies aimed to promote independence and autonomy by compensating for lost cognitive skills, for example, by providing reminders via a sound, a light, and/or a written or spoken message. Because cognitive impairments affect occupational performance, compensatory technology can be useful for some. Lancioni et al (2010) tested verbal instruction technologies to remind persons with MCI/D about the steps in a given task, and this strategy seemed to help them recapture the performance.[31] One study presented occupational performances of self-chosen, everyday technologies,[45] and found that both intrapersonal capacities and environmental characteristics influenced the performance of handling the technology.

## Usability and acceptability of technology for entertainment and social communication

Six studies tested computer tablets and iPads with people with MCI/D.[21,46–48,50,51] The purposes were mainly to provide meaningful engagement[21] and cognitive stimulation from photos, music, and games.[46,48,50] De Oliveira Assis et al (2010) found that 50 minutes of cognitive stimulation programs twice a week positively influenced cognitive functioning, as demonstrated with pre–post measures on the Mini-Mental State Examination.[50] Another study used tablet computers in art activities, which was appreciated by participants with MCI/D. They expressed excitement about the novelty of the device and satisfaction with the art they made.[47] The therapists, however, remained uncertain as to whether the MCI/D participants were truly satisfied with the tablet computers.[47]

Astell et al (2010) evaluated tablets as social communication and reminiscence devices between staff and people with MCI/D. They compared the use of tablets to traditional reminiscence work, and found that the tablets increased the interaction between staff and residents, empowering people with MCI/D and redressing the status hierarchy during the course of the interaction, as well as leading to increased job satisfaction in staff members.[21]

Tablets were also explored regarding entertainment and joy. Kerssens et al (2015) found that the majority of seven persons with MCI/D enjoyed the touch-screen shows, which brought back memories and helped with relaxation and joy. However, two of the six persons with MCI/D did not use the touch screen independently.[46] Lim et al (2013) found in their study of 21 people with MCI/D that almost 43% used the tablet independently for more than 10 minutes/day, which proved to be helpful for FCs. However, 18% of the people with MCI/D expressed a clear disinterest. The study concluded that user needs must be considered on a case-by-case basis, along with access to informal support.[48]

## How users were involved in technology development

This subsection answers the third research question: How are users involved in the reviewed technology studies?

One major finding, represented in all 29 papers, emphasizes user involvement in preimplementation technology design and development and feasibility testing. Several studies highlighted the need to identify and confirm user needs in older adults with MCI/D in order to develop useful technologies, as earlier studies had mainly asked proxy persons these questions. Potential users of the technology include persons with MCI/D, their FCs, and staff, and they took all part in the studies we reviewed (see column four in Table 3).[28,29,37,38,41,42,52] Some studies showed prototypes or mock-ups of the technology in question, in order to facilitate users' responses on perceptions and opinions.[29,41] Involving people with dementia in the process of participatory design is feasible. This could lead to the development of devices that are more acceptable and relevant to their needs.[41] According to Cavallo et al (2015), the involvement of persons with MCI/D and FCs in the design of technologies was fundamental for participation in a trial.[19] Meiland et al (2014)[29] and Hattink et al (2016)[27] explicitly recommended user participation in the design of new technologies and evaluation of their user friendliness and usefulness.

The study designs for user involvement varied. The most frequent design was the focus group. Five studies carried out focus groups for MCI/D and four for FCs.[29,37,38,42,52] Two studies used workshops as the method for user engagement,[29,41] and six studies used observation as method.[28,40,43–45,53] Most studies used more than one method for data collection (see column five, Table 3).

Nine studies were experimental trials, which often started with a workshop or focus group with MCI/D participants and FCs/staff to identify user needs and requirements.[19,29,38] Thereafter, the same participants were invited to give their opinions on a mock-up or prototype device installed at home, in order to evaluate usability and acceptance. The primary aim was to hear the voice of the MCI/D participant and to learn about the usability of the device. Only three studies were randomized controlled trials, with a pre–posttest design and control group.[29,36,39]

Some studies underlined the necessity of tailoring the technology to the user's needs and preferences.[33,43,48] Pot et al (2012) stated that the specific problem for the person with MCI/D and FC must be defined, in order to identify the most appropriate solution.[33] During the user-needs assessment, it is thus important to assess the user's ability to manage the everyday technology that they already possess and are familiar with before any new technology is introduced.[45] According to Malinowsky et al (2010), intrapersonal skills and environmental characteristics influence performance and management of technologies, but at the same time, the "person–environment fit" is dynamic, ie, it will change over time.[44] Adaptation of the social and physical environment can facilitate the management of everyday technologies by people with MCI/D.[44] Further, each user's customization to the technology always depends upon the self-perception of his or her own goals.[43] If the technology was evaluated as positive, it proved successful in improving the social (care) network and reduced stress in FCs.[40]

# Discussion

This review aimed to obtain an overview of the types of technologies being explored with persons with MCI/D, identifying the usability and acceptability of such technologies with regard to occupational performance, QoL, and human dignity, as well as to learn how user involvement of those with MCI/D and FCs was achieved in these studies.

## Types of technologies

The reviewed studies showed a wide range of technologies, such as GPS, monitoring systems, tablets, touch-screen computers with calendar, clock and task reminders, verbal instruction technology, and robot technology, which we categorized into four domains related to the purposes of everyday living: safe walking, safe living, independent living, and entertainment and social communication. However, the technologies within the domains may overlap. For example, a stove timer with the purpose of safety at home can be a "stand-alone" device or a part of AAL technologies, with the potential to send an emergency alarm. Likewise, a digital calendar for supporting a person's memory may be a separate device, as well as part of a digital structure enhancing safety at home. Sometimes, technologies may benefit others than the person with dementia. Gibson et al (2016, p. 7) conducted a scoping review and found 171 types of assistive technologies, which they divided across three areas: "assistive technology used 'by', 'with,' and 'on' people with dementia."[54] Another divide can be between "active" and "passive" technologies,[63] depending on the person with MCI/D's role as a technology user. Lindqvist et al (2015) stated that the person with MCI/D's perception of the extent to which their own goals have been achieved must be included to assess the usability of a product or solution.[43]

## Usability and acceptability

Technology that is simple to use and enables a person with reduced cognitive capacity to cope independently with daily tasks and obligations is classified as being usable and acceptable. The usability of technology was defined as user friendliness, usefulness, and effectiveness,[28] and by the extent to which a product can help a user to achieve a specific goal. User-friendly technologies are thus a means to enable older adults and people with reduced capacities to engage in activities and participate in society, equal to other citizens. McCreadie and Tinker (2005) found that a technical device must address a person's "felt need" in order to be perceived as useful.[55] This is in line with Peek et al (2014, p. 242), who found that a perceived personal need for technology was the most frequent factor mentioned for technology use and acceptance.[56]

Several authors referred to the International Organization for Standardization's definition of usability.[19,43,47] However, it may be interesting to discuss usability related to utility and identity. Ravneberg and Söderström (2017) stated that usability is used synonymously with user friendliness and easy to use/learn, while utility is the functionality of the technology, and identity is connected to a user's opinion of whether the device/aid matches the user's personal character and reflects the person's identity.[15] These aspects may be difficult to distinguish and will influence the acceptability of a device. The degree to which the technology was accepted depended upon the end users' experiences of reliability and stability of the technical performance of the device.[28] Acceptability also considers whether the device matches the user's identity.[15] This may explain why users may hesitate to wear a device (eg, GPS) in their belt or pocket. The device may make the user feel stigmatized and result in rejection of the device. Some older adults will perceive a technology as being more relevant for other elderly people with more extensive functional impairments[56] and be less motivated to use it themselves. One major consideration is the ability and motivation of the person with MCI/D to accept and incorporate such technologies in their everyday living.[24] A Swedish study that found that older adults with MCI strived to downsize their approaches toward everyday activities, owing to changing abilities. They achieved this by using familiar technologies in a new way, by replacing old technology with something simpler. Sometimes they chose to stop using technology, although they needed it, or they had a desire to update their technology use.[57] However, downsizing use of technologies will become a challenge when the health services seek to implement new technologies. Older adults may be reluctant to use new technology that they not yet are familiar with.[58]

However, one finding was that usability of technology often was rated low at the beginning of the project,[19] which may be associated with late or nonadopters of technologies, or with skepticism toward new technologies. Also, it could be that FCs were unaware of the potential of the technologies and feared that they would not be appropriate for the person with MCI/D. Peek et al (2016, p. 4) revealed that older adults stated that such technologies were not necessarily intended for them, but rather "for others, less healthy older people."[58]

Engaging older adults in a preimplementation study thus risks obtaining a "prototypical result," according to Peek et al (2014).[56] Posttrial evaluation of usability and acceptability was more positive as users had experienced the technologies' potential to improve the quality of care.[19]

A clinical trial allowing end users to try the technology at home, in real-life situations, seemed to be an eye-opener by giving older adults the opportunity to realize how technology may, or may not, be of benefit. Therefore, clinical trials with end users are needed to evaluate the usability and acceptability of technologies.

Surprisingly, less than half of the 22 reviewed studies on technology trials reported the perceptions of the participants with MCI/D on the usability and acceptability of the explored technologies. The proxy opinions of FCs and staff were mainly reported. This finding leads us to ask why the opinions of the participants with MCI/D were so scarcely reported.

## User involvement in the studies

User involvement was included in all the reviewed studies, which involved both persons with MCI/D and their FCs or staff. User involvement requires a bottom–up approach: that developers and researchers assess persons' experiences with technology tried at home and consider those opinions when furthering development work. The evaluation of a product or solution with potential end users is a way of ensuring that the device works sufficiently for the target group. Some of the studies highlighted that the technology must be tailored to the user in order to be useful and usable.[19,43,45,52] The study by Robinson et al (2009) contained a three-stage user-centered design (UCD) process involving persons with MCI/D and FCs[41] (UCD was introduced by Rubin in 1994,[59] as a method to explore user needs and requirements and put the user at the center of the design process.). Robinson et al (2009) concluded that user engagement resulted in products that were more acceptable and relevant to the users' needs.[41] Augusto et al (2014) implemented technology in accordance with UCD principles, to monitor the sleep/wake patterns in five households dealing with persons with dementia and their FCs. Thereafter, they developed an appropriate technological solution together. This exploration informed improved design of user interfaces.[38]

Even if it is challenging to include people with MCI/D in a user-driven development process, it is worthwhile.[42] Meiland et al (2012) recommend a user participatory design with direct involvement of people with MCI/D and FCs, from the beginning of the project and through the whole process.[28] McCabe and Innes (2013) stated that user engagement in product development provided valuable inputs on how GPS might be designed and used.[37] They stated that successful devices are those that give consideration to real-life use and concerns from potential users.[37] In other words, developing user-friendly interfaces, which are found to be usable and acceptable by the end users, requires user involvement. However, the terms "user" or "end user" might include both persons with MCI/D and FCs in the reviewed trials. We found it difficult to distinguish between the opinions of the person with MCI/D and those of the FC or staff on the technologies tried at home. Further research should investigate and report possible discrepancies between these parts.

Finally, the duration of the intervention and the study design influenced results on assessing usability and acceptability, since MCI/D usually progresses over time. Five of the studies lasted for less than 2 months, and eight lasted 6 months or longer. In one study,[32] the person with dementia and his spouse left the trial after only 1 day. No information or training was provided prior to the trial, which in other studies seemed to be important. For how long should people with MCI/D try a product in order to be able to appraise it?

Attitudes toward MCI/D are changing, and nowadays people with MCI/D are more aware of their needs and rights. The European Dementia Working Group's slogan, "Nothing about us without us,"[60] underscores their desire for user participation in all service planning and authorizes their expression of own needs and preferences for technological or human support. The findings of this review clearly underscore the value of user involvement in technology development and clinical trials. More research is needed on what happens when technology is introduced to people with MCI/D and their environments, and whether technology will accommodate the needs and wishes stated by people with MCI/D and their FCs in a just and ethical way.

## Possible biases

First, our search strategy may contain biases. We had many search words, which were challenging to include in one search. The search stories became long and we had to put extra effort into screening more titles for relevance.

Most of the studies reviewed had small sample sizes, and 10 out of the 29 studies had 10 participants or fewer. This is often criticized as a possible bias because generalization of results is not possible. However, our aim was to explore the width and depth of technology interventions, and small sample sizes nevertheless provided rich data. Further, multiple publications from the same authors/projects[24–27,38,39] may also skew the impression of the extent of the research.

Another possible bias is the close and regular relation between the participants and the researchers over time, as mentioned by Browne et al (p. 719).[49] Since many of the experiments had a pre–post design, and follow-up after a period, many participant–researcher relations may have developed beyond a neutral and formal attitude, to a more informal and friendly relationship. However, this is difficult to avoid in a participatory action research approach, where the research process relies on collaboration between the researcher and participants.[61]

One bias may be the use of the MMAT matrix for quality assessments of the 29 eligible papers. Five team members rated one-fifth of the papers individually, before comparing the assessment results with another team member. If discrepancies arose, a third team member was involved in the decision. Even though we chose not to exclude any of the papers owing to low quality, the quality assessment provided an overview of the quality of the papers included in our review.

## Conclusion

The research about technologies to support people with MCI/D in everyday living seems optimistic, and a wide range of technologies has been evaluated at home with persons with MCI/D and their FCs. A major and representative finding was the importance of including those with MCI/D and their FCs in research, in order to learn about required design features to enhance usability and acceptability. Few studies reported findings on people with MCI/D's perceptions of the acceptability and usability of the technologies or on the consequences of technology for QoL and occupational performance. None reported the consequences of technology use relating to human dignity.

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## Author contributions

TH, first author, PhD student, led the review, took part in the literature searches, screened half of the titles, and reviewed all abstracts before a full-text reading of all included papers. She prepared and wrote all versions of this paper for discussion with co-authors, and later completed the paper for submission. All authors contributed toward data analysis, drafting and revising the paper and agree to be accountable for all aspects of the work.

LH, second author, mentor, took part in the literature searches, screened half of the titles, reviewed one-fifth in full text, and carried out the quality assessment according to MMAT. She judiciously contributed to the design of this paper, endorsing and commenting on the work during the entire process, as well as critically revising the article for final approval.

DK, third author, took part in the literature searches, screened half of the titles, reviewed one-fifth in full text, and performed a quality assessment according to MMAT. He contributed to the design of this paper and offered discerning appraisal during the writing process, critiquing and revising this paper for intellectual content.

K-AH, fourth author, entered the author group somewhat later. She read one-fifth of the titles in full text and assessed the quality of the papers according to MMAT. She read three versions of this paper and contributed with critical appraisal during the writing process.

AL, fifth author, took part in the literature searches, screened half of the titles, reviewed and quality-assessed one-fifth of the full-text papers, contributed to the design of the review, and contributed to the writing process. She revised this article for intellectual content and for final approval before it was submitted for publication.

## Disclosure

The authors report no conflicts of interest in this work.

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# Paper II

Torhild Holthe, Liv Halvorsrud, Erik Thorstensen, Dag Karterud, Debbie Laliberte Rudman, Anne Lund. C**ommunity health care workers' experiences on enacting the policy on technology to citizens with mild cognitive impairment or dementia.** Published online June 2, 2020 in Journal of Multidisciplinary Healthcare 2020:13.

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ORIGINAL RESEARCH

# Community Health Care Workers' Experiences on Enacting Policy on Technology with Citizens with Mild Cognitive Impairment and Dementia

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**Purpose:** Assistive technologies and digitalization of services are promoted through health policy as key means to manage community care obligations efficiently, and to enable older community care recipients with mild cognitive impairment (MCI) and dementia (D) to remain at home for longer. The overall aim of this paper is to explore how community health care workers enacted current policy on technology with home-dwelling citizens with MCI/D.

**Participants and Methods:** Twenty-four community health care workers participated in one of five focus group discussions that explored their experiences and current practices with technologies for citizens with MCI/D. Five researchers took part in the focus groups, while six researchers collaboratively conducted an inductive, thematic analysis according to Braun & Clarke.

**Results:** Two main themes with sub-themes were identified: 1) Current and future potentials of technology; i) frequently used technology, ii) cost-effectiveness and iii) "be there" for social contact and 2) Barriers to implement technologies; i) unsystematic approaches and contested responsibility, ii) knowledge and training and iii) technology in relation to user-friendliness and citizen capacities.

**Conclusion:** This study revealed the complexity of implementing policy aims regarding technology provision for citizens with MCI/D. By use of Lipsky's theory on street-level bureaucracy, we shed light on how community health care workers were situated between policies and the everyday lives of citizens with MCI/D, and how their perceived lack of knowledge and practical experiences influenced their exercise of professional discretion in enacting policy on technology in community health care services. Overall, addressing systematic technology approaches was not part of routine care, which may contribute to inequities in provision of technologies to enhance occupational possibilities and meaningful activities in everyday lives of citizens with MCI/D.

**Trial registration:** NSD project number 47996.

**Keywords:** older adults, community health care services, discretion, street-level bureaucracy

## Introduction

Assistive technology (AT) is increasingly promoted as a means to enable independent living in older adults, as well as reduce public health care costs. For example, the European Union (EU) strategy for long-term care identified technologies as a key enabler for aging in place policies and the sustainability of welfare states.[1,2] Seeing AT as a means of enabling older adults to age in place and has thus garnered particular interest in the UK at a time of reduction in government funding for adult social care departments.[3]

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The concept of AT has been defined as

> [. . .] a product, equipment or device, usually electronic or mechanical in nature, which helps people with disabilities to maintain their independence or improve their quality of life,[4]

Including assisting with daily living tasks, reducing risk of harm, and enhancing communication. In the context of dementia care, focus has been on AT designed to reduce risk of harm and improve safety. AT to support older peoples' needs for assistance have been categorized into four domains; for safety and security, for coping with independent living, health technologies for assessment and treatment at home, and to support well-being related to health conditions.[5]

As part of the Assisted Living Project (2015–2019), which was an interdisciplinary project on responsible innovations for dignified lives at home for persons with mild cognitive impairment or dementia, one of the work tasks was to investigate how health care workers enacted AT to clients with MCI/D. A systematic literature review from 2018 demonstrated that AT has the potential to support people with MCI/D, and a wide range of technologies (GPS, wayfinding by RFID (radio-frequency-identification), monitoring systems and night-time security system, multifunctional technology with reminders, verbal instruction and easy to use telephone, as well as touch screen tablets and camera for recollection of events) have been evaluated in homes with people with MCI/D and their family carers.[6] A major finding was the importance of including these user groups in research in order to learn about the required design features to enhance usability and acceptability. Surprisingly, very few studies reported the consequences of AT use regarding quality of life, occupational performance, or human dignity.[6]

The first author did a new literature search January 2020 utilizing the same search strategy as in 2016.[6] Interestingly, the search revealed more published references over the last three years (2017–2020) compared to the last decade (2007–-2017) included in the 2016 search, and resulted in 404 and 369 references, respectively. Fifteen papers were eligible for review and the technologies reported were to some extent the same as reported in 2018, however, more multifunctional technologies were tried out, and newer devices like VR (virtual reality) and videoconferencing through socially assistive robots (SAR).

Despite various types of AT are tried out with user groups, and despite AT having potentials to support older people at home, current research reports a slow integration of technology in community health care services due to several reasons.[5,7–13] Nilsen et al (2016) found there was resistance towards implementation of technologies in all groups of employees and at all organizational levels in community health care services. This resistance was linked to ways that implementation of technologies might influence the stability and predictability of tasks for community health care workers, their roles, and group identity, as well as basic values in their care practices.[9] This is in accordance with Batt-Rawden et al (2017), who found that the technology adoption phase was characterized by chaos and instability since many care workers found it difficult to operate the technology equally, and since technologies challenged patient security and created feelings of work dissatisfaction and disempowerment in staff.[7]

The Norwegian Technology Program in Community Health Care – NVP 2013–2016 initiated different small-scale technology trials in 34 municipalities, in order to kick-start implementation of welfare technologies; ie, as electronic medicine dispensers, electronic door locks, GPS locator technologies, digital monitoring during the night, and alarm systems in institutions.[10] The program demonstrated economic gains regarding saved time and avoided costs, as well as increased quality of services for the recipient, next-of-kin, and employees.[12,13] Subsequently, results of projects linked to this program were drawn upon to provide the basis for a national strategy for large-scale integration of AT in community health care services.

## Enacting Policies for the Promotion for Assistive Technology Use in Community Health Care Services

Enacting policies refers to how health care workers understand their role and comply with and change their practices in mediating an official policy. AT among citizens with MCI/D and their caregivers can contribute not only to independence, safety and security but also to occupational possibilities.[14] The construct of occupational possibilities refers to ways and types of doing that come to be viewed as ideal and possible within a specific historical context, and that come to be promoted and made available within that context, and thus may create meaning to everyday living.[14]

In Norway, integration of AT into community health care services is an expressed national aim, framed as a necessary and desired means to address the needs of an aging population. All municipalities are legally required to offer health care services to citizens currently staying in the municipality. In this paper, the concept of community health care workers refers to health professionals and applied services that usually are included in the community health care services in Norway; nursing, home help (eg, cleaning and shopping), physiotherapy, and occupational therapy. According to Norwegian Statistics, 189,520 people received community health care services in 2017, with the majority of recipients being older adults above 65 years of age.[15] Additionally, a significant proportion of these older adults have mild cognitive impairment (MCI) or dementia (D). For example, one Norwegian study found that the prevalence of MCI/D within recipients of home care services counted 27.8% and 41.5%, respectively.[16]

Today, Norwegian policy encourages use of AT in community health care services, under the argument of optimizing service efficiency, flexibility, and quality, as well as anticipating being cost-effective and making older citizens more self-sufficient.[5,10,13,17] The Norwegian guidelines for dementia, a national strategy for optimal dementia care published in 2017, recommends that all municipalities assess whether or not access to AT may enhance everyday living at home for people with dementia, as well as relieve the burden of care for next-of-kin.[18] However, assessment of user needs in care recipients with MCI/D is a complex matter, and may explain studies addressing the slow technology uptake in community health care services.[8] Within their role, community services are responsible for assessing user needs and then planning, carrying out, evaluating, and adjusting the services to be in line with the law and regulations. The law on health personnel states that they

> shall perform the work in compliance with requirements for professional justifiability and caring support, which can be expected from the personnel's qualifications, the nature of the work and the current context. (Chapter 2, §4)[19]

As such, health professionals (nurses, occupational therapists and physiotherapists) are expected to act in accordance with policies and evidence-based guidelines, but also to exercise professional discretion based on their expertise and consideration of the user and contextual particularities in line with what Lipsky called street-level-bureaucrats.[20] The theory of street-level-bureaucracy provides a means of looking at the complexity of policy implementation, recognizing the role of public workers in implementing policies within citizens' everyday lives aligned with laws and regulations. This theory acknowledges that "authorized use of discretion" by front-line workers is necessary to adapt policy to individual needs and circumstances.[21] As such, Lipsky contends that street-level workers "do" public policy in the sense that they are mediating current policy to different citizens and using professional discretion for adopting services to a certain citizen in a certain situation.[20] In other words, street-level bureaucrats, such as community health care workers, are responsible for putting public policy into action.[21] Thus, given local decision-making authority, implementations of technology and supporting services are organized differently in each municipality or city district, in line with what are experienced as the most pressing tasks and issues.[22]

To the best of our knowledge, there is a lack of research on how community healthcare workers evaluate the benefit of technology to care receivers with MCI/D and experience daily work with technology with people with MCI/D. Thus, the overall aim of this paper was to explore how current policy on technology with home dwelling citizens with MCI/D was understood and managed at the level of service provision by community health care workers. We sought to highlight potential facilitators and barriers experienced in the enactment of policy, as a means to inform on-going efforts to optimize the use of technology to support home-dwelling clients with MCI/D. With respect to the knowledge gap we are addressing, our study contributes to understanding the enactment of technology in community-based health services for persons with MCI/D, as recommended by the current policy in Norway.

## Participants and Methods

We chose a qualitative design in order to have access to in-depth knowledge from community health care workers.[23] Five focus group discussions were conducted with 24 community health care workers. As semi-structured discussions focus groups enable exploration of a width of opinions and create opportunities for participants to adjust their opinions to others' reflections and statements in the group.[23]

We used an identical interview guide (Appendix 1) for the five separate focus groups. Different researchers (two men and four women) carried out the interviews in pairs: one moderator and one co-moderator, who took notes during the interview. The researchers were two Ph.D. students and four experienced researchers in nursing, sociology, and occupational therapy, respectively, all holding a Ph.D. degree. All the moderators and co-moderators met in advance to discuss and clarify how to use the interview guide. All interviews were voice recorded and transcribed verbatim.

To access the community health care workers, the project manager contacted the health administration office in the municipality and asked for approval of the project.

The leader of the health administration office provided names of contact persons (head nurses), who in turn contributed to the recruitment of community health care workers in each municipality by asking members of the staff in person to volunteer for the focus group discussions. The face-to-face focus group discussions took place at their workplaces, at the end of a day shift. The participants did not know the interviewers. Overall, 24 community health care workers (11 nurses, two home trainers, four physiotherapists, two occupational therapists, four home helps, and one care worker) were recruited.

The focus group discussions were conducted between June and September 2016 and had a pre-set time limit of 90 minutes. The discussions were conducted in Norwegian, and a professional translator translated all quotations into English.

## Analysis

An inductive thematic analysis was undertaken to identify key themes guided by Braun and Clarke's (2009) phases for analysis to understand the data, identify patterns, and reflect the main lines of meanings.[24] Analysis involved five researchers (authors 1, 2, 3, 4, and 6) with varying professional backgrounds. First step was to become familiar with the data: All five authors separately read and re-read the transcripts and wrote a short summary of each transcript. Anonymous summaries were shared among the five researchers before meeting face-to-face to discuss understandings and to compare them for essential meanings. Second, all five researchers manually and separately noted initial codes on the transcripts. They met to compare codes and constructed a mutual coding tree. Third, we searched for themes: Two of the transcripts were chosen for a more in-depth analysis, done separately by all five authors. We identified central quotations, which we inserted into a common matrix, with the headlines: quote, our understanding, theme, and subtheme/candidate theme deriving from the data (see Table 1). The last three transcriptions were read closely and coded by authors 1, 2, and 6. Forth, the themes were reviewed separately by the five researchers before the research group met and discussed the themes. We used yellow stickers to highlight themes emerging from each focus group discussion. Thereafter, we compared findings across all groups. One important step was to explore similarities and differences between the groups' answers on the same topic. The fifth step was to define and name themes: The researchers involved in coding had a back-and-forth process that included mutual reflections and further discussions of findings, resulting in the final form reported in this paper. The sixth and last step was to produce the report. The first author initiated writing the thematic findings, with all other authors involved in on-going commentary on the evolving writing.[24]

## Results

This study showed wide variations in how different community health care workers talked about their experiences and practices related to enacting policies on technologies for supporting citizens with MCI/D. We present two main themes with subthemes (Table 2).

## Current Use and Future Potential of Technology

### Frequently Used Technology

All 24 participants expressed being familiar with frequently used AT like the social alarm, stove timer, and automatic calendar. Some participants also expressed potentials regarding newer AT for citizens in community health care, particularly in relation to aims of independent living, enhancing coping, and optimizing everyday living and quality of life in citizens and enhancing efficiencies in health care services.

### Cost-Effectiveness

Some participants raised visions and expectations of more cost effective, "digitalized care", by remote health service monitoring of citizens taking a pill or exercising a training program, and expressed enthusiasm about working in such a manner:

> I watched a program from Sweden about a nurse who used Skype to keep in touch with quite a few users. To tell them to take their medicine or measure their blood sugar level [. . .]. Just one nurse looking after many users. It was wonderful to see. One nurse can do all this, instead of sending 20 nurses to 20 places. (Nurse FG2)

> [. . .] You can get very big screens and have exercise programs at home for many [citizens] at the same time. Then, training programs could actually be offered to them every day. Borough physios don't usually have time to visit patients in their homes more than once a week. [. . .] – how does that help if you want to exercise to become stronger? (Physio FG2)

A few implied that the underlying governmental rationale for promoting AT might be for economic reasons, rather than actually serving to better meet the needs of aging citizens. The cost-effectiveness of AT was often framed as a smart solution to the goal of improving services:

**Table 1** Examples of Analysis Process

| Quotation | Our Understanding | Main Themes | Subthemes |
|---|---|---|---|
| I watched a program from Sweden about a nurse who used Skype to keep in touch with quite a few users. To tell them to take their medicine or measure their blood sugar level, this and this and that. Just one nurse looking after many users. It was wonderful to see. One nurse can do all this, instead of sending 20 nurses to 20 places. Wonderful to see. | Enthusiastic about new telehealth technology that offers new ways of caring and which may be more cost-effective | Current and future potentials of technology | Cost-effectiveness |
| [.] you also notice things when you are there [in the client's home]. Very short of breath today, or the fridge is empty. [...] And when talking, are things going better or worse? Is someone lonely? You usually have to know someone to know whether they are lonely. Maybe [technology is suitable] for those who provide the service, but not so much for those who receive it. Because I think they will want human contact or to get activated a little. [...] So – technology, a robot? What can you do with someone with high degree of dementia? That I do not know. | Social contact vs technology | Current and future potentials of technology | "To be there" for social contact |
| It is very erratic. Someone can suddenly say in a report – "oh, he needs this and that, can we order it"? Then someone does something about it. But there are no procedures for doing this for all [citizens]. | Routines for assessing user needs for technology is erratic. | Barriers to implement technologies | Unsystematic approaches and contested responsibilities |

> It sounds so wonderful; there is a lot in the newspapers about them [older adults] getting help, that they can live at home and won't have to move to a nursing home. But it's not true. Even if it was, you must fight for it [to get access to AT]. I don't get the impression that more money will be saved. [...] the complete opposite, you will be rationalized out. I have a strange feeling about this. (Nurse FG5)

> It is good that technology can save time, but the time saved will not benefit the users. I get a bad feeling about this, that technology is just to save money. (Home help FG1)

## "to Be There" for Social Contact

Although there were examples of workers who trusted that AT had the potential to provide opportunities to guide citizens at home from a distance, other participants were concerned that AT would constitute threats, like loss of social contact and the care workers' opportunity to have a close relation with the care recipient:

> [.] you also notice things when you are there [in the client's home]. Very short of breath today, or the fridge is empty. [...] And when talking, are things going better or worse? Is someone lonely? You usually have to know someone to know whether they are lonely.

> Maybe [AT is suitable] for those who provide the service, but not so much for those who receive it. Because I think they will want human contact or to get activated a little. [...] So – technology, - a robot? What can you do with someone with high degree of dementia? That I don't know. (Nurse FG5)

One expressed that her citizens rejected aids and AT because they were afraid of losing contact with the health care workers (FG4). Another anticipated that AT might create passivity and loneliness, especially in citizens with MCI/D, and that providing AT was "a way of robbing them of human contact" (Nurse FG5).

**Table 2** Overview Over Themes and Sub-Themes

| Main Themes | Subthemes |
|---|---|
| Current and future potentials of technology | Frequently used technology<br>Cost-effectiveness<br>"To be there" for social contact |
| Barriers to implement technologies | Unsystematic approaches and contested responsibility<br>Limited knowledge and training<br>Technology in relation to user-friendliness and citizens' capacities |

## Barriers to Implement Technologies

Although the participants reported on a variety of knowledge and potentials on implementing technology different barriers were revealed related to; unsystematic approaches and contested responsibility, knowledge and training, and technology in relation to user-friendliness and citizens capacities.

### Unsystematic Approaches and Contested Responsibility

Many participants indicated that assessing needs for technological assistance was not done in a systemic way as part of their routine practice. The participants highlighted several issues that bounded if and how they moved forward in addressing AT with citizens with MCI/D. Overall, the procedures for technology assessment and implementation seemed unsystematic and fragmented, and responsibilities were contested. Several participants seemed to find it challenging to identify needs for technology for their citizens. A few participants stated that procurement of AT was not yet an integrated procedure for all citizens:

> It is very erratic. Someone can suddenly say in a report – "Oh, he needs this and that, can we order it?" Then someone does something about it. But there are no procedures for doing this for all [citizens]. (Nurse FG3)

> If you go to the same user every day, you become a bit blind. It's always been that way [in that home]. So, you don't think about trying other things. But, it's a lot about how you handle it, who has a right to it [implement AT], who is going to pay, and there are many who don't have money or who would prioritize using money on it. (Nurse FG3)

A few expressed hesitations about taking on the responsibility for addressing technology in their practice. Further, they seemed unsure whether the "application office", the occupational therapist, or next-of-kin should introduce technology to the person with MCI/D.

> Often, they [next-of-kin] know what the family members are entitled to, or what they might get [from NAV]. (Nurse FG3)

The participants could refer the older person to the "application office" or an occupational therapist for a need assessment. Then a home visit could be arranged to assess user needs and initiate provision of technical aids. After such referrals, the home-based services divert the responsibility to someone else, and are no longer in charge of procurement of AT. Since the participants painted a picture of being erratic and uncertain about addressing AT and responsibilities this can be understood as unsystematic and a fragmented responsibility for both need assessment and provision of technologies as part of routine care.

## Limited Knowledge and Training

Although many had heard about other AT than social alarm and stove timers, they indicated that they knew too little about potential possibilities.

> There is an ocean of opportunity, and I know about 0.0% of that ocean. (Nurse FG2)

> Yes, I know you can get those floor mats, but none of ours have them. Also, lights that turn themselves on. We're not good at using them. Mostly, no, not so much of it. (Nurse, FG3)

This lack of knowledge of more diverse AT could sometimes lead participants to doubt the utility and relevance of particular AT. For example, in one municipality the dementia team had recruited two citizens to an ongoing research project on GPS. The focus group participants knew about the project but knew nothing about how a GPS worked since the community health care services and the dementia team were two different units and never shared this knowledge.

Several of the participants said they could not recall any specific training in the use of AT; they all felt more or less self-taught. However, they also reported having had frequent access to information and training courses on AT run by the technology education center in the municipality. Still, many participants expressed what we understood as feelings connected to a lack of competence and uncertainties regarding assessing user needs and requirements. A few participants expressed worries about having to learn more than needed to do a good job:

> So - how much do I, professionally, need to get involved in? [There are many] things I don't need to use or know anything about. It can end up being a lot, knowing everything about all the equipment. (Physio FG2)

In addition to pointing to limits of current approaches to education, participants forwarded ideas regarding how training could better support them. One participant perceived technology training as burdensome and preferred to start by using the technology by herself and to learn step-by-step. When and if facing an issue, she wanted to have the opportunity to ask a "super-user" colleague. Another stated that workplace-adjusted training courses are essential and wanted more of this, as well as training in operating the citizens' aids.

## Technology in Relation to User-Friendliness and Citizens' Capacities

As mentioned earlier, participants in our study knew and used AT like the social alarm, stove timer, and digital calendar for citizens with MCI/D. However, they pointed to ways that such technology was not user friendly for citizens with MCI/D, referencing both design features and citizens' competencies. For example, the stove timer, whose purpose is to prevent fire, was reported to cause many troubles. Usually, the stove timer is pre-set to shut off after 30 minutes. Since boiling potatoes normally take 40 minutes, the citizen would need to re-set the stove to get ten more minutes of power. This re-setting represented a cognitive challenge, since all the buttons on the stove must point at 0 (zero) simultaneously to re-set the timer. Another reported issue was citizens putting a plastic water-boiler pot on the stove. Such events happened from time to time and had caused fire department visits. One participant claimed that a stove timer would not prevent improper use of the stove, and that anything may catch fire after exposed to high temperatures or after a certain length of time. Even simple AT like the social alarm represented a problem for some.

> A few don't quite understand the social alarm [. . .] for example, they press the button if they need the loo. That's all wrong. The social alarm is for when you fall or are very, very unwell. You should then really call an ambulance and only press the button if you can't manage it. Some, however, think the button calls the district nurse. Especially, those with dementia. (Home help FG 4)

Overall, according to the participants, poor user interface for older adults with MCI/D is the major issue regarding operating technology. Also, TV remote controls with many tiny buttons were frequently mentioned as not user-friendly. Being unable to operate the TV controls prevented one from watching the news and other programs for entertainment and joy. The participants agreed that new technology was often difficult for older adults to operate, especially for people with MCI/D, due to too many tiny buttons, or requiring too many steps. Design of the device, use of color contrasts, avoiding reflection from screens, and quality of sound/speech were reported to be important features. One explained:

> Imagine being home alone all day and wanting to watch TV or listen to the radio – and you cannot cope with the remotes! Of course, you would become depressed! (Nurse FG 5)

Further, the participants stated that AT might not work due to unstable internet connections and/or lack of battery charging. For example, one assisted living facility installed tablets by all residents as a means of communicating messages, informing them about the day's menu, and booking appointments at the hairdresser and pedicurist. Although quite a few benefitted from the information, Facebook, YouTube, etc., most of the residents struggled to include their tablet in their everyday lives, which led to extra work for the care worker, especially regarding the updates.

> The residents can't do it themselves. I, therefore, must update all the tablets myself. Or they will stop working. It's so stupid – I understand that it's necessary, but . . . It's a huge amount of extra work! (Care worker FG2)

Misfits arising from how citizens' cognitive impairments could limit the correct use and benefit of AT, were expressed as reducing value. Non-use or wrong use led to uncertainty, hesitation, and the citizen feeling incompetent, and more work and stress for the employee. For example, one participant explained that a citizen had been in hospital for a while, and after returning home she had forgotten all about her online banking.

> I have spent three days trying to help her to log in. It's going really badly! (Care worker FG2)

Another participant had tried to install a simple TV remote control for a citizen with dementia. However, the citizen's established habit of unplugging all the sockets, TV included, prevented her from any benefits of new AT. The participants' expressed frustrations regarding the limits of AT and its lack of fit with citizens' capacities also point to the complexities of putting the plan for the integration of technologies into the homes of people with MCI/D into action with the contexts of citizens' lives.

Some also expressed the limits of age and cognitive capacity of the citizens, appearing to take up potentially negative assumptions related to desires and capacity of citizens to use AT based on age and/or cognitive capacity. These examples might reveal a more or less taken-for-granted assumption about older adults, often with a hidden devaluation of the person masked as admiration:

> [. . .] one has an iPad [. . .] He uses it to read papers and such things (laughter). (Nurse FG3)

> She is quite cool, the woman who has this blog [. . .] she is 92 or something (yes) and she got help from her grandchildren to become a blogger (laughter). (Nurse FG1)

> Yes, she is 92, and blogs [...] She is talking about life when being 92, just like younger bloggers. On the national day she had one [drink] in each leg. And when she returned from respite care, there was a bunch of laundry on the floor, which she crawled over and had a glass of red wine (instead). (OT FG1)

## Discussion

This study aimed to explore how current policy on technology with home-dwelling citizens with MCI/D was understood and managed at the level of service provision by community health care workers. The findings point to how the experiences of the community health care workers highlight the complexities involved in attempting to enhance everyday living for people with MCI/D by using AT. The health care workers' practice demonstrated that they were bounded within current and future potentials of technology and barriers to implementing AT successfully for the citizens. Drawing upon Lipsky's (1980/2005) theory of street-level bureaucrats, these findings can be interpreted in relation to the positioning of community health care workers as mediators of governmental policy within citizens' everyday lives.[20]

In this perspective, the daily decisions of the community health care workers have consequences for how the policy is mediated; that is, whether it is taken up, adapted, challenged, or resisted within service provision.[25] The care recipients are dependent upon and must trust in the professional workers. Thus, professionals must be worthy of that trust, and in return they will be rewarded with status and authority.[26] Related to our findings, the community care workers appeared to mediate the policy of integrating technologies into community health services in different ways. In some cases, they aligned with the policy message that AT could be of great benefit to citizens, speaking to the possible potentials of remote training programs and medical counseling via Skype. However, the actual implementation of this policy message was bounded by some concerns, such as the suspicion that AT was promoted primarily for economic gain and was an inadequate substitution for traditional care and social contact by "being there." Some participants attempted to transform the policy into their current contexts of care and to individualize technologies to each user, for example, the nurse who tried to implement a simple remote TV-control. As shown in other studies, a diversity of approaches towards AT was expressed, resulting in variations in how the policy for enhanced technology was mediated within everyday practice.[7,9,27] Overall, this resulted in an unsystematic and fragmented implementation of policy, which can be related to constraining forces that bind possibilities for enacting the policy directives in everyday practice. Also, the community health care workers perceived they had inadequate knowledge about AT, leading them to be hesitant in providing it to citizens. This might imply a lack of repertoire and might influence their professional discretionary work. Additionally, some community health care workers seemed to distance themselves from responsibility to enact policy on AT, which also shaped their professional discretion.

The participants expressed a lack of familiarity with different AT, exemplified in quotations like "There is an ocean of opportunities, and I know about zero percent of the ocean." Enhancing competencies in working with AT seems to be challenging but is nevertheless an important requirement for exercising discretion. Lack of competence is supported by a recent Norwegian survey, which found that only four of ten municipalities plan to increase the technology competences of their community care workers.[9] This survey reported a slow uptake of AT in community health care services, and only three of four municipalities had education and training for health care workers regarding work-related technology and digital competence. Further, six of ten health managers confirmed that care workers asked for such training only to a small degree or not at all.[8] Our study revealed that some participants reported having participated in training courses about AT for people with dementia; however, they claimed that this knowledge was seldom used in their current practices. Pols (2017) argues that end-users (nurses and patients) must establish knowledge and a relation with the technology; otherwise, they often do not know the purpose or the use and function of the technologies.[28] This is an important aspect and reveals that slow adoption can be linked to more than lack of technological maturity or lack of integration of AT into community health care services.[29] It could also be due to a low understanding of the script of the device; that is, understanding the potential of the technology and how it might be configured to a certain user.[30] Lastly, the participants in our study reported frustrations regarding the limits of the AT and its lack of user interface with citizens' capacities, which points to the complexities of implementing a plan for the integration of AT into the homes of people with MCI/D and into action with the contexts of citizens' lives. Small buttons, lack of contrasting colors, and interfaces that were not user-friendly made some of the devices less useful for citizens with MCI/D. The low user interface of people with MCI/D leads to a larger question of whether such technologies can actually succeed in meeting the needs of citizens with MCI/D. An important question, according to Gibson et al (2015), is why AT is widely promoted despite the absence of a solid evidence base, especially if the services related to the daily use and utility of the technologies are immature, absent, or unstable.[31]

The staff's expressions of uncertainty and poor competence also found in this study may demonstrate slow technology adoption.[32] Rogers' diffusion model of technology adoption explains that people usually adopt technology in accordance with personal attitudes and interests.[33] In other words, personal characteristics decide that some health care workers may be innovators or early adopters of technology, while others are late adopters or even laggards.[34] Dugstad et al (2019) found that implementation of digital technologies into health care services was complex and that one important success criterion was to expect and accept the inherent slowness.[27] Also, McGinn et al (2011) referred to the similarities and differences between stakeholders to explain the interests and slowness of technology adoption and stated that the unique perspective of each user group must be taken into consideration.[26] Our study supports these findings on slow technology adoption as well as the complexity of enacting technology in the work context of the community health care workers.

Within this study, findings suggest the possibility that ageism and ableism can intersect in ways that foster taken-for-granted assumptions in community care services that bind when and how technologies are addressed. Ageist attitudes are those that assume limited capacities on the basis of age,[35] while ableist attitudes convey negative and discriminatory attitudes towards others whose bodily and mental capacities are deemed to be impaired.[36] Such attitudes can shut down the possibility of moving forward with practice approaches, including technology, based on the assumption that older, disabled citizens neither wishes nor are capable of engaging in such approaches. For example, McGrath's (2017) study on older adults with age-related vision loss demonstrated ways in which disabilities were shaped through environments that embedded ageist and ableist assumptions, rather than being a "natural" outcome of impairments. In other words, disability was socially constructed partly through the integration of ableist and ageist attitudes into practices, systems, and societal structures, such as the design of buses and streets in ways that assume a normative level of vision and mobility.[37]

In our study, community workers sometimes expressed that AT was neither relevant nor possible for persons with MCI/D. The comments from the participants seemed to imply that advanced age, combined with cognitive impairment, meant that citizens would have decreased motivation, interest, or capability to use advanced technologies. In turn, these assumptions were employed as a rationale for not moving forward with integrating AT into routine care. This can contribute to reducing the citizens' occupational possibilities for performing meaningful everyday lives. The recent report on older adults' human rights concludes that nobody should be exposed to discriminative conduct due to long-term physical, mental, intellectual, or sensory impairment.[38]

## Methodological Considerations

The five focus group discussions provided rich data on the "reflective-level" and the "experience-level;" in other words, what they think and how they talk about what they do, which can be a strength in this study.[23] However, there are some limitations. First, the lack of consistency in the professional composition of the groups, with two focus groups having multi-professional staff members and three having mono-professional staff members, may have influenced the findings. Second, the lack of consistency in the research team members who served as moderators in the focus groups may also have led to inconsistencies in how the focus groups were carried out, despite the use of a common interview guide.

Alternatively, the fact that the six researchers who did the interviews and the five participating in the analysis had different professional and research backgrounds and pre-understandings might strengthen the analysis process because it shed light on the themes in various ways and enabled rich and interesting discussions.

We asked about the participants' perceptions of technology, being aware that this might represent a range of technologies. This is in line with Gioia et al (2012), who recommend not imposing prior constructs on informants as a preferred way of understanding a term.[39] Therefore, the answers probably provided heterogeneous reflections regarding technologies for citizens with MCI/D.

Our sample is quite small, so we cannot expect saturation, which, according to Malterud et al (2016) is an expression appearing from Grounded Theory to decide sufficiency of sample size. They instead propose the expression "information power" to decide a purposeful sample size.[40] The advantage of focus groups is that they allow the researchers to ask what the participants think and why they think that way, helping researchers gain insight into values and beliefs.[24] Disadvantages or weaknesses of focus groups may be that some voices are not properly heard, or some might not dare to express their views.

## Clinical Implications

The study found that AT as a support for citizens with MCI/D is very complex and not fully integrated into everyday practices of community health workers; rather, it is still in its initial stages. Nevertheless, our study suggests that citizens with MCI/D have a right, equally with others entitled to community health care services, to have their needs for AT support assessed.[38] The inconsistent and unsystematic approaches in the service provision of AT may create occupational inequities, marginalizing citizens with MCI/D from desired occupations, and thereby represent an ethical challenge. A systematic lack of assessing eventual needs for AT can perpetuate the silencing of this group of people and lead to inequity and discrimination. Therefore, our study suggests that community health workers receive organizational support and training to implement the policy, given the boundaries that surfaced in the study. Moreover, it supports the importance of further development of technologies that fit the needs and capacities of older adults with MCI/D. Despite the policy on addressing and implementing technology, there is still further need for research.

Developing knowledge and competences seem of importance as a contribution to reduce inequities and occupational injustices; however, organization of the services must also be considered. Organizational changes inevitably lead to changes in street-level bureaucrats' roles and tasks. For example, inclusion of AT will require community health care workers to prepare for more extensive collaboration with family caregivers and interdisciplinary teams. This is especially necessary since AT for citizens with MCI/D are seldom stand-alone solutions but usually a part of a safety net around the person.

## Conclusion

This study reveals the complexity of enacting policy aims regarding provision of AT for citizens with MCI/D in enhancing meaningful everyday lives. This study shed light on how community health care workers were situated between current policies and the everyday lives of citizens with MCI/D, and ways that their perceived lack of knowledge and practical experiences influence their exercise of professional discretion in community health care services. Overall, addressing systematic approaches for procurement of AT was not part of routine care, which may contribute to inequities in implementation of AT to enhance occupational possibilities and meaningful activities in everyday lives of citizens with MCI/D.

## Ethics

The Assisted Living Project (2015-2019) is performed in accordance with the Declaration of Helsinki and approved by The Norwegian Centre for Research Data, NSD 16.03.2016, Application number 47996. The focus group participants received a written invitation to participate in the focus group discussions and were asked to sign an informed consent before the focus group discussions took place. Participation was voluntary. All personal data, except professional titles, were left out.

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## Disclosure

The authors report no conflicts of interest in this work.

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## Paper III

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# Paper IV

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# A critical occupational perspective on user engagement of older adults in an assisted living facility in technology research over three years

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**ABSTRACT**

Digital assistive technology has potential for supporting older adults who depend upon community healthcare services. To boost the efficiency of those services, technological devices are often installed for care recipients as part of governed practice. However, the varying adoption of technology risks widening the digital divide. In response, the Assisted Living project engaged older adults in co-creating knowledge about users' needs, to guide the development of technological solutions designed to support everyday living. This study sought to investigate how eight older adults in an assisted living facility in Norway, aged 81–92 years, evaluated user inclusion in a 3-year technology-oriented research project. Individual interviews, dialogue cafés, interventions with environmental sensors, and a final focus group discussion constituted sites for co-creation of knowledge. Participants' answers to standardised questionnaires and statements during dialogue café meetings were collated into tables and the focus group discussion was thematically analyzed, with three themes identified: motivation for project engagement, experiencing and understanding participation in the project, and mixed feelings towards environmental sensors at home. The project revealed that older adults with impairments could nevertheless meaningfully contribute opinions about their needs. Applying a critical occupational perspective raised awareness regarding sociocultural assumptions about older adults in assisted living as frail and unable to participate, which may reinforce ageist and ableist stereotypes, as well as promote occupational injustice.

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Occupational science; Assistive technology; Community health care; Occupational justice; Technology imperative; User participation

In the past decade, assistive technology has been expected to support older adults at home, facilitate their independent living and safety, and contribute to their ageing in place (Gramstad et al., 2014; Thordardottir et al., 2019). However, older adults tend to adopt new technology slowly, which risks exacerbating the potentially serious social problem known as the *digital divide* (van Dijk, 2006). After all, some older adults gladly incorporate technology into their daily lives, whereas others hesitate or even refuse to do so, which reflects trends among people in general (Rogers, 2003). There are several reasons for late adoption of technology (Satariano et al., 2014), including technology illiteracy, poor user-friendliness of devices, lack of human support and training, and economic circumstances (Lee & Coughlin, 2015; Peek et al., 2014). In many regions, the digital infrastructure, or lack thereof, can exacerbate the delay; for example, many places in Norway remain without 4G mobile service and even lack Internet connections, which

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necessarily excludes some people from benefitting from digital services (Aftenposten, 2018).

To address the challenge of Norway's ageing society, Norwegian health authorities have developed plans to integrate technology into community healthcare services as an expressed national aim, a desired change, and a governed action. Amongst the effects to date, positive results from feasibility trials for the Norwegian Programme on Assistive Technology (2013–2015) were put into practice in national recommendations for all municipalities regarding electronic medicine dispensers, global positioning systems for locating lost individuals, electronic door locks for visitors from home care services (Norwegian Directorate of Health, 2015), plus alarm systems and digital monitoring at night in nursing homes (Norwegian Directorate of Health, 2017).

In such efforts, if the chief reason for using technology in community healthcare services is financial savings, then individual human needs are liable to be neglected. Thus, the consequences care recipients may face once technology is implemented warrant sustained attention, as do their living conditions (Thygesen, 2019). Therefore, policy accommodating the *technological imperative*—that what can be realised with technology should be realised—may pose unwanted consequences for many older adults who depend upon community healthcare services. First, thorough consideration of users' needs and the individual tailoring of technology are seldom made (Holthe et al., 2020). Second, imposing technology as a condition for receiving community healthcare services may challenge power relations and autonomy. Third, the technology imperative may also create and reproduce social exclusion as well as widen the digital divide.

Although a wide range of technologies have been evaluated in homes with people with mild cognitive impairment or dementia, reports on the consequences of using such technologies in terms of quality of life, occupational performance, and human dignity have been scarce (Holthe, Halvorsrud, et al., 2018). In response, additional studies addressing user engagement and occupational engagement in the co-creation of knowledge are needed to clarify users' values and needs concerning technology. Thus, to learn how older adults in assisted living facilities may experience and interact with technology, we sought to elucidate what they thought about technology in general, whether they used technology daily, and what was important for them to have meaningful days in assisted living.

This paper addresses the call for methodological contributions to occupational science and focuses on a potential social problem of neglecting older adults in assistive living facilities as citizens with needs and opinions on digital technology as a means of support for everyday living; that is, "the various everyday activities people do as individuals, in families and within communities to occupy time and bring meaning and purpose to life" (Asaba et al., 2016, p. 1). A critical occupational perspective is applied to generate insights on the residents' daily living and their experiences with marginalization and occupational injustice within the context of an assisted living. A critical approach may explore dominant concepts and taken-for-granted ways of thinking, reveal social and political dimensions, examine socially ingrained values and beliefs, and reflect on how things could be otherwise (Teachman, personal communication, March 22, 2019). In practice, we followed the framework of Njelesani et al. (2013).

## Older Adults' Participation in Technology Research and Development

In the past decade, user participation in research has increased (Romsland et al., 2019). Currently, Norwegian policy regarding research and innovation recommends engaging users in the co-creation of knowledge, and some research grants in Norway and many other countries even require user engagement. The philosophical perspective in this paper was to implement responsible research and innovation (RRI) in practice. One major methodological request for the Assisted Living Project (ALP) was the principle of inclusion, being one of the four RRI principles guiding our research. Inclusion is also a major concern in occupational science, based on the idea that social inclusion is both a process and an outcome for a person, group, community, organization, or population to participate in their society (Whiteford & Townsend, 2011). Social inclusion is closely related to human rights (Whiteford & Pereira, 2012).

We planned for a participatory approach by involving end users of the studied product or design in defining users' needs and challenges, prioritising their values and goals, elaborating solutions to their problems, making decisions about user requirements and, ultimately, implementing and practically using the product or design (Moser & Thygesen, 2019). In the research-related sense, *engagement* refers to a quality of users' experiences characterized in terms of challenges, positive effects, endurance, variety, novelty, interactivity, and perceived user control (O'Brien & Toms, 2008). User engagement thus implies a shift in the power relations between researchers and subjects. For older adults, that has meant no longer being viewed as passive receivers of services, care, and products but as citizens on equal terms with all other citizens and with personal needs, hopes, and goals, all of which are important factors to consider in planning future services (Royal Ministry of Finance, 2013). The view that a service user is actively involved in and an expert on their health and life is important for individuals' capacity to maintain or improve democratic rights, occupational justice, emancipation, and co-determination, as well as for adapting and enhancing health services to better address users' needs (Alm Andreassen, 2016; Askheim, 2016; Whiteford & Hocking, 2012).

User engagement is also recommended because users can contribute important expertise about theirs and other users' needs, especially concerning technology interfaces, which can, in turn, enhance technology's usability and acceptability (Holthe et al., 2018a; Lee & Coughlin, 2015; McCabe & Innes, 2013; Meiland et al., 2014). Hence, the shift in perception of older people as passive, frail recipients of care to operating as citizens and capable co-creators with expertise is even more evident. By extension, the shift aligns with the notion of occupational justice, which is underpinned by the idea that participating in various meaningful occupations matters to one's health. Thus, barriers to putting ideas into practice are considered to be forms of occupational injustice (Durocher et al., 2013).

### Forms of user engagement

User participation can take three forms: user inclusion, user involvement, and user engagement. For this paper, we have used the term *user engagement*, which aligns with the terminology of occupational therapy, especially the term *occupational engagement* (Townsend & Polatajko, 2007; Whiteford & Hocking, 2012), meaning "to involve oneself or become occupied" and "to participate in occupation" (Houghton Mifflin Company, 2004, quoted in Townsend & Polatajko, 2007, p. 370). Although user engagement is an important strategy towards facilitating dialogue, reflexivity, and the co-creation of knowledge, it can cast users in different roles: as sources of data (i.e., informants), as partners with researchers, and as independent investigators in relation to researchers as mentors (Hulatt & Lowes, 2005). In our study, to ensure the co-creation of knowledge about diverse occupations over a 3-year period, as well as considering older adults as experts on their own lives, we conceived user engagement as a partnership (Clarke & Keady, 2002). Our decision follows the thinking of Askheim (2016), who has argued that co-creation entails engaging citizens in actively taking part in innovation processes aimed at creating new and improved solutions for society.

### Context of the study

In consultation with the municipality's health authority, an assisted living facility with approximately 60 residents was selected as the project site. The ALP was designed to be an important contribution to both the innovation of technology in Norway, in line with the strategic priority in Innovation in Caring (Norwegian Ministry of Health and Care Services, 2011), and the enrichment of RRI in both concept and practice.

The assisted living facility included lifetime care dwellings for older adults not yet in need of nursing home placements but facing significant challenges in managing independent living in their own homes. The dwellings were physically adapted for older people and situated in connection to an activity centre, a canteen, and a reception area with staff. Qualified healthcare personnel were available around the clock. Residents could personally furnish their dwellings, paid rent, and purchased their meals in the canteen. All community home care services and services from allied health professionals (i.e.,

**Table 1.** Steps, content and findings of user engagement, 2016–2019

| Research-based occupation and date | Content | Findings |
|---|---|---|
| Information meeting<br>June 2016 | All residents in the assisted living and their next of kin were invited to an information meeting | Approximately 30 residents, a few next of kin and a few staff members met |
| Individual questionnaires (survey)<br>June 2016 onwards | Socio-demographic data<br>Opinions on technologies with instruments (ALP group in 2015)<br>RAND 12 – Health questionnaire (RAND Corporation, USA)<br>MCFSI – The Mail-In Cognitive Function Screening Instrument, Norwegian version (Michelet et al., 2018)<br>HADS – Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) | Currently under analysis |
| Dialogue cafés<br>26.10.16<br>14.12.16<br>06.04.17 | Three café meetings with 15-20 residents<br>The first café sought to identify users' needs and challenges concerning daily living<br>The second café discussed technological solutions following cartoon presentations of scenarios<br>The residents' opinions created a basis for making prototypes that were presented and appraised in the third café | The residents were concerned about falling, starting fires, and burglars, and wanted reminders that could help them to live safely and independently<br>The residents were particularly interested in technology that could provide help if they had fallen or verbal reminders if they had left the stove on or forgotten to turn off the coffee machine or left the apartment with the windows or balcony door open |
| Recruitment for the trial intervention<br>06.04.17 | After the three dialogue cafés, the residents were invited to take part in an intervention study that involved testing environmental sensors at home (Appendix 1: refer to online supplementary material) | 8 participants (2 men, 6 women) consented to participate in the trial. One withdrew from the focus group discussion and one withdrew from the final individual interview |
| Individual interviews<br>June 2016 onwards | The eight residents were interviewed with two standardised scales: the Canadian Occupational Performance Measure (COPM; Law et al., 2014), and the Everyday Technology Use Questionnaire (ETUQ; Nygård, Rosenberg, & Kottorp, 2015) | COPM results: Indicated that the three most meaningful activities were getting around outside the assisted living facility, going for walks in the neighborhood or grocery store to run errands or visit family, a hairdresser or a general practitioner; reading; and socializing with family and friends outside the assisted living facility<br>ETUQ results indicated the participants had and used a wide range of devices; most frequently used were the TV, rated as the most significant technology by four, and the mobile phone, which six had and two wanted |
| Feasibility study<br>21.06.17 | The first feasibility deployment of sensors took place in one of the apartments | The Medical Research Council's (MRC) framework was used for the process evaluation<br>Too few power outlets created problems with installation. Too many IP addresses competed, which caused lost connections with servers and created gateway errors. Some sensors tended to fall down due to their overly small frames on windowsills or uneven surfaces |
| Deployment of environmental sensors<br>August 2017 onwards | The sensors were deployed in the seven other apartments following a contract with each participant regarding sensor installation (Appendix 2: refer to online supplementary material) | Difficulties in addition to the feasibility study were unreliable technology and poor wireless connections causing extreme delays in installing and configuring the sensors (i.e., server connection sometimes failed, components could not communicate with each other). After 2 months, all movement sensors were repositioned to cover the desired areas of the apartments. Loss of connection with the server and gateway errors required resetting the system and resulted in frequent visits by the researchers and engineers<br>After 7-months the trial ended because the technology would not function as intended |

(*Continued*)

**Table 1.** Continued.

| Research-based occupation and date | Content | Findings |
|---|---|---|
| Focus group discussion 14.03. 2018 | The eight residents were invited to a final focus group discussion. The interview guide is presented in Appendix 3 (refer to online supplementary material) | Seven residents took part in an audio-recorded discussion led by a primary researcher and a doctoral student (TH and ET) |
| Individual follow-up interviews after 36 months<br>03.06.19<br>05.06.19<br>06.06.19 | Eight residents took part in individual interviews (the RAND-12, MCFSI and HADS and open-ended questions) | Data from the COPM, HADS, RAND-12 and MSCFI were compared with 2016 and 2017 data (Table 1). Results indicated the sample was highly stable both physically and cognitively over the 3-years |

occupational therapists and physical therapists) that residents had applied for were provided free of charge.

This paper presents a sub-study of the ALP conducted during a 3-year process of user engagement in a series of research-based occupations. Specifically, this study asked the question: How did eight older adults in an assisted living facility experience participating in a 3-year project involving various research-based occupations and testing environmental sensors in their apartments for 7 months?

## Method

### *Design*

To gain in-depth knowledge about the residents' everyday living and possible challenges in the assisted living facility, we collected data on their experiences with the technology trial, their perceptions of user engagement during the project, and their engagement in different research-based occupations, including individual interviews, dialogue cafés, interventions with environmental sensors, observations and follow-up conversations, and focus group discussion (see Table 1).

### *Steps of the user engagement process*

The ALP was approved by the Norwegian Centre for Research Data on 16 March 2016 (application no. 47996). Each participant received a written invitation to voluntarily engage in each research-based occupation, as detailed in Table 1, and each signed an informed consent before commencing participation Appendix 1: See online supplementary material). Data collection lasted from June 2016 until June 2019, and all personal data were anonymized to de-identify participants in line with the European Union's General Data Protection Regulation.

### *Description of the sensor technology deployed*

The sensors deployed in the project were wirelessly connected to a computerised control box that transmitted signals to a secure server at a commercial partner. The plan was to integrate a push-button and loudspeaker by the entrance door to the system such that when the resident was ready to leave the apartment, they could push the button to receive an audio message (e.g., "The coffee machine is on" or "Everything is turned off. It is OK to leave the apartment"). We ultimately used three types of environmental sensors: movement sensors that registered when the resident entered or left different rooms, power effect sensors that registered power being used by the stove, coffee machine, TV or radio, and magnet sensors that registered whether doors/windows were open or closed. All sensors were connected to the push-button and loudspeaker, which issued an audio message if the button was activated. A written contract between the researcher and the residents specified what types of sensors each of them would have (Appendix 2: See online supplementary material). In the trial, the developed solution targeted alerting or reminding only the resident, not any external partner or housekeeper. The first author visited the participants several times during the intervention to accommodate the commercial partner responsible for installing the sensors, the control box, and connection to a secure server.

### *Description of participants*

The inclusion criteria were being a resident in the assisted living facility; 65 years of age or

**Table 2.** Overview of participants' self-rated health status

| Participant Age in years in 2017 | RAND-12 (1–5) Self-rated health | Self-rated cognitive functioning (MCFSI) | HADS Anxiety | HADS Depression |
|---|---|---|---|---|
| A 85 | Good | 3.5 | 0 | 6 |
| B 80s | Very good | 4.5 | 2 | 3 |
| C 92 | Very good | 4 | 1 | 0 |
| D 82 | Fairly good | 2 | 1 | 0 |
| E 86 | Good | 1 | 0 | 0 |
| F 88 | Poor | 3.5 | 3 | 0 |
| G 81 | Good | 3.5 | 1 | 6 |
| H 88 | Fairly good | 6 | 3 | 0 |

RAND-12: 1 = *excellent*, 2 = *very good*, 3 = *good*, 4 = *fairly good*, 5 = *poor*

MCFSI: 1 = *yes*, 0.5 = *maybe*, 0 = *no*. According to a Norwegian validation study, the limit for recommending an assessment of cognitive functioning is 5 for self-scored responses and 7 for scores given by next of kin.

HADS: The instrument has scores for each item under Anxiety (A) and Depression (D) respectively. Number of scores: 0–7 = *normal* (no anxiety/depression), 8–10 = *borderline abnormal* (i.e., borderline case), 11–21 = *abnormal* (i.e., case).

older; and able to see, hear, and follow a conversation. As researchers, we sought knowledge about everyday living in assisted living and believed that by exploring the everyday lives of individuals we could understand how macro-level policy affected a group of residents, and vice versa. In other words, we used the home as the starting point for research on society (Gullestad, 1989).

Our sample consisted of eight older adults aged between 81 and 92 years. All were mobile, although half used mobility aids. Participants had resided at the assisted living facility from 6 months to 16 years. The participants' self-rated scores (baseline data from 2016) on the RAND-12 (RAND Corporation, 2019), MCFSI (Michelet et al., 2018; Walsh et al., 2006) and HADS (Zigmond & Snaith, 1983) can be found in Table 2.

## Data analysis

The principal unit of analysis was the research-based occupation of engaging with seven participants in a focus group discussion on 14 March 2018, focused on the residents' opinions about participating in a 3-year technology-oriented research project. The interview guide is presented in Appendix 3 (see online supplementary material). Other analyses were also performed for the research occupations: a process evaluation of the feasibility study (Holthe, Casagrande, et al., 2018), an inductive thematic analysis of the dialogue cafés (Lund et al., in progress), and a descriptive analysis of the individual interviews and questionnaire responses (Halvorsrud et al., in progress).

### Analysis of the focus group discussion

The analysis of the focus group transcript, consisting of 78 pages, was a data-driven, inductive thematic meaning condensation (Braun & Clarke, 2006). All three authors read the transcript several times to gain an overview of its content, after which each manually coded the transcript independently before reconvening to discuss the codes and emerging themes. After the meeting, the codes agreed upon were merged into the same document, with different colours to highlight relationships between the codes and themes. Examples of the analysis process appear in Table 3.

**Table 3.** Example of inductive thematic meaning condensation

| Quotation | Interpretation | Sub-theme | Overarching theme |
|---|---|---|---|
| *"I think that this [project] is a nice initiative, that it takes what can be positive for older adults seriously. Because it focuses on older adults and what can benefit them, they won't be forgotten so much"* | Taking part in a project that can improve the lives of other older adults is important and meaningful, especially because older adults represent a marginalized group that may be overlooked | Older adults appreciate engaging in projects | Motivation for project engagement |
| *"The one [sensor] under my bed was disturbing. It blinked when I got out of bed to go to the toilet. It came on all of the time"* | The movement sensor interfered with normal habits, and the participant did not like the light blinking all of the time | Technology as an occasional burden | Mixed feelings towards environmental sensors at home |

## Findings

From the focus group discussion, we elaborated three themes with sub-themes: 1) motivation for project engagement with the sub-themes openness to learning new things, preparing for own old-age, participation for others' benefit, and appreciating being treated as a citizen; 2) experiencing and understanding participation in the project with the sub-themes difficulty explaining the project to others, treatment as guinea pigs versus co-researchers, and commitment and feeling of responsibility; and 3) mixed feelings towards environmental sensors at home with the sub-themes using technology for hope and goals, technology as an occasional burden, and failure of technology. The findings are supported by illustrative participant quotes which were translated from Norwegian to English by the first author. The accuracy of the translations were checked by the second and third authors and modified as agreed by all authors.

### *Motivation for project participation and engagement*

The residents had different reasons for wanting to participate in the project with environmental sensors. One said, "*We [other residents and I] are happy about all of the research that's done. Doing research is good!*" (P1) Most participants agreed that they were curious about the project (P2, P4, P5, P6, P7), and one commented that it would have been strange to have not accepted the invitation to participate (P3).

#### *Openness to learning new things*

The participants typically distinguished old technology—familiar devices such as TVs and telephones—from new technology such as the tablet that they were offered as part of the assisted living facility's routine for providing information to residents. Many participants reported finding it difficult to learn how to use the tablet:

> *Yes, I think everything's new. We [older adults such as myself] have lived through all of the old, and it's gone now … Everything with technology is new, yet we live on. So, we can't stand still. We have to learn what's new. That's important, I think.* (P7)

Other participants wanted to learn to operate new technology but admitted struggling to do so: "*It isn't easy to get older and to adapt to all of these computer things. … It took me quite some time before I learned how to use it [the tablet]*" (P1).

#### *Preparing for own old-age*

In the focus group discussion, it became clear that all participants agreed that they did not currently need environmental technology or any other assistive technology. Nevertheless, they were interested in learning about supportive devices and potential solutions to their possible future needs: "*Even if I don't have needs and don't need it [technology] now, the years go by, and a person gets more impaired*" (P7); to which another participant added, "*That's just how it is. The day will come!*" (P6). Yet another elaborated that:

> *I don't need it [technology] now, because I'm 82 years old. However, it's important to be acquainted with such things and to learn how they work. And to be prepared, because in 10 years' time, things may get turned around, and I may really need it [technology], so it's important to learn how it works.* (P7)

Notably, all of the participants perceived the environmental technology as more appropriate for someone older and frailer than them, but that they expected to become frailer with age.

#### *Participation for others' benefit*

In line with preparing for possible future needs, several participants mentioned the value of doing good for others:

> *Perhaps a person has something to contribute, because he or she has lived for many, many years and has some experience. If that can contribute to developing new possibilities for others, then it'll be nice [for them] … and for oneself as well that he or she can be useful for something.* (P2)

### Appreciating being treated as a citizen

The participants agreed that they appreciated being invited to the project and asked their opinions on technology and everyday living:

> *I think that this [project] is a nice initiative, that it takes what can be positive for older adults seriously. Because it focuses on older adults and what can benefit them, they won't be forgotten so much.* (P2)

Another commented, "*I think that we [older adults such as myself] are being taken into consideration. Older adults who manage on their own are easily forgotten*" (P6). To that, another participant added, "*The goals of your project are nice, and your approach is very good. That's important. Plus, you show that you respect older adults*" (P5).

## Experiencing and understanding participation in the project

### Difficulty explaining the project to others

Some participants expressed knowing too little about the project, that they could not recall what they had read on the information letter and consent forms, and that they were largely unable to explain the project's purpose and methods. Several participants agreed that the project was complicated, and highlighted that words and expressions used in reference to the project were difficult to understand. One participant had even tried and failed to explain the project to a friend. None had explained the project and participating in it to their next of kin; neither had their next of kin asked them about the environmental sensors or the project. Nevertheless, all had been intrigued by the invitation to participate and were curious to learn more: "*Most of us [older adults at the facility] wondered what you [the researchers] were up to, so curiosity led us to show up at the meetings, right?*" (P4).

### Treatment as guinea pigs versus co-researchers

The invitation to participate cast the older adults in the role of co-researchers in a project about technology in assisted living. However, the participants perceived the term *co-researcher* to be flattering, even overly solemn, and joked about it. When one asked, "*Is that the politically correct name for a guinea pig nowadays?*" (P4) another responded with laughter, "*Yes, that's the word I've used when talking about the project!*" (P7). Another resident considered herself and the other participants to be the objects of the study, not active researchers. Nevertheless, they all seemed to identify with the term *co-researcher* and found that it elevated their status: "*I'd rather be a co-researcher than an old hag!*" (P6).

### Commitment and feeling of responsibility

Participating in a project for nearly 3 years can be assumed to require sustained interest and endurance, especially when it involves frequent visits to one's residence from engineers and researchers. However, the participants seemed to agree that having guests was a pleasure: "*Getting a visitor? All of them [researchers and engineers] were so nice!*" (P6). The participants were also permitted to call an engineer or researcher if they had any questions, if anything was wrong with the equipment, or if they needed to reschedule an appointment.

The participants agreed that they liked engaging in meetings and being part of a discussion group: "*I find it nice to be in a group where everyone can talk, and everybody can have their say*" (P6). To that, others added, "*Then we have to use our brains and not just sit still and drink coffee*" (P7) and "*It's a change from our somewhat dull old-age lives!*" (P5).

## Mixed feelings towards environmental sensors at home

### Technology installation requires time

Although installing the environmental sensors in each apartment took approximately 2 hours, none of the participants complained about it. As one commented, she and the other residents "*are used to the fact, through the years, that repairs and things need to be done and that people enter apartments to do work. They're not burglars!*" (P1). Another added, "*When something has to be done [fixed in the apartment], we're used to tolerating some noise*" (P2).

### Technology as an occasional burden

The movement detecting sensors resembled golf balls and were mounted on the walls in all rooms of the apartment and under the bed. They

**Table 4.** Framework for the critical occupational perspective (Njelesani et al., 2013, p. 213)

| |
|---|
| What are the relevant sociocultural structures and processes that may mediate and constrain participants' perspectives?* |
| Which occupations are seen as being preferable? How are they discussed or represented in the data?* |
| What appears to be understood as the preferred way to engage in occupations? |
| What assumptions underpin the ongoing valorisation of some occupations and the rejection of others? |
| What power relations are at play?* |
| Whose interests do the occupations serve?* |
| Who is privileged as participants in the occupations? |

flashed every time a movement was detected. The participants reacted differently to the blinking. Some were disturbed, especially at night: "*The one [sensor] under my bed was disturbing. It blinked when I got out of bed to go to the toilet. It came on all of the time*" (P7). Some did not notice the blinking, whereas another reported that the blinking was reassuring: "*Then I know that it works!*" (P1). When we offered to disable the blinking, most participants accepted; whereas the two who declined explained that the blinking signified the technology's sound functioning.

### Failure of technology

Although the sensors and associated wireless network system had been tested in the engineers' laboratory and in private homes, they malfunctioned in the assisted living facility due to the building's old construction with thick brick walls and poor Wi-Fi readiness. Such failures of technology necessitated frequent visits from the engineers to reconfigure the sensors and resolve gateway errors with the local server. The participants seemed to agree that the problems were minor: "*Nothing's perfect! … I realize that the technology has to be adapted and experimented with*" (P5). Another had hoped for the successful installation of a remote light switch but was disappointed when the engineer failed to make this work. On the whole, the residents agreed that interacting with technology demands patience and that they would consider using the technology in the future but were currently in no hurry to embrace it.

## Discussion

User engagement in research has become an important strategy; however, there is the risk that older adults in assisted living facilities will be excluded from participating in research-based occupations due to ageist attitudes and occupational injustice. Because that risk constitutes a social problem that demands attention, we strove to engage the residents as partners in our research project.

Our research question for the focus group discussion was: How did older adults in assisted living experience participating in a 3-year project involving different research-based occupations and a trial with environmental sensors in their homes? User engagement experience is discussed first. Thereafter, to gain a broader understanding of our findings in response to that question, we applied a critical occupational perspective in viewing our results according to the framework of Njelesani et al. (2013) (Table 4) and selected four of the framework's questions, marked with an asterix in the table (Njelesani et al., 2013). To conclude, we discuss the importance of building a social relationship during participatory research.

### The user engagement experience

Eight of the participants engaged in several research occupations during the 3-year study period. Although we, as researchers, perceived them as co-researchers, they argued that the term *co-researcher* was flattering and even overly solemn; they considered themselves to be participants in a project without any particular responsibilities. It remains questionable whether they would have formed a different impression of their role had the technology functioned as intended, which would have granted them access to unique experiences and likely empowered them in their role.

Another question is whether we succeeded in engaging the participants as partners or co-researchers or whether they became additional sources of data and justification for our goal of studying user engagement. The latter possibility has been described as *tokenistic user involvement* (Romsland et al., 2019), meaning that research participants have no real influence because their abilities are underestimated, their tasks condescending, or their different backgrounds responsible for a lack of mutual understanding (Morrison & Dearden, 2013). The opposite of tokenistic user engagement is *meaningful engagement*, which refers to participants' contributions that are made valid and understandable (Morrison & Dearden, 2013; Romsland et al., 2019). Extended over 3-years, user engagement and reciprocal communication can be understood to constitute user engagement for the co-creation of knowledge (Askheim, 2016).

In our study, which was guided by RRI principles (Norwegian Research Council, 2015), we strove to facilitate dialogue and co-creation of knowledge by engaging users in a focus group discussion and other research-based occupations. The participants agreed that research is generally important, were pleased with not being overlooked as a social group, and appreciated being able to contribute knowledge about their lived experiences for others' benefit. Thus, participating in the project generally seemed meaningful to them.

### Applying a critical occupational perspective

Anchored in occupational science, an occupational perspective maintains that all humans are occupational beings, and that health and well-being as broad concepts closely relate to occupation and participation (Whiteford & Hocking, 2012). A critical occupational perspective may shed light on how occupations are understood, which occupations are selected, who is engaged, and what characterizes the contexts of those occupations (Njelesani et al., 2013). It focuses on the ways in which social power relations form and perpetuate occupational inequalities and injustices, along with how they are socially and politically (re)produced (Laliberte Rudman, 2018). By asking critical questions about the data generated, we challenged certain assumptions, hegemonic practices, and ways in which power relations influence the co-creation of knowledge.

### Relevant sociocultural structures concerning assisted living residents and project participation

Regarding the study's context, assisted living facilities are places for living between a private home and a nursing home for older adults who have become frail and need safety, social inclusion, and home care services. The hegemonic sociocultural environment of the facility resembled the sociocultural structure within nursing homes, with inherited assumptions about the roles and power relations of staff and residents. Sociocultural processes mediated everyday occupation and structure in the facility and residents were expected to adapt to and comply with the norms of assisted living culture.

The participants perceived themselves as autonomous citizens entitled to respect and dignity despite their impairments. Invariably, they continued to want to contribute to society. Self-management was the most crucial occupation for all of them, even though many needed practical help with showering, shopping, or using medical supports. That trend is evident in the residents' self-rated health and quality of life (see Table 2).

Several of the residents' quotes implied that they felt fit regardless of age and health conditions. One 82-year-old participant reported wanting to prepare for old age with the expectation that in 10 years' time "*things may get turned around, and I may really need it [technology]*"; therefore, she was motivated to learn about technology now. Many participants expressed striving to keep pace with modern times and wanting to learn how to operate new technology in order to participate in society. Such notions align with recent policies on ageing that have introduced terminology such as *healthy ageing* (World Health Organization, 2019), *productive ageing* (Laliberte Rudman, 2016) and *successful ageing* (Baltes & Baltes, 1993). Such policies belong to a new trend of thinking, embedded in neo-liberalism, which holds all citizens responsible for staying active and healthy, engaging in productive work (Laliberte Rudman, 2016), staying autonomous and empowered, and maintaining a positive sense of self (Baltes & Baltes, 1993).

### Which occupations were seen as being preferable? How were they discussed or represented in the data?

Participating in research-based occupations seemed to be meaningful to the residents and thus preferred. One underscored that preference by saying, "*Being part of a group that discussed something important and getting to use our brains was far more stimulating than just sitting together drinking coffee*".

### What power relations were at play?

Although researcher–participant relations may vary from project to project, we intended to engage the residents as users in different research-based occupations in response to the project agenda's needs and RRI principles (Norwegian Research Council, 2015). According to Farias et al. (2019), it is important to reflect on the power relations in a study before, during, and after it is conducted, and researchers should strive to facilitate user engagement throughout their studies.

The participants were important stakeholders throughout the project, albeit in varying relations of power with us as researchers. During recruitment, the residents exercised power by deciding whether and when to consent to participation. During the project itself, however, we exercised the most power by controlling the frequency of the occupations, which the residents usually accommodated. The power relations in the occupations also generally favored us as researchers.

### Whose interests did the occupations serve?

The research-based occupations foremost served us as researchers, for we needed data to document and explain our findings to the project's funders. Indeed, older adults often are marginalised and excluded from research and development projects due to presumptions that they are frail and cannot meaningfully participate in research (Morrison & Dearden, 2013). The older adults' participation in our study challenges those assumptions embedded in ageist and ableist rhetoric often hidden in society.

### Social relations are more important than technology

The participants seemed to agree that the technological failures were a pity and that patience is typically required with technologies, which are generally perceived as being sophisticated, if not also complicated. Even so, the participants trusted that we would ultimately succeed in our work. The participants also appreciated being asked about their opinions and felt committed to continuing to participate in the project, even when the technology failed and required far more visits than planned. The latter was not a burden, as we had expected; on the contrary, the residents appreciated our visits, which they viewed as offering respite from their boredom. None of the participants withdrew from the project even if the technology failed. Their chief interest was forming social relations with us as researchers and, due to the malfunctioning of the technology, the engineers and researchers who often had to visit their apartments. Such visits became revitalising events during dull days or weeks at the assisted living facility.

## Strengths and limitations

Despite having impairments, the participants in our 3-year longitudinal study were able to contribute their opinions and reflections about the various research-based occupations in which they engaged. Although user engagement in research can be time-consuming, our longitudinal design enabled us to communicate with the participants over time, which facilitated meaningful engagement and positive social relations. Such close relationships may face criticism for risking bias in the data; however, in participatory research, researchers have to be a part of the dialogue in order to enable an egalitarian co-creation of knowledge that reflects reality (Bakhtin, 1981), as well as taking a reciprocal exchange of assumptions and ideas into consideration (Frank, 2005).

Our study's limitations included that the technology failed, which required multiple visits and revisits to participants' apartments. Although we anticipated that such nuisances might become a burden for the residents, they were typically pleased to have visitors and expressed that they did not urgently need the technology anyway. Another limitation was the small sample size of eight residents. This may be a consequence of the recruitment strategy, and the house-keepers' time and ability to identify residents and motivate volunteers for project participation.

### *Study implications and further research*

Older adults in assisted living are important stakeholders in research concerning them as a user group. As a case in point, the residents were interested in learning about technology, what technology could become of interest to them later in the lives, and what technology might appeal to other older adults. Every citizen should be engaged in the process of implementing technology that is relevant in their life. It is important to assess personal preferences and needs as well as perform on-site acceptance tests before installing new technology, as revealed in our study. Furthermore, when technology is implemented, it is important that all stakeholders involved in the person's daily living—the head nurse, community healthcare workers, next of kin and even cleaning staff—know about the technology's existence in the apartment, its purposes, how it functions, and how it can be reset when necessary.

Technology has to inspire collaboration, safety, and coping as well as avoid creating digital gaps and unequal power relations. In that light, it indeed matters what terms and expressions are used if technology is to become familiar and incorporated into one's everyday life. Further research may consider the values of technology for the residents, to generate insights regarding usability and useworthiness of the technology (Krantz, 2012), as well as the participants' opinions on the activities in question as doable and doworthy (Krantz, 2012). However, since the technology in our study failed, we were never in a position to address these issues.

## Conclusion

Older adults in assisted living facilities may easily be excluded from user engagement in service development and research-related occupations. The co-creation of knowledge in our sub-study of the ALP suggests that older adults in assisted living, despite being impaired in some way, were able to meaningfully contribute their opinions about their needs in relation to technology. The method of user engagement in our longitudinal study facilitated social relations, partnership over time, and the co-creation of new knowledge. Our findings imply that older adults should be recognized as important co-creative partners in future health research concerning any matter of interest to them. These findings contribute to occupational science by emphasizing social inclusion regardless of age and living arrangements, and safeguarding human rights and occupational justice. Applying a critical occupational perspective on the research raised awareness about sociocultural assumptions about older adults in assisted living as frail and unable to participate, which may reinforce ageist and ableist stereotypes, and foster occupational injustice.

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No potential conflict of interest was reported by the author(s).

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