User involvement and welfare technology

A qualitative study of health professionals, patients, and relatives experiences within home care services

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ABSTRACT

Background: An increasingly ageing population, a shortage of health professionals, and the transfer of specialised healthcare services to primary care are among the challenges currently facing home care services. Norwegian authorities emphasise the rationalisation potential of older people living longer in their homes and using welfare technology in order to meet these challenges. Furthermore, there is a call for increased user involvement focusing on the co-production of the services. Moreover, such initiatives also involve ethical challenges that must be addressed.

The overall aim of this PhD study was to explore and describe the experiences of users' involvement in the implementation and use of welfare technology from the perspective of home-dwelling older patients, their relatives, and health professionals. Furthermore, the goal was to identify and elucidate the ethical aspects that come into play in home care services.

Methodology: This qualitative study is based on three sub-studies, all with an explorative and descriptive design. This design enables exploration and, thus, a deeper understanding of participants' experiences, thereby yielding a description of the complex context of this study. Inspired by the work of van Manen and Gadamer, the scientific theoretical approach is phenomenological-hermeneutical. The empirical data consist of focus-group interviews with16 health professionals and individual interviews with 16 patients and 18 relatives recruited from six municipalities in South-Eastern Norway. Reflexive thematic analysis by Braun et al. was used to analyse the data.

Results: The nature of home care services in Norway is changing, and the findings indicate new ways of providing and receiving healthcare. There is an increased awareness of the various factors that affect the experiences of patients, relatives and health professionals with involvement and welfare technology. These may include the persons involved, tasks to be solved, tools and types of technologies to be used, infrastructure, organisations, and environmental factors. The experiences related to user involvement and welfare technology are also linked to the physical, mental, and social conditions of the parties involved. Further, it was found that patients, relatives, and healthcare professionals have very different needs, wishes, and values, which, in turn, affect their experiences. An individual approach is,

therefore, desirable but is challenged by the expectations of controlling expenses and the tension between standardisation and individualisation. Ethical concerns about user involvement in pursuing co-production alongside welfare technology arise from the experiences of healthcare professionals, patients, and relatives. I identified the need for the respect and recognition of different competence and efforts, as well as pressure toward patients' and relatives' autonomy. Furthermore, a worry for patient safety, privacy, and how equal access to technology and services was safeguarded was identified.

Even though health professionals found that welfare technology made their work more efficient and manageable, there was nevertheless some resistance to its use. This finding seemed connected to a lack of information, knowledge, and training. Some health professionals were concerned that the reduced number of home visits engendered by welfare technologies made the professional assessment of patients' health more difficult and thus also negatively affected the relationships with patients and relatives. Limited time and arrangements to facilitate the co-production were experienced. Health professionals felt that management considered their knowledge of services and patients when purchasing and implementing new welfare technologies to an insufficient extent.

For the patients in this study, welfare technology was appreciated when it increased their safety, independence, and the opportunity for them to stay at home. They were not concerned about being monitored with welfare technology fitted with such as GPS trackers. Some patients expressed their desire to be more involved in discussions on technology and the care they received. Others, however, chose to rely on health professionals to make sensible choices on their behalf since they did not have the energy to be involved. Nevertheless, patients wanted to be asked about their needs and wishes and expected their autonomy to be respected. Further, patients and relatives were concerned about inequality in the services and their access to technology.

Relatives felt responsible for identifying and providing long-term care for the patients. Welfare technology largely led to positive experiences in terms of patient safety, and the use of tracking technology entailed the possibility of freeing up personal time for both patients and relatives. However, the increased use of welfare technology also reduced the number of visits made by health professionals. Therefore, relatives experienced an increased transfer of tasks and responsibilities without prior discussion or any assessment of their familial and work obligations. The study's results show that the dissemination of reliable information,

trust, power-sharing, and respect for the different knowledge of those involved is essential for user involvement and co-production.

Conclusions: This study finds that patients and relatives primarily value welfare technology, while health professionals had more reservations about its use. However, early involvement, sufficient information, increased knowledge and an individual approach are prerequisites for user involvement and welfare technology success. More attention must be paid to the ethical concerns that arise due to changes in relationships, tasks and responsibilities, autonomy, and the risk of inequality. Home care services seem unprepared for the increasing use of welfare technology and user involvement toward the ideal of co-production. This study enhances the extant understanding of the complexities of user involvement when new technological solutions are introduced and used.

SAMMENDRAG

Bakgrunn: En stadig aldrende befolkning, mangel på helsepersonell og overføring av spesialiserte helsetjenester til primærhelsetjenesten utfordrer i dag den kommunale helsetjenesten. Norske myndigheter vektlegger rasjoneringspotensialet ved at eldre bor lenger hjemme og bruker velferdsteknologi for å møte disse utfordringene. Videre etterlyses det mer brukermedvirkning med fokus på samproduksjon. Disse initiativene innebærer imidlertid også etiske utfordringer som må håndteres.

Det overordnede målet med denne doktorgradsstudien var å utforske og beskrive hvordan skrøpelige hjemmeboende eldre pasienter, deres pårørende og helsepersonell opplever brukermedvirkning ved implementering og bruk av velferdsteknologi. Videre var målet å identifisere og belyse etiske aspekter som spiller inn i dagens hjemmetjeneste.

Metodologi: Denne kvalitative doktorgradsstudien er basert på tre delstudier, alle med et utforskende og beskrivende design. Designet innebærer en mulighet til å utforske og å få en forståelse av deltagerens erfaringer og opplever, og gjennom dette kunne beskrive den komplekse konteksten deltagerne befinner seg i. Den vitenskapsteoretiske tilnærmingen er fenomenologisk-hermeneutisk inspirert av van Manen og Gadamer. Empirien besto av fokusgruppeintervjuer av 16 helsepersonell og individuelle intervjuer av 16 pasienter og 18 pårørende. Deltakerne ble rekruttert fra seks kommuner i Sørøst-Norge. For å analysere dataene ble refleksiv tematisk analyse av Braun m.fl. brukt.

Resultat: Hjemmebaserte tjenester i Norge er i endring og funnene indikerer nye måter å gi og motta helse tjenester på. Det er behov for økt kunnskap rundt faktorer som påvirker opplevelsen av implementering og bruk av velferdsteknologi. Dette kan være personene som er involvert, oppgaver som skal løses, verktøy og type teknologi som brukes, miljø, organisering og infrastruktur. Opplevelser knyttet til brukermedvirkning og velferdsteknologi henger også sammen med personenes fysiske, psykiske og sosiale forhold. Pasienter, pårørende og helsepersonell har videre svært forskjellige behov, ønsker og verdier som påvirker deres opplevelse og som det bør tas hensyn til. En individuel tilnærming er derfor ønskelig, men blir utfordret av forventninger om å kontrollere utgifter og spenninger mellom standardisering og individualisering. Helsepersonell, pasienter og pårørende har etiske bekymringer rundt brukerinvolvering i retning av samproduksjon, og velferdsteknologi. Jeg identifiserte behov for respekt og anerkjennelse av ulike kompetanse og innsats, press mot både pasienters og pårørendes autonomi, og en bekymring for pasientsikkerhet, personvern og hvordan lik tilgang til teknologi og tjenester blir ivaretatt.

Selv om helsepersonellet opplevde at velferdsteknologien effektiviserte arbeidet og ga bedre oversikter, var det var en viss motstand mot bruk. Dette synes være knyttet til mangel på informasjon, kunnskap og opplæring. Noen av helsepersonellet var bekymret for at redusert antall besøk vanskeliggjør faglig vurderinger av pasientenes helse og påvirker deres realsjoner negativt. Tilstrekkelig tid og tilrettelegging for samproduksjon var i begrenset grad til stede i tjenesten. Videre opplevde helsepersonellet at ledelsen ikke bruke deres kunnskap om tjenesten og pasientene når ny velferdsteknologi skulle anskaffes og implementeres.

Pasientene i denne studien vedsatte velferdsteknologien når den bidro til en opplevelse av sikkerhet og selvstendighet, samt mulighet til å bo hjemme lengst mulig. De var ikke bekymret for å bli overvåket, blant annet, ved bruk av trygghetsalarmer og klokker med GPS. Noen pasienter ønsket å være mer involvert i diskusjonen rundt velferdsteknologi og helsetjenestene de mottok. Andre stolte på at helsepersonellet tok fornuftige valg på deres vegne siden de i liten grad orket å involvere seg. Pasientene ønsket likevel å bli spurt om deres behov og ønsker, og forventet at deres autonomi ble respektert. Både pasienter og pårørende var bekymret for ulik tilgang til tjenester og teknologi.

Langvarige relasjoner medvirket til at mange pårørende følte ansvar for å identifisere og gi omsorg til pasientene over tid. Velferdsteknologien bidro til positive erfaringer med tanke på pasientsikkerhet, og bruk av sporingsteknologi medførte mulighet for egentid for både pasienter og pårørende. Bruk av velferdsteknologi reduserte imidlertid antallet besøk fra helsepersonellet. Pårørende opplevde at dette medførte økte overføringer av oppgaver og ansvar til dem, uten at tilstrekkelig kartlegging og diskusjon i forkant ble gjort av deres øvrige familie- og arbeidsforpliktelser. Studiens resultater viser at pålitelig informasjon, tillit, delt makt og respekt for ulike kompetanse og innsats hos de involverte er essensielt for brukermedvirkning og samproduksjon.

Konklusjon: Denne studien finner at velferdsteknologi stort sett blir verdsatt av pasienter og pårørende, mens helsepersonell hadde mer reservasjoner i forhold til bruk. Tidlig involvering, tilstrekkelig informasjon, økt kunnskap, og en individuell tilnærming er viktige forutsetninger for å lykkes med brukermedvirkning og velferdsteknologi. Mer oppmerksomhet bør vies etiske aspekt rundt endring i relasjoner, overføring av oppgaver og ansvar, og risiko for ulikhet. Hjemmesykepleien synes uforberedt på den økende bruken av velferdsteknologi og brukermedvirkning i retning av samproduksjon. Resultatene i studien gir kunnskap om kompleksiteten i brukermedvirkning når nye teknologiske løsninger tas i bruk.

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LIST OF PAPERS

Paper I

Glomsås, H. S., Knutsen, I. R., Fossum, M. & Halvorsen, K. (2020). User involvement in implementing welfare technology in home care services: The experience of health professionals - A qualitative study. *Journal of Clinical Nursing*, *29*(21-22), 4007-4019. https://doi.org/10.1111/jocn.15424

Paper II

Glomsås, H. S., Knutsen, I. R., Fossum, M. & Halvorsen, K. (2021). “They just came with the medication dispenser”- A qualitative study of elderly service users’ involvement and welfare technology in public home care services. *BMC Health Services Research*, *21*, Article 245. https://doi.org/10.1186/s12913-021-06243-4

Paper III

Glomsås, H. S., Knutsen, I. R., Fossum, M., Christiansen, K. & Halvorsen, K. (2022). Family caregivers' involvement in caring for frail older family members using welfare technology: A qualitative study of home care in transition. *BMC Geriatrics*, *22*(1), Article 223. https://doi.org/10.1186/s12877-022-02890-2

LIST OF TABLES AND FIGURES

Table 1 gives an overview of the aims, designs, data collections, settings, and participants in the papers on which this thesis is based.

Figure 1 illustrates a ladder of involvement concerning welfare technology.

Figure 2 illustrates the socio-technical system theory used in the SEIPS 2.0 model.

DEFINITION OF CENTRAL CONCEPTS

User involvement	"User involvement means that the user is considered an equal partner in discussions and decisions concerning his or her problem. At the same time, user involvement has a therapeutic value and is a means of improving and ensuring the quality of services" (Norwegian Directorate of Health, 2022). My translation. "User involvement covers various approaches with different degrees of involvement" (Fischer et al., 2019, p. 514).
Co-production	"An asset-based approach to public services that enable people to provide and people receiving services to share power and responsibility and work together sharing in equal, reciprocal and caring relationships" (The Co-production and Involvement Network for Wales, 2021).
Welfare technology	"Welfare technology means, first and foremost, technological assistance that contributes to increased security, safety, social participation, mobility and physical and cultural activity. It also strengthens the individual's ability to manage themselves in everyday life despite illness and social, mental or physical disability. Welfare technology can also function as technological support for relatives and otherwise help improve accessibility, resource utilisation and quality of service provision. Welfare technology solutions can, in many cases, prevent the need for services or admission to an institution" (NOU 2011:11, p. 99). Translation by Hole (2017).
Home care services	"Home care is an offer of health care for people living at home when illness, impaired health, old age or life circumstances mean they need help for a shorter or longer period. There is no restriction related to age or illness, but an offer to everyone who needs the necessary health care at home" (Fjørtoft, 2016, p. 17). My translation.

1.0 INTRODUCTION

> *"They just came with the medication dispenser….. It would have been nice if the health professionals had asked me."*

This statement from one of the patients in sub-study two (Glomsås et al., 2021) encapsulates the broad agenda of this PhD. This qualitative study focuses on the experiences of older patients, relatives, and health professionals as active partners when welfare technology is implemented and used in home care services. Further, the study sheds light on ethical aspects that come into play with increasing user involvement and the use of welfare technology.

Home care services are under pressure due to the increased number of older people with multiple and chronic diseases, reduced hospital stay, and a shortage of health professionals (European Commission, 2020; OECD, 2019). One policy approach to these challenges has been to improve home care services by involving patients and their relatives in the care (European Commission, 2018; Eurostat, 2020; Ministry of Health and Care Services, 2020). During my work with this PhD, my understanding of the complexity of the concept of user involvement has increased and changed. I have learned that user involvement occurs in many ways and levels. Patients and relatives are expected to commit to taking more responsibility and being active partners in care as co-producers (Askheim et al., 2017; Loeffler & Bovaird, 2017; Vennik et al., 2015). Researchers have further pointed out that co-production is a prerequisite for healthcare service innovations (Askheim et al., 2017; Fusco et al., 2020; Jenhaug, 2018; Røiseland & Lo, 2019). Since there are considerable variations in the needs, expectations, knowledge, and mental and physical capacity of patients and relatives, the research underlines the necessity for an individual assessment of how they should be involved in the care and for the use of welfare technology (Dyb et al., 2021; Nakrem et al., 2018; Santana et al., 2018).

Another policy initiative to meet home care challenges is the expectation of increased use of welfare technology (Eurostat, 2020; Meld. St. 26 (2014–2015); Meld. St. 29, 2013). Like all municipalities in Norway, the six municipalities involved in this study are obliged to implement and use welfare technology in home care services. However, the implementation and use of welfare technology in Norwegian home care services have hitherto been slow (Halvorsrud et al., 2021; Rostad & Stokke, 2021). The implementation of welfare technology requires changes in how care is given and received and entails new and changed requirements for competence and relations (Holden et al., 2013; Zander et al., 2021). The research has identified several barriers to implementing and use of welfare technology, such as lack of information and knowledge, resistance to change, infrastructure and the organisation of home care (Dugstad et al., 2019; Nilsen et al., 2016; Nilsen et al., 2020). Further, different technologies and use create challenges that will thus impart manifold consequences on health professionals', patients', and relatives'.

In the course of my study, ethical aspects of user involvement have been identified. Some of the concerns explored are also illuminated in other studies, such as threats to autonomy (Lilleheie et al., 2019), conflicting goals and values (Vahdat et al., 2014), changes in relations and responsibilities (Bjørkquist et al., 2019; Vahdat et al., 2014), trust and respect (Bjørkquist et al., 2019; Gheduzzi et al., 2021b), and justice and equal access to service (Gheduzzi et al., 2021a). Further, this study, as well as others, have also identified several ethical aspects of the implementation and use of welfare technology, such as threats to autonomy (Zwijsen et al., 2011), safety (Brims & Oliver, 2019; Hofmann, 2013; Sánchez et al., 2017), vulnerability (Hofmann, 2013), monitoring (Hofmann, 2013; Sánchez et al., 2017), and equal access to the technology (Hofmann, 2013; Zwijsen et al., 2011).

This thesis comprises papers from three sub-studies (Glomsås et al., 2022; Glomsås et al., 2020, 2021). The three papers separately examine patients', relatives', and healthcare professionals' experiences concerning their involvement in welfare technology and what factors influence their experiences. This thesis aims to explore further how different values, interests, and realisations within and between these three groups of welfare technology users influence each other and their experiences.

1.1 Introduction to the methodology and theories

This study is grounded in a scientifical theoretically phenomenological-hermeneutical approach inspired by van Manen (1990/2015) and Gadamer (1960/2010). It was essential for me to capture and understand the richness, complexity and individuality of real-life circumstances regarding the actions, attitudes, and relationships that exist among health professionals, patients, and relatives (Gadamer, 1960/2010; van Manen, 1990/2015). Since the study aimed to grasp the participants' everyday experiences, qualitative focus-group interviews were chosen for the health professionals and individual interviews for the patients and relatives; this approach was drawn from Bowling (2014) and Brinkmann and Kvale (2015). The reflexive thematic analysis described by Braun, Clarke, Hayfield and Terry (2019) was taken advantage of in the analysing process.

To explore the ethical challenges identified in the study, I found the ethics of care theory by Virginia Held (2006) and Joan Tronto (1994) to be applicable, together with the principle-based biomedical ethics of Beauchamp and Childress (2013). The ethics of care theory highlights the importance of context, relations, responsibility, respect, trust, and the balance of power (Held, 2004; Tronto, 1994). Principle-based biomedical ethics supports the discussion of autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2013). Rather than being competing or mutually exclusive approaches to moral theory, these two theoretical perspectives supplement each other and are valuable in discussing the ethical aspects of involvement and welfare technology.

Through working on the study, I have become increasingly aware of the mutual influence patients, relatives, health professionals, technology, and other system factors have in the pursuit of optimising healthcare to the best possible use of welfare technology and efficient home care services. The human factors will play an essential role in the future of technological advances, where people and technology are being integrated more closely and intensively than ever before (Carayon & Hoonakker, 2019). Therefore, it was necessary to construct a simplified picture of how people influence each other and are affected by technology and other elements such as organisation, environment, culture, and infrastructure. I found socio-technical system theory built on human factors to be suitable and useful in this regard (Carayon et al., 2020; Holden et al., 2013; Leeds University Business School, 2021).

The socio-technical system theory is also appropriate for an individual approach where the focus is on the person or group of people at the centre of healthcare. Efforts to support people through individual care to fit their capabilities, limitations, and performance needs are essential for optimising the use of welfare technology (Dul et al., 2012; Holden et al., 2013).

1.2 My engagement in the study

My engagement with welfare technology goes back several years when I worked for a company that developed an electronic patient record system for hospitals, and later as a nurse responsible for implementing welfare technology in a home care setting. I recognised through these experiences that welfare technology could be positive for patients, relatives, and health professionals. However, I was also able to witness that there exist certain barriers to the successful implementation and use of such technologies. Nevertheless, a sense of optimism concerning the use of welfare technology marked my preconceptions upon embarking on this study.

There was limited focus on user involvement in my earlier work environments, at least in terms of understanding patients and relatives as partners in care. Recognising the potential of user involvement as a way of working, thinking, and improving the implementation and use of welfare technology gradually aroused my interest. When I first began to develop the present study, my level of understanding was such that I thought that user involvement amounted to a simple “yes or no” question. However, my deepening understanding of the complexity of user involvement can be traced through the increasing problematisation of the concept in the papers and further in this thesis. It has become clear that the concept is exceedingly broad and features many nuances, angles, levels, and ways of understanding. Therefore, I have limited my discussion of user involvement in this thesis as primarily related to user involvement in the direction of co-production.

Further, as a nurse, I feel obliged but also curious to explore and be aware of the ethical aspects of user involvement and welfare technology. I became interested in the importance of positive relations between patients, relatives and health professionals as a prerequisite for meaningful involvement in the use of welfare technology. Further, autonomy and equality as basic human rights were also at the centre of my attention. Moreover, the question of who benefits from increased use of welfare technology and user involvement caught my interest.

My curiosity in this field was further aroused when I, as an assistant professor in nurse education, was invited to join a project titled “Support Quality of Life (SOL)” (Kunnskapsbyen Lillestrøm & Karlstads kommun, 2018). The overall goal of SOL was to increase the quality of life and self-efficacy of people needing help by using the support that technology could provide. The study took place from 2016 to 2018, and this PhD study is a further development that has its origins in the sub-study of the SOL project, “Knowledge-based introduction of welfare technology in home-based service”. Data from the SOL sub-study concerning health professionals are in addition to new data used in sub-study one of my PhD work (Glomsås et al., 2020).

1.3 Relevance of the study

In recent years, welfare technology has gained momentum in home care services, and the available types and uses thereof are constantly changing. Therefore, further research on the experiences of user involvement of those involved in implementing and using such technology is needed (Kamp et al., 2019; Oelschlägel et al., 2021).

Health services are increasingly occurring within patients’ homes, which means that for some, welfare technology has become a part of their quotidian domestic environments. It is essential to verify whether the experiences of health professionals, patients, and relatives in such home care set-ups are in accordance with health policy expectations, including such factors as empowerment, independence, and safety for the patients and their relatives (Eurostat, 2020; Kamp et al., 2019). Further, the extant research highlights that the use of welfare technology in care seems to be only as successful and suitable as organisational culture, infrastructure, work practices, and local government finances allow it to be (Carayon et al., 2014; Frennert & Östlund, 2018; Holden et al., 2013). The research mentions different forms of health professionals’ resistance to welfare technology, such as organisational, cultural, technological and ethical resistance, which all affect the use of welfare technology (Dugstad et al., 2019; Nilsen et al., 2016). There seems, however, to be limited knowledge about whether such resistance also applies to patients and relatives. A recent systematic review identified capacity, attitudes and values, health, expectations, participation, identity, and lifestyle as the main barriers to using welfare technology (Zander et al., 2021). Nevertheless, there is a lack of knowledge about how patients and relatives experience welfare technology with regard to their relationships, responsibilities, and co-production with health professionals.

There is an expectation of increased user involvement in the direction of co-production in the way of thinking, working, and responding to the challenges present in home care services (European Commission, 2020; European Public Health Alliance, 2019; Eurostat, 2020). The implementation and use of welfare technology demand the interaction and involvement of patients, relatives, and healthcare professionals alike. However, despite decades of focus on user involvement, it still does not seem to be an integral part of mainstream healthcare practice (Angel & Frederiksen, 2015; Gulbrandsen et al., 2016; Johannessen et al., 2018). Therefore, it is relevant to extend the extant knowledge on how patients, relatives, and health professionals experience the changes in home care. The research indicates that user involvement in care is complex and can occur differently (Malloggi et al., 2020; Omeni et al., 2014; Vahdat et al., 2014). Further, knowledge of user involvement in home care is scant since the research thereon is primarily from the perspective of mental healthcare, hospital care, and transition care (Johannessen et al., 2018; Lilleheie et al., 2019; Millar et al., 2016). In this thesis, I have mainly chosen to examine user involvement, and the concept of co-production since this seems to be the expected level of user involvement (Clarke et al., 2017; Greenhalgh & Papoutsi, 2019; Redman et al., 2021). Despite the increased political focus on co-production in health care, few studies have evaluated how co-production is experienced by patients, relatives, and health professionals and whether it is in line with the political ambitions of health services (Redman et al., 2021).

To understand patients', relives', and health professionals' experiences of user involvement and the use of welfare technology, it may be valuable to look more closely at its social and technical aspects. The social aspect largely concerns a person's contact, cooperation, interaction, and feelings of togetherness and involvement. The technical aspect focuses on how the technology is designed and works, the network for internet use, routines, environments, organisation, and follow-ups. As Holden (2013) points out, there is increasing recognition of the value of human factors, the influences of decisions and experiences, and a need for individual approaches whenever technology is employed. Further, how the demand for efficiency and cost-saving practices influences the experience of user involvement and participation is essential knowledge in the pursuit of enhancing the quality of home care services.

According to several researchers, further research is required to describe the ethical aspects of care in the transition to patients' homes and the call for their increased involvement in welfare technology (Bennett, 2019; Hofmann, 2013; Mort et al., 2015). An exploration of changes with regard to power balance, respect, relations, values, and trust between patients, relatives, and health professionals is thus relevant (Held, 2004, 2006; Mort et al., 2015; Vanstone et al., 2019). It has been noted that health professionals' attitudes and practices can threaten patients' and relatives' autonomy (Entwistle et al., 2010; Gheduzzi et al., 2021a). Another ethical concern is related to the reduced number of physical visits from health professionals due to the increasing use of welfare technology. Even though this is a health policy goal, there may be a concomitant safety risk and dehumanisation of the care when face-to-face encounters are replaced with technology (Brewster et al., 2014; Saborowski & Kollak, 2015). It can further take away some of the relational dimensions of care, which poses a further challenge for user involvement since it may affect the settings and perceptions people have of each other (Nordang & Halvorsen, 2022). There are also concerns over the transfers of tasks and responsibility to patients and relatives since these patients are generally frail and vulnerable, and relatives also have other commitments to attend to (Haukelien, 2020; Stokke et al., 2019). Health professionals are further concerned that tracking technology can threaten the sanctity of patients' private lives (Bartlett et al., 2019; Dahl & Holbø, 2012). Questions should be asked about whether patients and relatives have equal opportunities for healthcare services and access to welfare technology (Beauchamp & Childress, 2013; Held, 2006; Patient and User Rights Act, 1999; Tronto, 1994; United Nations, 1948).

This study presents a critical view and new knowledge of contemporary perspectives connected to user involvement in pursuing co-production in welfare technology use. It identifies and discusses further the ethical aspects underlying user involvement in welfare technology. The knowledge generated in this thesis can help to improve the quality of home services if it is used sensibly.

1.4 Aim of the study

Based on the challenges and changes encountered in home care services, the overall aim of this PhD study was to explore and describe user involvement experiences in the implementation and use of welfare technology from the perspective of home-dwelling older patients, their relatives, and health professionals. Further, the goal was to identify and elucidate the ethical aspects that come into play in contemporary home care services.

The aims of the three sub-studies were:

- Sub-study one aimed to learn more about the factors that promote or inhibit user involvement among health professionals when implementing welfare technology in home care services.
- In sub-study two, the aim was to explore older patients' experience of user involvement in the implementation and everyday use of welfare technology in home care services.
- Sub-study three aimed to explore the relatives' experiences of involvement regarding caring for frail older patients who are receiving home care and are supported by welfare technology, as well as the possible ethical aspects that arise.

1.5 How users are defined in the papers and in the thesis

In this thesis, the users of welfare technology are frail older patients, their relatives, and health professionals with daily patient contact. The health professionals comprised registered nurses and nursing assistants. A relative, as defined in this study, was a person registered as the closest relative in the electronic patient record. In this thesis, I largely use the terms "patients," "relatives," and "health professionals." However, different terms are used in the papers, as explained below.

In paper two, patients are called "service users" after discussing the term "patient" with the PhD advisory team (the team is described in section 1.7). The patient representative did not want to be called as such. In paper three, patients are called "care receivers" or parents, siblings, and spouses to highlight the close relationships between the family members. However, I have returned to the term "patient" in this thesis for two main reasons; first, using both "service users" and "users" is likely to confuse readers, and second, since all patients in this study received home care services, they are patients according to the law and thus have certain rights and obligations, such as being involved in their own care (Patient and User Rights Act, 1999). The relatives are called “next of kin” in papers one and two. In paper three, they are called “family caregivers” or “spouses,” “sons,” “daughters,” and “siblings” to show their close relationship with the patient. In this thesis, I use the term “relatives” since it appears from the description of the inclusion criteria that they are the patients’ closest relatives (described in section 5.3.1).

1.6 Welfare technology used in the participating municipalities

Technological solutions in the Norwegian health care context fall under the welfare technology umbrella (Kamp et al., 2019). Kamp et al. (2019) point out that the term is broad and loosely defined, thereby covering many technologies. In the international literature on health care technology, terms like “telecare,” “telehealth,” “assistive living technology,” and “e-health” are commonly used, but their definitions and the dividing lines between them seem to be blurred (Cook et al., 2016; Greenhalgh et al., 2013; Solli et al., 2012). In this study, all the health professionals had access to electronic patient records on digital tablets, and digital door locks were widespread. Further, the patients used digital medication dispensers and personal safety alarms (analogue and digital) with and without an integrated global positioning system (GPS). A few watches fitted with GPS, stove guards, window and door sensors, and digital calendars and planners also supported patients receiving home care services and their relatives.

1.7 The PhD advisory team

Connected to my PhD work, we settled on an advisory team. Two members of this team were recruited from two pensioners associations and one from the Norwegian Institute of Public Health resource group of relatives. The team consisted of one patient receiving home care and two relatives, one of whom was also a retired nursing assistant. The members of this team acted as discussion partners in designing the interview guides and interpreting the findings. The goal of the team was to discuss and strengthen how the result could be understood and interpreted from the point of view of patients and caregivers. The team met twice a year, and input and reflections on results were additionally exchanged by e-mail to me.

1.8 Structure of the thesis

Chapter 1 introduces this thesis' focus, theoretical framework, design and methodology, relevance, aim, the designation of the participants and the structure of this thesis.

Chapter 2 describes the background regarding the key concepts, namely home care services, innovation and welfare technology, user involvement, and co-production.

Chapter 3 presents the research status of a home care service in change, welfare technology, user involvement, health professionals, patients and relatives as co-producers.

Chapter 4 presents the theoretical framework: the theory of ethics of care, principle-based theory within biomedical ethics, and socio-technical system theory.

Chapter 5 presents the design, data collection methods, and data analysis.

Chapter 6 comprises discussions of ethical considerations and methodology.

Chapter 7 briefly presents the main findings from the three sub-studies.

Chapter 8 comprises a discussion of the significance and consequences of the overall findings of the three sub-studies.

Chapter 9 comprises the main conclusions, implications for practice, and suggestions for further research.

2.0 BACKGROUND

Increased longevity in the life expectancies of older people, a lack of health professionals, early discharge from hospitals, and scarce resources in public healthcare place pressure and restrictions on home care services (European Commission, 2020, 2021; Eurostat, 2020). With these challenges, it is argued for the importance of fulfilling a healthcare policy that emphasises the concept of "Aging in place" (Pani-Harreman et al., 2020; World Health Organization, 2015b). This implies that older people are expected to live in their homes for as long as possible, supported by relatives, home care services and welfare technology. Further, even though many patients are old, frail, and vulnerable, it is still expected that they should take more responsibility for their health with the support of welfare technologies (Jacobsen, 2020; Peek et al., 2014; Wiles et al., 2011). Relatives are also expected to be more actively involved in patient care (Callaghan, 2012; Søvde et al., 2019; Tønnessen et al., 2016). In this context, health professionals experience more tasks with less time to see and follow up with patients and relatives (Fjørtoft et al., 2020).

2.1 The home as the site of care

Today, Norway has approximately 5.4 million inhabitants and is divided into 356 municipalities (Statistics Norway, 2021). The number of people over 70 years of age in Norway was 12.4% in 2020 and is expected to reach around 22.4% in 2060 (Statistics Norway, 2021). An overview from Statistics Norway shows that 28.6% of inhabitants over 80 use home care services, a percentage that is on the rise (Statistics Norway, 2022).

Home care services in Norway are organised geographically, and municipalities are obliged to provide primary health care (The Health and Care Services Act, 2011). All Norwegians with health-related needs have the legal right to receive public home care services free of charge (Patient and User Rights Act, 1999), which municipalities primarily finance through the receipt of taxes (Magnussen et al., 2009). This approach to healthcare is called the Scandinavian or Nordic welfare model (Kamp & Hvid, 2012). The Nordic welfare model is based on solidarity and focuses on universal human rights and the protection of minorities.

The home as an important arena for healthcare services was taken up politically in the 1970s (Ringard et al., 2013), and the Act on Municipal Health Services (1982) required municipalities to offer home services to all citizens. Until the 1980s, the extant services mainly focused on care for older people. However, in the following years, a series of reforms and escalation plans gave municipalities the responsibility of providing long-term care services to users of all ages and with multiple diagnoses and disorders (Gautun, 2020; Gautun & Grødem, 2015; Otnes, 2015). During the same period, the political objective to transfer more tasks from hospitals to municipalities has also taken precedence. This focus on and development of home care services in Norway were further strengthened when the Coordination Reform was implemented in 2012 (Meld. St. 47 (2008-2009)).

Due to financial pressures in healthcare, there is a focus on extracting maximum value from the healthcare budget and moving as much healthcare as possible to patients' homes (Henderson et al., 2012; World Health Organization, 2015a). There are considerable savings to be made when older people live longer at home in contexts with tight local budgets. A report by the Norwegian Directorate of Health on unit costs in municipalities in 2018 shows that they can save NOK 700,000 per year for each senior who lives at home rather than in a nursing home (Norwegian Directorate of Health, 2019a). Nevertheless, the operation of home care services is expensive for municipalities, and the cost is only increasing due to the increasing number of older people needing such services. Further, access to sufficient staff with the requisite expertise is an issue that European home care services must deal with (Rafferty 2018; White et al., 2019).

2.1.1 Demands for innovative thinking

From a political point of view, innovative thinking is highlighted as a response to the demographic, organisational and economic challenges in home care services. (Meld. St. 15 (2017-2018); Ministry of Health and Care Services, 2015a). Innovative thinking and working are described as necessary factors for transforming today's system of care into one of more sustainable service delivery.

The World Health Organization (2021) explains the concept of “health innovation” as follows:

> Innovation identifies new or improved health policies, systems, products and technologies, and services and delivery methods that improve peoples’ health and well-being. Health innovation responds to unmet public health needs by creating new ways of thinking and focusing on vulnerable populations’ needs. It adds value in improved efficiency, effectiveness, quality, sustainability, safety, and affordability. Health innovation can be preventive, promotive, curative, rehabilitative, or assistive care.

As noted above, innovation is not just seen as a new idea or intervention. It can be connected to things as well as relations. For example, it can include developing user-friendly and resource-saving technologies to support patients and relatives or improving and streamlining services. Innovations can also be understood as a new way of involvement, such as the co-production of care to save municipal resources or improve caring processes due to a new way of thinking.

2.2 The political expectations of welfare technology

During the 2000s, technological solutions gained increasing attention in Norwegian healthcare (Meld. St. 47 (2008-2009); NOU 2011:11). Welfare technology is expected to contribute to the innovation of healthcare services with a focus on effectiveness and improved quality. The white paper “An innovative and sustainable Norway” (Meld. St. 7 (2008–2009)) proposed that the government find new, innovative solutions to meet tomorrow’s care challenges. The white paper “The right treatment - in the right place - at the right time” (Meld. St. 47 (2008-2009)) highlighted the need to develop new technological solutions in healthcare. However, it was not until the white paper “Innovation in care” that the term “welfare technology” was launched and a definition given (NOU 2011:11). The definition has since been used widely in Norway:

> Welfare technology means, first and foremost, technological assistance that contributes to increased security, safety, social participation, mobility and physical and cultural activity. It also strengthens the individual's ability to manage themselves in everyday life despite illness and social, mental or physical disability. Welfare technology can also function as technological support for relatives and otherwise help improve accessibility, resource utilisation and quality of service provision. Welfare technology solutions can, in many cases, prevent the need for services or admission to an institution (NOU 2011:11, p. 99). Translation by Hole (2017).

To strengthen the ability of the healthcare sector to innovate and enable new solutions to be developed, tested, documented, and put into use, the national welfare technology program in Norway was initiated in 2013 (Norwegian Directorate of Health, 2019b). The program's main goal was that welfare technology should be an integral part of healthcare services by the end of 2021 and be offered to users at the same rates as other services (Breivik et al., 2021). Due to delays, the national welfare technology program has been extended from 2022 to 2024 (Prop. 1 S (2021–2022)).

Some welfare technologies are offered for free; others are provided as a voluntary service and are not required by law. Most municipalities, therefore, charge a monthly fee for some welfare technologies based on Section 11-2 of the Health and Care Services Act (2011) and on regulations on deductibles for municipal health and care services (The Regulations on Deductibles, 2011).

2.3 Opportunities for user involvement

User involvement is a central perspective in this study. Its provenance can be dated back to the Universal Declaration of Human Rights in 1948 (United Nations, 1948). The declaration establishes that everyone has the right to a good, safe, and meaningful life based on their capabilities and that all people enjoy the same rights. In terms of health, user involvement and empowerment are often connected to the World Congress in Ottawa (World Health Organization, 1986). The Congress represented a paradigm shift from a traditional and paternalistic way of thinking based on health professionals' authority to an understanding of patients' rights and power to participate in the decision-making processes that concern them (Kökény, 2011; Tveiten & Boge, 2014). User involvement has historically been linked to a democracy-oriented and market-oriented perspective (Andreassen, 2017; Christensen & Fluge, 2016). However, there is an increased focus on co-production in user involvement, where patients and relatives are supposed to assume more responsibility and become partners in their own care (Dent & Pahor, 2015; Greenhalgh & Papoutsi, 2019).

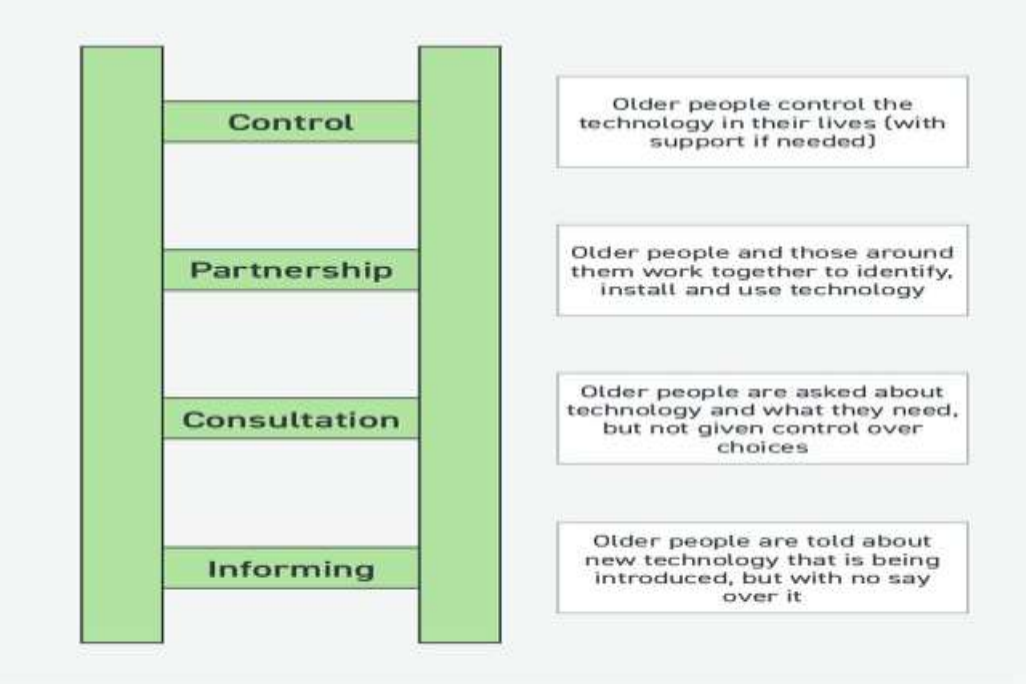
There are requirements to involve patients and their relatives in their healthcare in various European green and white papers (Dent & Pahor, 2015; European Commission, 2021; United Kingdom Parliament, 2012). Further, section 3-1 of the Norwegian Patient Rights Act (1999) contains a clear statement on the obligation of healthcare services to ensure that patients play an active role in decisions concerning their own lives: "Patients and service users are entitled to participate in the implementation of their health care. The form of involvement shall be adapted to the individual patients' ability to give and receive information" (My translation). Relatives also have the right to be involved in the care when the patient wishes to. They may also have to take over patients' decisions when patients can no longer decide for themselves, as in cases of cognitive impairment (Patient and User Rights Act, 1999).

2.3.1. Co-production

User involvement, described as the "co-production of care," was first conceptualised by an academic team led by Elinor Ostrom at Indiana University (Realpe & Wallace, 2010). Initially, the idea referred to a co-production between health professionals and patients, but later definitions were expanded to include relatives and civil society as actors (Pestoff, 2014; Realpe & Wallace, 2010). Co-production can be seen as a step toward increased democratisation and patients' right to be involved in the care (European Commission, 2018; Hamann & Heres, 2019; Vennik et al., 2015). Policy decision-makers want a healthcare service based on active collaboration where power and responsibility for care are shared between patients, relatives, volunteers, and health professionals in planning, implementing, and evaluating certain measures (Beresford et al., 2015; Christensen & Fluge, 2016). Further, policymakers all over Europe have embraced co-production since it can reduce public costs when patients and relatives take more responsibility for their provision of care (Loeffler & Bovaird, 2017).

In this thesis, I use the following definition of co-production: “an asset-based approach to public services that enable people to provide and people receiving services to share power and responsibility and work together sharing in equal, reciprocal and caring relationships” (The Co-production and Involvement Network for Wales, 2021).

Figure 1: Ladder of involvement in relation to welfare technology



Older people control the technology in their lives (with support if needed)

Older people and those around them work together to identify, install and use technology

Older people are asked about technology and what they need, but not given control over choices

Older people are told about new technology that is being introduced, but with no say over it

The figure is from the report “Aging well with assistive technology: Co-production technological solutions with older people. A scoping review of the evidence” by Rolfe et al. (2021) and is inspired by the work of Arnstein (1969). The figure is used with permission (Appendix XI).

Figure 1 visualises the different levels of involvement. It shows that the higher the patient’s level of involvement on the ladder, the more responsibility and additional tasks are added, but also an expectation of transfer of power from health professionals to patients and their relatives.

3.0 RESEARCH STATUS

In section 3.1, I present the current state of Norway's home care services. The expectations surrounding welfare technology as an integral part of home care services are also described. In section 3.2, I present the research status for the concept of user involvement, followed by an elaboration on the notion of co-production in care.

3.1 Home care is changing

The research presents home care services as a practice with many expectations, requirements and ethical challenges (Andersen et al., 2018). At the same time as the number of older patients is increasing, the number of nursing homes has been reduced. The threshold for securing a place in a nursing home has become increasingly higher, with the upshot that patients have to stay at home for longer (Gautun, 2020). A further consequence is that patients who live in their homes and receive home services are considerably older and frailer today compared to those who lived at home in the 1970s and 1980s (Gautun, 2020). As a result of the increasing number of patients in need of home care services, the research has pointed out that health professionals experience time pressures amid more tasks and responsibilities as well as conflicting expectations and demands (Fjørtoft et al., 2022; Strandås & Bondas, 2018). This may potentially challenge health professionals' relationships with patients and relatives and compromise their professional obligations (Martinsen et al., 2018; Møller & Delmar, 2019). It has been found that the municipalities have not been provided with enough resources to meet the increasing number of challenges following health reforms, such as the Norwegian coordination reform (Haukelien et al., 2015; Kristiansen et al., 2019; Theie, 2018). Increasingly tighter resource limits have also led to changes in who receives home services as well as the content thereof (Kristiansen et al., 2019).

The typical geriatric patient receiving home care services undergoes age changes and may have multiple diseases and often different forms of functional and mental impairment. The frail older patient is particularly vulnerable to injury and illness (Ranhof, 2020). Clegg et al. (2013) state that almost half of those over 85 are probably frail. It is important to note that frailty can affect user involvement when welfare technology is implemented and used (Bjørkquist et al., 2015; Lilleheie et al., 2019).

3.2 The use of welfare technology

The research indicates that the use of welfare technology amid the possibility of remaining in one's familiar environment can improve empowerment, increase feelings of safety and independence, and strengthen patients' ability to cope with their life situations (Bennett, 2019; Halvorsrud et al., 2021; Sánchez et al., 2019; Zander et al., 2021). When welfare technology is used, the patient's physical and mental ability should be considered (Holden et al., 2013; Vahdat et al., 2014). We know that an individual's state of health, attitudes, values, expectations, identity, and lifestyle are important factors regarding the use of welfare technology (Frennert & Östlund, 2018; Stokke et al., 2019; Zander et al., 2021). Involving older patients in implementing welfare technology is further desirable but challenging due to the lack of capacity, information, and competence surrounding the available technology and what they may benefit from (Bjørkquist et al., 2015). Additionally, some health professionals are worried that patients perceive the use of such technology leads to an infringement on their privacy by being monitored (Boise et al., 2013). However, several studies indicate that patients are more concerned about how welfare technology can contribute to their security, safety, freedom, and mobility than concerns over being monitored (Bartlett et al., 2019; Karlsen et al., 2018; L. Liu et al., 2017).

For relatives, welfare technology can support them in providing care and reducing potential stress and strain when caring for frail older patients (Czaja et al., 2016; Kamp et al., 2019; Karlsen et al., 2018). However, with the increased use of welfare technology and fewer visits from health professionals, there is a risk of the perception that more of the responsibility and care workload will fall on relatives (Karlsen et al., 2018; Oderud et al., 2015; Sriram et al., 2019).

For health professionals, welfare technology is meant to support and streamline their daily work and support their decision-making processes (Kamp et al., 2019; Kirkegaard & Andersen, 2018; Majumder et al., 2017). Welfare technology is also expected to save costs with more efficient workflows and reduced patient visits (Kamp et al., 2019; Snoswell et al., 2020). However, welfare technologies can also threaten stability and predictability, power, role and group identity, and fundamental healthcare values (Nilsen et al., 2016). With the reduction of face-to-face meetings, health professionals' opportunities to see patients and make professional assessments of their health status are challenged (Saborowski & Kollak, 2015).

A study by Kleiven (2020) showed that new technology is often based on how designers picture its use, which might not fit users' needs and practices. Since not all technology is suitable for all users, welfare technology must be assessed in view of the individual user's needs and requirements (Halvorsrud et al., 2021). Another study indicates that new technology should be tested and customised before being used (de Veer, Fleuren, Bekkema, & Francke, 2011). Further, as Cresswell et al. (2013) point out, the extant infrastructure is often insufficient when implementing welfare technology. Network instability is an issue that can undermine trust in welfare technology and lead to uncertainty, frustration, and concern about the quality of care (Andersson & Edberg, 2012; Barrett et al., 2014; Kruse et al., 2017). Other concerns about welfare technology include equal access and cost (Kruse et al., 2016).

Welfare technology is still not fully implemented in Norway's home care services. There are substantial local differences in the technological solutions the management chooses to purchase and in how advanced municipal healthcare is in the process of implementation and use (Halvorsrud et al., 2021; Rostad & Stokke, 2021). There may be discrepancies between expectations and the complex reality these technologies are part of (Stokke, 2018). As Halvorsrud et al. (2021) also point out, the implementation and use of welfare technology are multifaceted and complex.

3.3 Prerequisites for user involvement

The research highlights that patients, relatives, and health professionals should all be involved in innovation processes in healthcare since users have different desires and needs to be considered (Barber et al., 2019; Bergerum et al., 2020). User involvement has been credited with improving information availability and service accessibility, thereby leading to increased empowerment, confidence, and patient satisfaction (Alm Andreassen, 2018; Kaltoft et al., 2014; Omeni et al., 2014). Further, meaningful discussions and a shared understanding of what user involvement entails and why it is essential are prerequisites for reaching each party's respective goals (Johannessen et al., 2018; Mathisen et al., 2016). Access to reliable information can also be necessary to make informed choices between reasonable alternatives (Glicksman, 2018; Sedig, 2016). The research indicates, however, that health professionals' attitudes, knowledge, and time allocated to cooperation are essential for patients and their relatives' opportunities for involvement (De Rosis et al., 2020; Dugstad et al., 2019; Saborowski & Kollak, 2015). The research underlines the importance of empowerment processes that involves being heard, seen and respected, to increase user involvement (Dent & Pahor, 2015; Spreitzer, 2008). Additionally, the studies indicate that when patients feel empowered and are actively engaged in their healthcare, they are liable to experience autonomy, better health outcomes, and improved care experiences (Kuosmanen et al., 2021; Vahdat et al., 2014). Furthermore, trust, respect, and mutual recognition are also prerequisites for adequate involvement in care relations (Held, 2006; Tronto, 1994). However, it is not necessarily the case that user involvement automatically leads to a better quality of healthcare service provision. In their research, Williams, Kang and Johnson (2016) note the risk of power imbalance and stereotypical prejudices in users' involvement in care. According to various personal ideologies, circumstances, and needs, other studies have revealed that health professionals, patients, and relatives can have different perceptions and understandings of what user involvement means and entails (Dent & Pahor, 2015; Fudge et al., 2008; Skjeldal, 2021). Differences in the values of patients, relatives and healthcare professionals can create conflicts in the provision and the involvement of care (Hofmann, 2013; Sánchez et al., 2017; Vanstone et al., 2019). However, planning and performing the services together can deepen their understanding of each other's competencies and values (Batalden et al., 2016; Hvitstein-Strøm, 2019).

Older patients are a highly heterogeneous group with different wishes and needs (Grates et al., 2019). They are also often unfamiliar with the concept of user involvement in healthcare since they are accustomed to the traditional, paternalistic, and task-oriented care approach (Dyrstad et al., 2015; Hestevik et al., 2019; Johannessen et al., 2018; Olsen et al., 2019). Bennet (2019) further states that patients' decision-making capacities must be considered. Older patients often struggle to understand and remember information about welfare technology, which challenges the extent to which comprehensive user involvement is possible (Lilleheie et al., 2019). Furthermore, identifying and redistributing power for promoting patients' and relatives’ relationships with health professionals is needed since paternalistic working methods and attitudes are not always easy for health professionals to put aside (Askheim et al., 2017; Christensen & Pilling, 2019).

Relatives usually have close, long-term relationships with patients and wish to be involved in care decision-making (Held, 2004; Tronto, 1994). The research shows that relatives can bring valuable knowledge about the patient’s values, resources and needs (Manias et al., 2019; Ris et al., 2019; Wilson et al., 2017). Such knowledge can improve the quality of home care (Callaghan, 2012; Tønnessen et al., 2016). However, they often have other private tasks and responsibilities in addition to providing care to the patient, which affects the capacity to be involved in the care (S. Liu et al., 2017; Wulff et al., 2020). One must therefore be aware of the potential burden of the responsibility of giving care to older family members (Plöthner et al., 2019; Tønnessen et al., 2016). To what extent and how relatives want to be involved in the decision-making will differ and must also be respected as part of individuals’ autonomy (Elwyn et al., 2012; Johannessen et al., 2018; Wiig et al., 2020). The research has revealed that involvement opportunities based on mutual dialogue and cooperation with health professionals can lead to feelings of coping, self-efficacy, autonomy, and self-determination on the part of relatives (Sakanashi & Fujita, 2017).

Studies on user involvement are primarily concerned with understanding and practising the involvement of patients and relatives (Ocloo & Matthews, 2016; Ree et al., 2020). Electronic patient records and work lists on tablets, as well as digital door locks and alarms, indicate that health professionals are also users of welfare technology; opportunities for user involvement in the workplace are important principles that promote democratisation, job satisfaction and empowerment, among them (Spreitzer, 2008). Satisfied users are often more optimistic and willing to engage with others. Further, since health professionals provide information and facilitate follow-ups on patients’ use of welfare technology, they need adequate information and competence in welfare technology (Brewster et al., 2014; Dugstad et al., 2019).

3.3.1 Health professionals, patients and relatives as co-producers

The co-production approach rejects the traditional understanding of patients as dependent and instead focuses on public services that redefine the user relationship as one of co-dependency and collaboration, thereby focusing on patients as partners with resources (Boyle & Harris, 2009; Turakhia & Combs, 2017). The co-production perspective emphasises an understanding of user involvement, which, in addition to involvement and influence, highlights patients' and relatives' feeling of responsibility for contributing to their healthcare as equal partners of health professionals (Batalden et al., 2016; De Rosis et al., 2020; Loeffler & Bovaird, 2017). Health professionals are expected to have an individual approach when meeting the multidimensional needs and preferences of older people dependent on care by acknowledging the carers and the patient's family. By considering each individual's needs, limitations, goals, and abilities, the probability of involvement in the use of welfare technology can be strengthened, and quality improvement of health care services may increase (Ebrahimi et al., 2021; Kogan et al., 2016). Health professionals are essential in facilitating patients' and relatives' opportunities for involvement in co-production (Batalden et al., 2016; De Rosis et al., 2020).

Recent studies have suggested co-production as an intervention to increase satisfaction and trust in health professionals (Jo & Nabatchi, 2019), enhance innovation (Palumbo et al., 2018), and improve the effectiveness and efficiency of products and services (Brandsen et al., 2018; Luo et al., 2019). Co-production may support services of seeing patients and relatives as equal participants in their care and strengthens the possibility of individualised care (Blunden & Calder, 2020). Nonetheless, co-production may also pose harmful and unintended consequences. A higher degree of involvement may not always benefit all users of welfare technology (Tritter & McCallum, 2006). Larkin and Milne (2014) further argue that the concept of co-production in care does not allow for a focus on relatives' perspectives and needs. It is of much concern that the expectations of co-production in care can impose an additional heavy burden on relatives in terms of the responsibility and tasks in care they may be saddled with (Callaghan, 2012; Tønnessen et al., 2016).

4.0 THEORETICAL FRAMEWORK

This chapter presents an overview of the theoretical perspectives I have used to grasp the complexity and ethical aspects of patients', relatives', and health professionals' experiences in their respective involvement and use of welfare technology in home care services.

First, neither user involvement in care nor welfare technology is value-neutral in meeting the challenges of home care services (Hofmann, 2019). Therefore, assessing the ethical aspects of these interventions in municipal healthcare contexts will be necessary. Changes in services influence autonomy, power shifts, relations, interactions, the need for trust, and questions of inequality. Values further influence user involvement and welfare technology and can trigger tensions between patients, relatives, and health professionals (Beauchamp & Childress, 2013; Held, 2006; Tronto, 1994; Tronto, 2013). Based on this, I needed suitable ethical frameworks on which to base both my analysis and discussions. Therefore, ethics of care theory inspired by Held (2006) and Tronto (1994) and biomedical theory based on the work of Beauchamp and Childress (2013) were used and are presented in this chapter.

Second, changes in home care services can be understood and improved if both "social" and "technical" aspects are brought together and treated as interdependent parts of a complex system (Ackerman et al., 2018; Bossen, 2018). For this thesis, I have used socio-technical system theory to discuss and understand the interdependent and complex human and technical factors in home care services (Carayon et al., 2020; Holden & Carayon, 2021; Holden et al., 2013).

4.1 Ethical theory

Ethics of care theory adopts a relationship-based approach, thereby focusing on how people interact and respect each other (Held, 2006; Tronto, 1994). The theory highlights that care ethics is both a practice and a value and impacts human interactions (Held, 2006). The biomedical ethics principle by Beauchamp and Childress (2013) focuses on a person's *autonomy* and how increasing welfare technology and increased responsibility for care tasks can lead to a focus on *non-maleficence* if not used as intended. Further, it involves a moral discussion on who will *benefit* from the changes in home care services. The final principle is *justice*, which focuses on human rights and justice for all to have equal services and access to welfare technology.

4.1.1 Ethics of care theory

Ethics of care theory arose from a feminist appreciation of the importance of care and caring labour and was developed by Sara Ruddick, Carol Gilligan, and Nel Nodding (Held, 2006). Virginia Held and Joan C. Toronto further developed the theory, and their approach is used in this thesis (Held, 2006; Tronto, 1994). This approach focuses on the interconnectedness of humanity and places a moral significance on relationships. Through this study, I have realised that relationships intrinsically influence how patients, relatives, and health professionals experience their respective involvement and use of welfare technology.

Ethics of care theory is an approach to personal, social, moral, and political life that operates from the reality that all human beings need to receive care and care for others (Held, 2006; Tronto, 1994). Care relationships among people are part of what marks us as humans, and we are always interdependent beings (Tronto, 1994; Tronto, 2013). The ethics of care points out that the ability to provide care cannot be considered pure theory' but requires a particular type of competence and sensitivity to the specific needs of others. Respect, trust and a balance of power are essential elements that are necessary for healthy relationships (Held, 2006; Tronto, 1994). These elements are thereby vital for understanding users' experiences of their involvement in welfare technology in home care services.

Held (2006) describes a caring person as one with the commitment and appropriate motivation to care for others by adopting practical caring approaches. For that reason, a caring person could be either a health professional or a relative. She further argues for limiting market provisions for the care and legalistic thinking in ethics, asserting that care ethics has superior resources for dealing with the power dynamics that imbue all relations. This focus on relationships is often situated within contexts of power and control. The power distribution can be seen in the desire for co-production in the involvement and willingness of health professionals to hand over more of their power to patients and relatives. She also argues that care ethics can help to promote healthy social relations rather than pursuing self-interest. Held (2006) further suggests that care should be performed and caregivers valued in public and private spheres, including input concerning user involvement.

In this thesis, the "four phases of caring" are drawn on to explore the experiences of giving care (Tronto, 1994, pp. 105-108). The phases include "caring about," where the focus is on recognising patients' need for care; "taking care of," which assumes a feeling of responsibility for care; "caregiving," when health professionals or a relative provide care; and, finally, "care-receiving," which is about how well the caring needs are met. Further, Tronto's five moral elements of care that arise from the four phases of caring are used, namely attentiveness, responsibility, competence, responsiveness, and trust (Tronto, 1994, pp. 127-136). Tronto (1994) further emphasises that people cannot be fully autonomous since they are interdependent social beings who rely on others for advice and support. Tronto is also concerned about the inequality that arises when people with high incomes and social status purchase caring services, thereby delegating the burden of care to healthcare professionals so as to avoid responsibility for the adequacy of hands-on care (Fieser & Dowden, 2021).

It is claimed that the focus on relationships prevents a focus on more systemic injustice in public life (Pettersen, 2008). Further, Beauchamp and Childress (2013) criticise the ethics of care theory for being incomplete in determining what is right to do in any context. However, especially when it comes to user involvement, a focus on relationships between involved partners and the experience of duty of care can be useful. Ethics of care theory will thus be useful to complement the biomedical model described in the next section.

4.1.2 Biomedical ethics

The "Principles of Biomedical Ethics" by Tom L. Beauchamp and James F. Childress (2013) first appeared in 1977; this thesis uses the 8th edition. The four principles are autonomy, non-maleficence, beneficence and justice, thereby involving fairness in distributing benefits to all (Beauchamp & Childress, 2013).

The first principle is respect for a person's *autonomy* as a universal moral principle. According to Beauchamp and Childress (2013), all people have a right to make their own choices and the freedom to live their lives following what they deem to be in their best interests and in line with their desires, beliefs, and preferences. Autonomy is also at the very foundation of human rights (United Nations, 1948). The principle highlights the right to choose what welfare technology to use and how to be involved in care. The second principle is to prevent death and suffering due to illness and to save lives. To cure, care, and comfort are stated in the Oath of Hippocrates, with the primary call to not harm (Hajar, 2017). This later became known as the principle of *non-maleficence* (Beauchamp & Childress, 2013). In this thesis, examples of non-maleficence may be connected to patients' lack of knowledge, their inadequate mental capacity to handle welfare technology, or when too much responsibility is transferred to patients or relatives. The principle of *beneficence* reflects a moral obligation to act for the benefit of others. The idea behind this principle is that health professionals have a duty to be concerned about any benefit to the patient and take positive steps to avoid harming them. The utility form of benefits requires focusing on the overall result by balancing benefits, risk, and cost. This approach may emphasise what is important for patients and their relatives and how this can be supported by co-production and welfare technology. The principle of *justice* deals with the expectation that all people have equal access to care in the same circumstances, which is also described in the Norwegian Patient Rights Act (Patient and User Rights Act, 1999). The principle also implies fairness in providing healthcare to patients regardless of gender, race, or religion, as stated in the Human Rights Declaration (United Nations, 1948). Healthcare professionals are further obliged by their social mandate to deliver healthcare resources reasonably and efficiently with an overall concern for the healthcare budget with fair, equitable, and appropriate distribution of benefits and norms (The Health Personnel Act, 1999). However, this ideal is challenged by limited healthcare resources.

Biomedical ethics has not been without its critics. Hedgecoe (2004) claims that biomedical ethics presents an idealised, rational way of thinking and tends to exclude social and cultural factors, relegating them to the status of irrelevancies. Huxtable (2013, pp. 40-41) notes four problems with the four principles: first, the principles fail to recognize the diversity of extant traditions and perspectives even within the societies they purport to reflect; second, they are inapplicable since particular problems are said to arise when the principles confront patients who lack autonomy; third, they are inconsistent since the principles do not significantly help to identify moral problems and there may be situations wherein they simultaneously pull a conscientious health professional in different directions; fourth, they are inadequate in that they fail to provide solutions to the very dilemmas in which one might legitimately expect such a framework to assist. By using ethics of care, some of this criticism can be met.

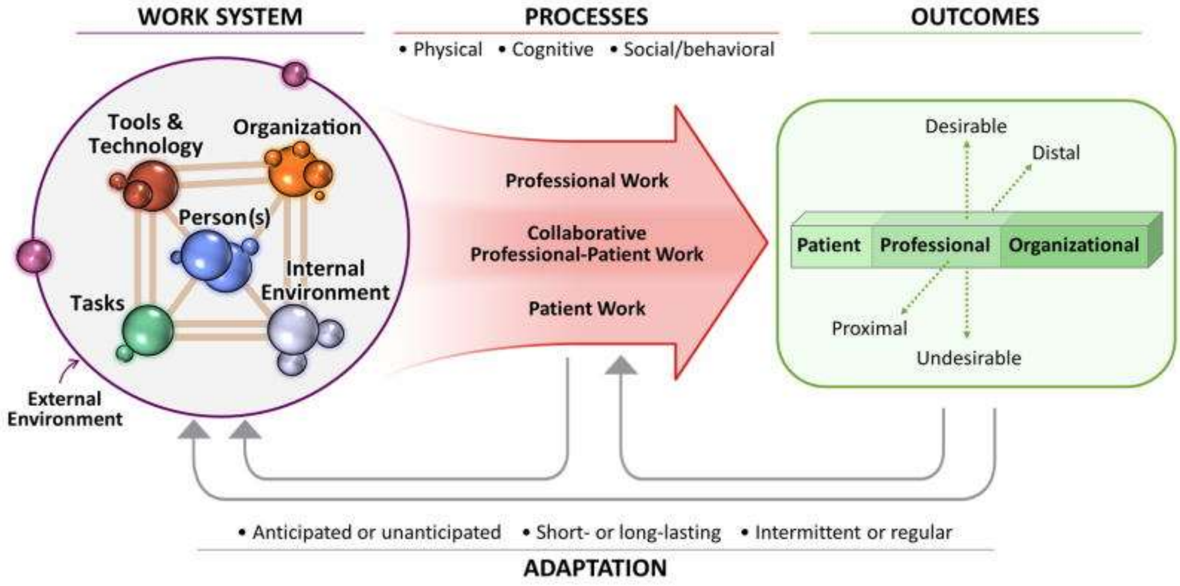
4.2 Socio-technical system theory

Socio-technical system theory is the result of Eric Trist and Ken Bamforth's studies into the organisation of work' in the British coal industry in the 1950s. It features a focus on effectiveness and the satisfaction of employees (Fox, 1995; Trist & Bamforth, 1951). Since the key goals of involvement and welfare technology are to improve the quality of care and reduce costs, socio-technical system theory can be useful in this context. User involvement, such as co-production, is crucial for promoting ownership of innovative collaboration processes and using tools like welfare technology, an ideal that socio-technical system theory also emphasises (Aanestad & Olaussen, 2010).

Socio-technical system theory focuses on interactions between individuals in an organisation and technology (Carayon et al., 2020; Dul et al., 2012; Leeds University Business School, 2021). Human factors describe an individual's capabilities and limitations in performing tasks and functions, their understanding of information, and the environment that suits each user's skills and resources. Efforts must be made to an individual support people through a co-production design that fits their capabilities, limitations, performance needs, and other characteristics, and not the other way around (Holden et al., 2013). A further key factor is where the tasks take place (Carayon & Hoonakker, 2019). A consideration of the context in which the system will be used and social and cultural factors, including care practices and the structure of the organisation, is essential (Baxter & Sommerville, 2010).

Welfare technology is often blamed when errors and adverse events occur, such as unstable network coverage (Joshi & Woll, 2015). However, the cause could also be attributed to how welfare technology is used, insufficient training, or a lack of resources. Therefore, to understand the outcomes of welfare technology, it is necessary to investigate the whole work system and not just a single element (Committee on Patient Safety and Quality Improvement; Institute of Medicine, 2012). This means that rather than simply putting people into existing technical systems, technological solutions should be designed so that individuals and technology can coexist in care contexts.

Figure 2 illustrates the socio-technical system theory used in the SEIPS 2.0 model



This figure is from the article “SEIPS 2.0: A human factors framework for studying and improving the work of healthcare professionals and patients” (Holden et al., 2013). Copyright has been obtained (Appendix XII).

The general structure of the SEIPS 2.0 model is that the socio-technical work system produces work processes that shape outcomes (Holden et al., 2013). It conforms to the input-transformation-output framework (Karsh et al., 2006). The theory also supports the inclusion of feedback loops, which represent the need for constant adjustments to improve the services (Holden et al., 2013). The person(s) in this model can be patients, relatives, health professionals, or anyone involved in care. The focus on persons as the core factor fits the individualised approach in co-production and user involvement. The model highlights further interactive factors such as technology and tools, the organising of services, the tasks to be solved, and internal and external environments. The SEIPS 2.0 model does not include infrastructure as a separate factor. For the purposes of this thesis, however, I have decided to include it as a factor, as others have done before me (Leeds University Business School, 2021;

Shepherd & Clegg, 2011). All factors influence systems and individuals differently, and understanding these interrelated factors is essential for the successful involvement, implementation, and use of welfare technology (Sittig & Singh, 2010).

The processes illustrated in Figure 2 are where the involvement takes place. It can be divided into physical, cognitive, and social/behavioural processes for collaboration (Holden et al., 2013). An example of a process could be the administration of medication, which could be subdivided into tasks such as patients accepting, learning, and handling the medication regimen, and health professionals training the patients, refilling medications and documentation thereof.

The outcome can be experienced differently from the point of view of patients, relatives, health professionals, and the organisation (Holden et al., 2013). What concerns patients and relatives in their desire for an outcome is not necessarily the same as what is important to health professionals or management.

Socio-technical system theory focuses on the interactions between human resources and technology. However, socio-technical system theory is not useful for discussing ethical values for different users when new technology is selected, implemented, and used, or when they are expected to be involved in such processes. Biomedical ethics can, however, look into the values and moral rules of human activities that occur within these systems and give direction toward the right choices. Further, ethics of care theory focuses on the importance of the relationships between people and the use of technology. In this way, the two ethical theories combined address the relational and moral deficiencies of socio-technical system theory.

5.0 METHODOLOGY

I have chosen qualitative research methods to explore and understand the experiences of health professionals, patients, and relatives in this study. This approach allowed me to uncover trends in opinions, get close to the participants, and explore their experiences of user involvement and welfare technology. The study draws on a phenomenological-hermeneutical philosophical approach inspired by van Manen (1990/2015) and Gadamer (1960/2010). It is phenomenological in that the goal is to grasp the participants' meaning-making processes underlying their lived experiences and hermeneutical in that the method is based on the interpretation of textual data from interviews. The empirical data in this study are derived from qualitative interviews of health professionals, patients and relatives. The interviews were analysed using reflexive thematic analysis inspired by Braun, Clarke, Hayfield, and Terry (2019, pp. 852 -857).

Table 1 presents an overview of the aims, designs, data collections, settings and participants in the three papers on which this thesis is based.

	Aim	Design	Data collection	Setting	Participants
1	To learn more about the factors that promote or inhibit user involvement among health professionals when implementing welfare technology in home care services.	Qualitative exploratory and descriptive	Five focus group interviews	Three interviews were conducted at the participants' workplaces. The two follow-up interviews were conducted at the university.	Sixteen health professionals. Nine nurses and seven nurses assistants. Three men and eleven women, ranging from 33 - 62 years of age. The inclusion criteria were that the health professionals had worked in home care services for at least six months, in at least a 50 % position.
2	To explore older patients' experience of user involvement in implementing and everyday use of welfare technology in public home care services.	Qualitative exploratory and descriptive	16 individual interviews	Three interviews took place at a day activity centre for seniors, and the rest in the participants' homes.	Sixteen patients. Five males and eleven females, ranging from 65 to 95 years old of age. The inclusion criteria were that the patient could give consent, had used welfare technology for at least six months, was 65 years old or older, and was able to sign an informed consent.

3	To explore relatives' experience of involvement and possible ethical aspects of caring for frail older patients receiving home care services supported by welfare technology	Qualitative exploratory and descriptive	16 individual interviews were planned. However, in two interviews, one extra sibling asked to be present. A total of 18 relatives participated.	Nine interviews were conducted by telephone, and seven were conducted face-to-face, two in private homes and the remaining in quiet public places.	Eighteen relatives. Eight men and ten women, ranging from 54–77 years of age. The participants included two spouses, six sons, nine daughters, and one sibling. The persons had to be noted as the closest relative in patients' electronic medical records to be included. In addition, the patient they were related to had to have used welfare technology for at least six months and be over 65 years old.

5.1 An explorative-descriptive design

There has been an increasing focus on user involvement and welfare technology in Norwegian home care services (Brandsen et al., 2018; Meld. St. 47 (2008-2009)). Nevertheless, there is limited knowledge of users' experiences of being involved in the introduction and use of welfare technology, namely from the perspective of patients, relatives, and health professionals. An exploratory design allows the researcher to explore a topic that has received given scant attention earlier and enables the study participants to enhance their knowledge of the field (McCallum & Howes, 2018; Patton, 2014). Further, a descriptive design is suitable for characterising individuals, situations or groups more accurately (Patton, 2014). This design was used since the purpose was to increase the level of knowledge and descriptions of the participants' experiences and situations and how certain factors were related to each other (Patton, 2014). Information related to the participants' attitudes, attributes, behaviour, beliefs, and experiences was collected through interviews, in line with Sim and Wright's (2000) description of descriptive research.

5.2 A phenomenological-hermeneutical approach

A phenomenological-hermeneutical philosophical approach was adopted since the relationship between phenomenology and hermeneutics can be seen as one of reciprocity (Lindseth & Norberg, 2004). The goal was to capture and understand the richness, complexity, and individuality of the participants’ experiences. When the participants expressed their lived experiences of user involvement and use of welfare technology, I wanted to understand the described actions, attitudes, relations, and other human aspects of the phenomena in line with my understanding of van Manen’s (1990/2015) phenomenology. The term “life-world” is not used in the papers. However, this is the basis of phenomenology as I read van Manen, and the term is thus used in this thesis. The hermeneutic part of this study is oriented toward interpreting the textual data of the interviews with the participants and is inspired by Gadamer (1960/2010).

5.2.1 A phenomenological approach

A phenomenological approach has the way individuals act, feel, experience, and understand as its starting point. Max von Manen’s (1990/2015) phenomenological life-world concept provided the necessary inspiration to understand the meaning behind the participants’ lived experiences that emerged from the interviews and the transcribed material: “Anything that presents itself to consciousness is the potential of interest of phenomenology, whether the object is real, imagined, empirically measurable or subjectively felt” (van Manen, 2017, p. 2). Using a phenomenological approach helped to reduce imposing personal values on the data by constraining assumptions about what the phenomena are like or how they should be studied. It is essential to acknowledge that the background and knowledge of the patients, relatives, and health professionals largely determined their experience, areas of interest, and understanding of the changes taking place in home care. It is thus reasonable to believe that individuals have different experiences when approaching, for example, welfare technology. Such differences are important in the exploration of various experiences. As a researcher, I draw on the participants’ lived experiences of certain phenomena as they describe them themselves (Creswell, 2014; van Manen, 1990/2015).

5.2.2 A hermeneutical approach

Inspired by Gadamer (1960/2010), the hermeneutical approach was used to achieve a good understanding and valid interpretation of the experiences expressed by the health professionals, relatives, and patients in the interviews and in the field notes. In this study, hermeneutics was not used as a method but more as a philosophical approach. However, the hermeneutic approach is visible through the description of the reflexive thematic analysis in section 5.3.3.

Hermeneutics is often understood and explained using the terms preconceptions, horizons, and the hermeneutic circle (Gadamer, 1960/2010). As Gadamer (1960/2010) points out, a person's *preconceptions* are rooted in their education and are experienced throughout life. The goal is to view a text or an encounter with people with as little bias as possible. However, Gadamer (1960/2010) rejects the objective, entirely neutral, or value-free readings of texts and instead outlines the intersubjective aspects of meaning-making or understanding. When I approached the research field, my background was rooted in humanistic values, my prior experience as a registered nurse and a teacher of nursing students, and my previous knowledge about user involvement and welfare technology in home care.

As described in the chapter "My engagement in the study," I already had some experience implementing and using welfare technology and caregiving in home care services when starting this PhD study. I expected other health professionals to be enthusiastic and willing to use technology as well as to involve patients and relatives in their care. However, this expectation turned out to be inconsistent with reality. Further, most of the patients participating in this study were frailer than I had expected. Nevertheless, they expressed a positive attitude towards the use of welfare technology. However, some patients were sceptical concerning their involvement. Ultimately, I had expected a more homogeneous group of patients, relatives, and health professionals than was the case.

My understanding of user involvement has been challenged throughout the course of this study, and the concept appeared to be more complex than expected. To a limited extent, I had reflected on the challenges inherent in the involvement of frail older patients and the potential feelings of burden and obligation for responsibility and tasks for relatives. Knowing myself, increasing my level of awareness, and having a reflective relationship with my preconceptions have all been essential factors in this process. They may have influenced how the research methods were conducted, how the results were understood, and what findings I considered most appropriate.

An interesting aspect of hermeneutics is the concept of *horizons of understanding*. These encompass my overall perceptions, experiences, and prejudices at a given time (Gadamer, 1960/2010; Thornquist, 2018). The context involving, for example, the location, amount of time spent, and the participants' horizons may affect both communication and content. In line with Gadamer (1960/2010), horizons enable the transfer of meanings, and one must challenge oneself by looking at the same issue in different ways. My horizon and the situation changed when I interacted with the participants and listened to their experiences. New understandings were acquired by revising my evaluations or setting the participant's assessment amid a larger context of possible reviews. Through this process, the participants' horizons merged with my own into a new, common horizon. An example of this kind of "fusion" of horizons was when my experience and pre-understanding of older patients' scepticism about welfare technology were changed after interviewing one of the oldest patients. The participant showed me how he ordered technical aids online himself and told me that the technology had provided him with a safe and active lifestyle and that the aids were easy to use. However, he pointed out that many of his friends, also seniors, did not know how to use the internet, which was an obstacle to obtaining the correct information by themselves. A new common horizon emerged wherein older people may like to try new technologies but are often dependent on others as facilitators.

Put simply, the *hermeneutic circle* describes the parts from the whole and the whole from the parts (Gadamer, 1960/2010). This philosophical way of thinking also coincides with Braun et al.'s (2019) reflexive thematic analysis method, which I will return to in section 5.3.3. As a researcher, I can neither understand the whole text nor any individual part without reference to another; hence, it is a circle. The hermeneutic circle illustrates how understanding, as a process, differs from holistic understanding via partial understanding to a new holistic understanding. It describes a process of dynamic cognition that oscillates between part and whole in an attempt to understand both (Gadamer, 1960/2010). The circle is often described as a spiral to show that an understanding changes over time with no end. As a researcher, I must be open to change and possible improvements throughout the process (Thornquist, 2018).

5.3 Interviews

Qualitative interviews were a natural choice to elicit reflections and experiences from the participants in the search for a deeper understanding of user involvement and welfare technology.

5.3.1 Recruitment and sampling

Understanding the subjective reality of the experiences of user involvement and welfare technology cannot be achieved with a large representative sample but with a limited sample and open interviews with participants representing typical examples of the field under study. I wanted to draw on participants who could share their unique experiences of their life-world to increase my understanding and knowledge of the focus of the study.

Before the data collection process started, representatives from municipalities taking part in the SOL pre-study (described in section 1.2) were invited to a joint information meeting. The management of these municipalities was informed about this study’s objective and planned research design and accepted the invitation to participate further and recruit health professionals. Additionally, three more municipalities were invited to recruit patients and relatives to ensure that there would be enough participants (Appendix VI).

Before the interviews were conducted, I telephonically contacted managers for further information. Furthermore, the home care services management contacted, informed and recruited the participants. They combined their knowledge of potential participants with the inclusion criteria and our request for both genders of different ages. The management did not state how many participants refused to participate when invited. The plan was to have focus group interviews with health professionals and solely individual interviews with patients and relatives. However, in two of the interviews with relatives, an extra relative asked to participate. For that reason, a total of 16 patients, 18 relatives, and 16 health professionals participated. The size of the focus groups varied from six to eight participants, as recommended by Malterud (2015) and Brinkman and Kvale (2015).

To obtain more satisfactory information strength concerning user involvement and the use of welfare technology emerging from the first three interviews of the SOL project, we performed two follow-up interviews with the health professionals in sub-study one until we were satisfied. The total number of focus group interviews was five. When the 16 interviews with patients and the 16 interviews with relatives were completed, and a preliminary analysis was carried out, the authors assessed and concluded that satisfactory information strength had been achieved for these groups, in line with the recommendation of Malterud (2016). As Clark and Brun (2021) argue, it is necessary to dwell on uncertainty in thematic analysis and recognise that meaning generated through interpretation is inescapably situated and subjective; it also cannot be determined in advance of the study.

In order to be eligible for recruitment, the health professionals had to be registered nurses or nursing assistants and to have worked in home care services for at least six months in at least a 50% position. By choosing to include only nurses and nurse assistants and not unskilled carers, I expected the participants to have some professional competence in communication, ethics, and user involvement as well as the ability to reflect on and professionally discuss certain topics during the interviews. Having a position above 50% meant that the health professionals regularly saw and experienced user involvement and welfare technology in home care services. In addition to these inclusion criteria, I asked for participants of varied ages and gender. I wanted the selection to be heterogeneous to reduce bias and strengthen validity.

Since the patients were frail and old, it was ethically important to consider their ability to provide informed consent. Therefore, management was asked to consult health professionals who knew the patients well to be particularly aware and to consider their ability to consent before asking them to participate. Since experiences often change over time, the patients should have used welfare technology for at least six months. I also had the preconceived notion that younger patients would differ in their use and experience of technology. Therefore, I wanted the patients to be 65 years and above. In addition, I wanted this group to vary in their gender, age, experience, and interest in welfare technology to strengthen validity.

I asked for relatives with status as the closest relative in the patients' healthcare records since they probably had more in-depth knowledge about the patients and were more actively involved in their care than other relatives might be. The patients they were related to had to have used welfare technology for at least six months so that the relatives could have gained the requisite experience over time. To strengthen the study's validity, I wanted the experiences of both males and females, relatives living with the patients and outside patients' homes, and relatives of different ages so as to obtain a varied picture of relatives' experiences of involvement and welfare technology.

5.3.2 Data collection using focus groups - and individual interviews

Interviews are among the most familiar strategies for collecting qualitative data (Brinkmann & Kvale, 2015). In all the interviews, semi-structured interview guides were used (Appendix V and X). While a structured interview entails a rigorous set of questions, a semi-structured interview is more open, allowing new ideas to be brought up during the interview based on the interviewee's responses (Brinkmann & Kvale, 2015). The importance of flexibility is essential for the explorative part of the design.

In all the focus group interviews, I was the moderator, while my principal supervisor had the role of a secretary who took notes and regularly summed up the talking points to validate the discussions. In the individual interviews, I performed the above actions alone and wrote my reflections in my field notes after the interviews. During the interviews, I was attentive to the respondents' narratives and was sensitive to surprises, topics, and opinions that might challenge my preconceptions, in line with the recommendations of Brinkmann and Kvale (2015).

Through the *focus group interviews*, health professionals could describe, reflect on, and discuss their subjective experiences, opinions, views, or attitudes related to involvement, welfare technology, and relevant ethical aspects (Brinkmann & Kvale, 2015). As Brinkman and Kvale (2015) describe further, the focus group discussion aim is not to reach a consensus about a topic or find solutions to the issues discussed but to bring forth different viewpoints. Focus groups are also suitable for finding areas for improvement in what the participants perceive as inadequate or lacking or for providing ideas for what should be done differently in home care. Focus group interviews provide greater opportunities for reflection than individual interviews because when several participants engage in discussion together, they inevitably influence each other's thoughts and understandings. The group dynamics between the participants generated a wide variety of ideas and views in the five focus group interviews in the study.

I experienced high activity across all five interviews with the health professionals. However, some participants were more verbal than others. Bowling (2014) points out that a weakness of focus group interviews may be caused by the composition of the group or the dominance of certain views among group members. Therefore, I encouraged certain participants to speak up about their views and experiences in order to obtain the richest possible material, as Brinkmann and Kvale (2015) recommend. The participants expressed nuanced opinions and were not afraid to discuss various situations and different views. The discussion took new and unexpected turns in some situations, as is to be expected in an explorative design. An example was an intense ethical discussion of GPS trackers in one of the focus group interviews.

The *individual interviews* allowed me to encourage patients and relatives to speak about their attitudes, beliefs, desires, and experiences. More detailed questions could be asked and thus the deeper interactions were useful in getting to know the participants better than in the focus group interviews, as Bowling (2014) suggests. The patients in this study were frail and all had health problems that required home care. Therefore, I paid special attention to their capacity to give informed consent to the interviews before starting them. If I had been unsure of their informed consent or whether they were able to cope with the interview, I would have chosen to talk to them only briefly and not use those interviews in this study. However, this did not occur. All the participants in the same group of users were asked the same general questions, but the follow-up questions were based on how they described their experiences (Brinkmann & Kvale, 2015). In my study, I could better address individual needs during these individual interviews than in the focus group interviews, for example, in some situations where patients had problems expressing themselves due to mild cognitive impairment or having previously had a stroke. These health challenges also meant that adjustments were necessary on my part to specify and explain some questions in more detail. For that reason, simple verbal prompts were used to improve communication in some of the patient interviews. Moreover, some patients expressed exhaustion during the interviews, and so, in a few situations, the interviews had to end earlier than planned because of the patient’s health status.

Being present in the same room as the person being interviewed allowed for numerous observations, such as looking at the participant’s clothes, body posture, and facial expressions. My field notes included these observations in line with Brinkmann and Kvale’s (2015) recommendations. Other advantages of face-to-face interviews were that I, as the interviewer, could give responses to non-verbal expressions and clarify any ambiguities and contribute to creating an impression of the whole situation.

Further, Bowling (2014)) points out that it cannot be assumed that the participants share the same frame of reference, values, and underlying beliefs as the interviewer or would interpret the words of each question in a similar way. There were examples of patients asking what welfare technology was, even when they had used medicine dispensers and safety alarms for some time. In one municipality, the health professionals I talked to before the interviews recommended using the term “the box” when I talked about the medication dispenser. This enabled me to share a common understanding of this item with the participants.

I also planned face-to-face interviews with all the relatives. However, several were very busy with their private lives, making it difficult to find time for the interviews. Many accepted the invitation to participate when offered telephonic interviews instead of conducting them face-to-face. Telephonic interviews also made it easier to reach relatives living far away. However, when interviews are conducted telephonically, one cannot see the participant’s body language or observe their environment, which can be essential for a more comprehensive picture of the context (Brinkmann & Kvale, 2015). Bowling (2014) points out that telephonic interviews are only suitable for short questions and non-sensitive topics. My experience was that sensitive issues were nevertheless brought up and discussed over the phone. Still, the overall time spent on those interviews was generally shorter than in the face-to-face interviews and tended to be less deep.

The interviews were transcribed verbatim and de-identified. The transcriptions were verbatim because of the importance of including all spoken words, which is essential for capturing the nuances of the transcribed material. The texts were de-identified during transcription to ensure anonymity. I transcribed the follow-up interviews of the health professionals, eight of the patient interviews, and five of the interviews with relatives. Professional transcribers transcribed the rest of the interviews. During the transcription work, I became more familiar with the data and more aware of my interview style.

5.3.3 Data analysis

The interviews were analysed within the phenomenological and hermeneutic tradition, taking advantage of reflexive thematic analysis as developed by Braun et al. (2019, pp. 852 -857). Being reflexive is about identifying one's personal beliefs and assumptions that may affect the research. Further, thematic analysis involves reading through the data set gleaned from the interviews and identifying patterns in meaning therein. This method was chosen because it enabled the effective categorisation of the perceived changes in home care services. Thematic analysis is a flexible method and should not be used step by step (Braun & Clarke, 2019). In my study, it was used in an adjustable manner wherein we went back and forth between the different phases until an agreement was reached, a process that coincides with hermeneutic thinking. This approach is also compatible with phenomenological approaches; it describes or summarises participants' lived experiences rather than an approach that involves more interpretative or conceptual work (Braun et al., 2019).

All the authors of the three papers were actively involved in the six phases of analysis in the different sub-studies. The first step in the thematic analysis was *familiarisation*. I listened to all of the interviews and, as described above, transcribed some of them. All the other authors read the transcribed data and wrote informal notes about their first impressions of the text linked to the study aim in this initial phase. We reflected on the directly expressed experiences and interpreted them in light of our preconceived understanding and experiences. We also reviewed the secretary's field notes from the focus group interviews and my field notes from the individual interviews to obtain a richer picture of the participants' statements. In phase two, we explored each transcript and worked systematically on the data to *generate codes*. In this step, we moved to a more detailed and systematic engagement with the data, focusing on making sense of them. We organised the meaning content from the data around similar codes and meanings. In phase three, we *constructed themes* across the data based on the research questions and our interpretations. We created an overview of the tentative themes and sub-themes based on the patterns and statements in the text. We categorised some statements under more than one theme in this phase, as we still found them to overlap and be difficult to place. In phase four, we reflected on our themes and discussed them back and forth. We *revised the themes* to avoid overlaps and clarify how each theme was related to the others, and they were checked across the whole data set. In phase five, we sought to ensure that the names of the themes were clear, comprehensive, and captured the meaningful content of the data, and thereby produced the *final themes*. We wrapped up the analytical work in the sixth phase, namely, *producing the papers.*

5.4 Ethical considerations

Ethical considerations were ongoing across all stages of the study, from planning and designing to conducting interviews, analysing, interpreting, and reporting the results (Brinkmann & Kvale, 2015). The research goal chosen is not merely to contribute new scientific knowledge but also to include ethical aims based on the insights and reflections that are gained (Resnik, 2005).

This PhD study was undertaken in line with the Declaration of Helsinki (World Medical Association, 2017) and was registered with the Norwegian Centre for Research Data, reference number 473910 (Appendix I). In addition, the study was submitted to the Norwegian Regional Committees for Medical and Health Research (REK) with reference number 2018/2462. REK considered the study to be outside the scope of the Norwegian Health Research Act, and approval was deemed unnecessary (Appendix II).

All the participants were informed about the study and its aim. They provided a signed statement indicating informed consent after receiving oral and written information in line with the recommendations of Brinkmann and Kvale (2015) (Appendices III, IV, VII, VIII). This also included the assurance that the participants could withdraw their consent without consequence according to the GDPR (General Data Protection Regulation (GDPR), 2016) and the Personal Data Act (Personopplysningsloven, 2018). Relatives participating in the study got an information letter concerning the participation they cud give to the patient in their family (Appendix IX). Before the interviews started, I repeated the information in the consent form to ensure that their consent was still valid. The participants were also informed about the planned length of the interviews. Some choices were also made to reduce negative consequences for the participants before and during the interviews. For example, some interviews ended earlier than planned in situations where I assessed the patient to be too tired to continue.

Regarding anonymity and confidentiality, data was handled and stored securely in keeping with applicable rules and guidelines for storing research material at OsloMet (Oslo Metropolitan University, 2016). The digital recordings have been deleted and the transcribed material, names of participants and code key, and consent forms will be destroyed following the agreement with the Norwegian Centre for Research Data (Appendix I). My transcription was done on a research computer that was not connected to the internet. When sharing data with professional transcribers, they had to sign and follow OsloMet's agreement on data processing (Oslo Metropolitan University, 2022). All identifying names and places in the transcribed data were described as "***" to safeguard the anonymity and confidentiality of the interviews. Further, when quotations from the interviews were used in the papers, the participants' interview numbers were used instead of their names. When sharing de-identified data with the supervisors and co-authors of the papers, the data was sent in encrypted e-mails, where the code was sent separately to their mobile phones.

An essential value in academic quality is a high ethical standard. For example, anonymisation is essential as the patients and relatives in this study are vulnerable and dependent on certain services. It was important to protect the participants and encourage openness and honesty from them about their experiences without the concern of being recognised. Several of the patients also had mild cognitive impairment; therefore, as a researcher, I have a special responsibility to protect them. In addition, my responsibility also encompasses how the experiences of healthcare professionals are interpreted and presented.

In the following chapter 6, "Methodological discussion", reflexivity, reliability and validity will be addressed and discussed.

6.0 METHODOLOGICAL DISCUSSION

Brinkmann and Kvale (2015) emphasise that it is essential to consider quality criteria in research relating to reflexivity, reliability, and validity. These concepts are traditionally discussed in quantitative research, and there is a discussion in the qualitative research tradition about how they should be used. Brinkmann and Kvale (2015) argue for their relevance in a reconceptualised form, recognising that they represent a different truth from that of qualitative research (Brinkmann & Kvale, 2015). I have chosen to use these terms critically to discuss the methodological approach used in this study.

6.1 Reflexivity

Throughout my thirty years of nursing, I have always been concerned with the patient's best interests. However, over the years, I have changed my views on how nursing should be carried out and what it takes to support patients and relatives in the best way. For example, when I was a newly qualified registered nurse, I performed care *for* the patient. Today, it is important to me that care is done *with* patients and their relatives. Further, I have work experience from a computer company delivering electronic patient journal systems and ten years of work experience in municipal healthcare, focusing on quality work and welfare technology solutions. For that reason, I have experience with home care services, welfare technology, and increased awareness of the need for user involvement in care. However, home care services are changing, and new challenges and concerns are rising due to an increased focus on user involvement and welfare technology.

When focusing on reflexivity in the study, there is a need for continual reflection upon the research process and an awareness of my preconceptions as well as my background, beliefs, values, judgments, motivation, theoretical knowledge, life and work experience, expected findings, and how these factors collectively influence the research (Creswell, 2014; Polit & Beck, 2017). Reflexivity is important because it addresses an underlying threat to the validity of the research outcome. An awareness of misperceptions through reflexivity enables the interviewer to design specific questions for the interviewee that help inform and clarify the interviewer's understanding of the outcomes. In searching for the essence of the experiences of patients, relatives, and health professionals, I was aware of the risk of my personal bias in the research throughout the process, which is in line with Brinkmann and Kvale’s (2015) recommendations. An example of this was when I first entered this study; I had a preconception that older patients had a resistance to the use of welfare technology and a desire for more active involvement. This may have influenced my questions. Further, I had only, to a limited extent, reflected on the importance of relationships in care. This probably means that I had initially placed little focus on this in the interviews. This changed and, particularly after discussions following the analysis made with my co-authors, was given more space than I had first thought. However, my personal bias was reduced by being aware of and reflecting on these facts and discussing them with my supervisors and co-authors. Further, the results of all the sub-studies were presented to the members of the PhD advisory team (presented in section 1.7). The members of this team served as my discussion partners in interpreting the findings. Their responses did not produce any immediate changes but confirmed that the analytical reflections aligned with their experience. Regarding health professionals’ experiences, the results in the first three interviews were also brought back and discussed in the last two interviews, which helped me capture what was essential for the participants.

I had a leading role in all the interviews and was aware that the atmosphere and how questions were asked could affect the interview responses (Bowling, 2014). In line with Bowling’s recommendations (2014), I focused on not using leading questions, complex questions, and questions containing double negatives that might lead to biased replies. I was also aware of and recognized the power relationship between myself as a researcher and the participants. I listened actively during the interviews and encouraged the participants to deepen their reflections. Nevertheless, some participants gave short, single-word answers such as “yes” or “no” in a few situations due to their health conditions. To use these brief responses, I had to find other instances where the participants talked about the same topic and gave similar answers; I otherwise did not use such responses in the study. When re-listening to the interviews and reading the transcribed material, I became aware of having advised the relatives in a few situations. As a nurse, I knew of some of the difficulties the participants described and how they could be solved. However, this knowledge conflicted with my role as a researcher. As an interviewer, I should have been neutral, as Bowling (2014) suggests. However, this advices did not affect the interview focus and progress. As I see it in retrospect, one possible moral solution to the situation could have been to inform and advise the relatives after the interview had ended.

Through the research process and inspired by methodological literature, I have tried to reflect critically on how my knowledge, experiences, and attitudes might have influenced the interview situation, the data received, and the analysis. I have gradually become aware of my attitudes and knowledge gaps regarding welfare technology and the complexity of user involvement. My preconceptions might have led to hasty or premature deductions and influenced my interpretations, as some aspects may have been taken for granted (Brinkmann & Kvale, 2015). I may also have overlooked essential questions. Gadamer calls this "false prejudice," a situation wherein researchers do not separate the participants' experiences of phenomena and their own and the participants' experiences of phenomena (Gadamer, 1960/2010). During the study, it has been essential to not attempt to prove a point, my knowledge of the field, or my preconceptions but to consider a plurality of possibilities. In-depth reflections and discussions with my supervisors have been an essential part of the analysis reflexivity process. My reflections have matured my position as a researcher and my awareness of my role, skills, and understanding. I have gained valuable new knowledge that will be used in further research. Going forward, I will maintain this reflection and awareness in all my interactions with participants in interviews since new insight is revealed in each discussion of the interviews and subsequent analysis.

6.2 Reliability

In qualitative research, the researcher serves as an instrument for generating and analysing data (Brinkmann & Kvale, 2015). As Morse (1994) states, research has the goal of remaining relatively objective. The term "relatively" is used because the interpretation of interview data can never be wholly objective and dispassionate despite the researcher's efforts. To strengthen the reliability, I carefully considered and described all practical matters regarding sampling, the definition of the inclusion criteria, the preparation of the semi-structured interview guides, how the interviews were conducted, and the analysis process.

Before the recruitment of participants, I collaborated with my supervisors to design the inclusion criteria and requested variations in gender, age, and experience with welfare technology among them. The entirety of the recruitment process was conducted by the management of the home care services, which meant it might have been conducted using various methods. I conducted all the interviews following semi-structured interview guides. This helped me ask the questions as similarly as possible across the different user groups, which is a strength of this study. However, in line with Gadamer's description of hermeneutics, my knowledge and preconceptions changed while interviewing the participants and probably affected the questions and my perception of their answers (Gadamer, 1960/2010). Further, the interview follow-up questions varied in response to the participants' answers and, therefore, between the interviews. Nevertheless, one of the advantages of a qualitative process is that the researcher can learn certain lessons and thus ask new questions during the process. In several situations in the interviews, I asked questions based on the answers the participants provided. An example was when relatives described their feeling of responsibility for responding to the patient's care needs when they became frailer and when there was uncertainty about their coping with the welfare technology; new questions about how this affected the relatives' relationship with the patients' were raised. My attention to the complexity of care also increased by asking follow-up questions.

Moreover, I am aware that interviews can differ when they are conducted face-to-face or by telephone, in peoples' homes or in public places, and with or without other people nearby (Brinkmann & Kvale, 2015). The disadvantage of telephonic interviews must be weighed against the risk of not being able to include the desired number of participants in the study and the potential burden of time spent on the interviews of relatives. All the interviews were transcribed verbatim. When a professional transcriber did the transcriptions, I listened to the discussions to check and ensure the accuracy thereof. As Brinkmann and Kvale (2015) point out, when an interview is transcribed, the dynamics of a social interaction disappear, as does the unfolding of pace, tone of voice, and body language. Nevertheless, it remains necessary to structure the interviews to make them more suitable for further analysis. All the interviews were analysed similarly using reflexive thematic analysis (Braun et al., 2019). All the co-authors ensured reliability during the analysis process through discussion, mutual agreement, and refining the relevant codes and themes.

6.3 Validity

Even though I had conducted focus groups and individual interviews before this study, I am otherwise not an experienced researcher. Bowling (2014) states that the researcher's competence is a decisive factor in a study's validity. However, through discussion with my supervisors, the validity of the process was safeguarded and strengthened.

In creating the semi-structured interview guides, I discussed the content with my supervisors and the PhD advisory team. Further, I was inspired by the recommended interview questions of Brinkmann and Kvale (2015, pp. 160-164). I tested the interview guide for the health professionals on nurses from the municipalities participating in the SOL study team. The interview guides for patients and relatives were tested on one patient and one relative to ensure appropriate and understandable interview questions and that they reflected the aims of the sub-studies.

The goal of qualitative interviews is to go in-depth; there is less of an emphasis on breadth. (Brinkmann & Kvale, 2015). The number of participants will, therefore, usually not be representative. I wanted to gain a nuanced picture of participants' involvement in and use of welfare technology. I asked the management to recruit participants representing patients, relatives, and health professionals of various ages and gender. However, I was also aware of the possibility that it would be easiest to recruit socially advantaged individuals with the energy and interest to participate. However, several patients and relatives in this study mentioned their having a low income, even though I had not asked about it (Glomsås et al., 2022; Glomsås et al., 2021). Other participants stated that they were in a good financial position and thus were able to buy the technology themselves. Some patients were faced with cognitive challenges after suffering from a stroke, for example. They had difficulty finding the right words, became tired during the interviews, and reported having no social life outside their homes (Glomsås et al., 2021). This confirmed the assumption that the home care management had recruited a good mix of patients and relatives for the interviews.

Although it would have been desirable to obtain feedback from patients and relatives on the results to strengthen validation, as Brinkman and Kvale (2015) recommend, the patients and relatives were not asked for this. There was a risk that several of the patients had become frailer since the interviews had been done. Moreover, even for the first interview, it was challenging to reach some of the relatives. This strengthened the assumption that it would have been even more difficult to obtain their post-interview feedback.

Data were collected differently across the focus groups and individual interviews. Focus group discussions tend to describe, reflect, and bring out more nuanced points of view than personal interviews. I could, however, delve deeper into the individual interviews and give my complete attention to the individual participants. Further, telephonic interviews do not allow for the same observation of participants as in face-to-face interviews (Brinkmann & Kvale, 2015). Furthermore, the duration of the interviews and some of the participants' short answers may also have resulted in more superficial content than desired. In qualitative interviews, it is a common issue that some participants do not elaborate on what they mean and think in the same way as others. In consultation with my supervisors, I found that reflexive thematic analysis was a suitable method to answer the aims of the study based on the phenomenological statements made by the participants. These were further interpreted in a hermeneutic approach. In this approach to analysis, the subjectivity of the researchers is recognised and valued as an integrated part of the analysis process, in line with Campbell et al. (2021).

The results provide a limited picture of health professionals', patients', and relatives' experiences of user involvement and welfare technology since they are merely based on interviews of 16 health professionals, 18 relatives, and 16 patients from six municipalities. I cannot claim that the results from this study are generalisable to all home care service units in Norway. Nevertheless, the transferability of the gained knowledge was increased by having participants of different ages and experiences from several municipalities of different sizes and populations, all at different stages in implementing welfare technology. The findings are likely to be relevant to other units, patients, and relatives. Further, the results are confirmed with reference to international literature, which serves to strengthen this study's validity.

7.0 RESULTS

This chapter summarises the main findings from the three papers of the study. The research design, data collection, participants, and setting of each paper are summarised in Table 1 on pages 34-35. The results are extensively elaborated in the papers.

7.1 Paper I

Glomsås, H. S., Knutsen, I. R., Fossum, M. & Halvorsen, K. (2020). User involvement in the implementation of welfare technology in home care services: The experience of health professionals - A qualitative study. *Journal of Clinical Nursing*, *29*(21-22), 4007-4019. https://doi.org/10.1111/jocn.15424

In the paper, we explored a variety of experiences as factors that promote or inhibit user involvement in implementing and using welfare technology among health professionals working in home care services. We developed five interrelated themes based on a reflexive thematic analysis of five qualitative focus group interviews.

First, competence was highlighted as a critical component for involvement and preparedness for changes in home care services. Competence was also associated with confidence in welfare technology and concerns about the quality of the service.

Second, information on welfare technology was stated as a prerequisite for active user involvement. There were certain experiences reported by the health professionals wherein participants felt as though they were not being heard and management failed to note important patient care information.

Third, implementing welfare technology led to changes and new ways of working for health professionals. The use of welfare technology saved them time and improved access to information. Nevertheless, some choose to persist with old routines. The participants justified this by citing the unstable internet and a lack of knowledge and faith in the technology. The organisation receiving an increasing number of alarms from digital welfare solutions such as different forms of sensors, safety alarms, GPS’s and medication dispensers was found to be inadequate.

Fourth, the participants stated that their leaders did, to a limited extent, require their involvement in the procurement or facilitation of welfare technology implementation. In several situations, the health professionals found that their management was more concerned with costs than listening to their experiences about patients', relatives', or their own needs and wishes and how different technologies could improve care.

Fifth, health professionals also had several concerns about the changes in patient services and how this affected their relationships with patients and their relatives. This was connected to, for example, tracking technologies and the patients' right to privacy. Another concern was that the use of welfare technology reduced the number of visits and the opportunities for physical observation and assessment.

There appeared to be a lack of preparedness for the changes in home care services entailed by the implementation of welfare technology. The health professionals wanted to be more involved but emphasised that the key elements of competence, information, and collaborative arenas were missing. Competence also affected their attitudes and willingness to use the technology. The participants gave the impression of being in a dilemma between providing good care and improving the quality thereof, on the one hand, and having less time for patients and becoming more efficient, on the other.

7.2 Paper II

Glomsås, H. S., Knutsen, I. R., Fossum, M. & Halvorsen, K. (2021). 'They just came with the medication dispenser'- a qualitative study of elderly service users' involvement and welfare technology in public home care services. *BMC Health Services Research, 21,* Article 245. https://doi.org/10.1186/s12913-021-06243-4

Paper two focused on older patients' experiences regarding user involvement in implementing and using welfare technology in home care services. The reflexive thematic analysis of the 16 qualitative individual interviews resulted in four main themes.

First, the results indicate that the group of patients in the study had very different needs and wishes regarding user involvement. Some participants did not want to decide and be involved as partners in their care because they lacked either the energy or the requisite knowledge.

Others, however, wanted to be more involved and make active choices in their care and in the use of welfare technology. The participants found that health professionals merely introduced the technology and expected them to use it without any prior discussion.

Second, substantial individual differences in information, knowledge, and training in welfare technology challenged user involvement and affected the participants' ability to ask for more technologies and become involved in the decision-making process.

Third, the participants were generally positive about using welfare technology when it led to greater independence, safety, and getting help when needed. They were not concerned about monitoring when tracking devices were used. Standard offers and implementing welfare technology without user involvement resulted in some situations wherein welfare technology was not used as expected or not used at all.

Fourth, the participants wished to stay at home for as long as possible, and welfare technology aided this inclination.

The patients were generally positive about using welfare technology. They had, however, varying insights into welfare technology that challenged user involvement. The results reveal that user involvement should be facilitated and implemented carefully, highlighting autonomy and collaboration and focusing on respect, reciprocity, and participants' capacity.

7.3 Paper III

Glomsås, H. S., Knutsen, I. R., Fossum, M., Christiansen, K. & Halvorsen, K. (2022). Family caregivers' involvement in caring for frail older family members using welfare technology: A qualitative study of home care in transition. *BMC Geriatrics*, *22*(1), Article 223. https://doi.org/10.1186/s12877-022-02890-2

This third paper focused on relatives' involvement in and possible ethical aspects of caring for frail patients receiving home care services supported by welfare technology. To understand their experiences, we examined the importance of personal relationships and responsibility. A total of 18 relatives participated in 16 interviews, and five main themes were identified in the reflexive thematic analysis.

First, close and long-term relationships contributed to the relatives’ sense of moral responsibility and obligation to observe and respond to the patient’s needs. They felt that caring was meaningful but nevertheless also demanding. Support and discussion with health professionals were considered to be essential to coping with caregiving over time.

Second, some had experienced changes in roles, tasks, and responsibilities. Welfare technology helped the relatives deal with responsibilities and ensure the patient’s safety. However, the expectations from patients and health professionals challenged their sense of autonomy when they, in certain situations, felt forced to take responsibility for the patients’ care

Third, the relatives felt that, in several situations, health professionals determined the conditions for collaboration and did not discuss and adapt their capacity and opportunity for co-production in care. The participants further described the knowledge and information gaps they had in welfare technology and user involvement.

Fourth, it was found that sharing power and responsibility and respecting mutual knowledge must be paramount when improving the quality of home care for older patients.

Fifth, the relatives had concerns over the inequality engendered by their lack of knowledge and care receivers’ finances regarding fair access to healthcare and welfare technology.

Co-production is still not an integral part of home care services; however, it may not always be the preferred approach for user involvement. Care provision can be experienced as rewarding but also as a burden. The relatives appreciated welfare technology, but attention must be given to ethical concerns over autonomy, relationship changes, the transfer of tasks and responsibility, and the risk of inequality.

8.0 DISCUSSION OF RESULTS

The overall aim of this thesis was to explore and understand patients', relatives', and health professionals' experiences and perspectives of user involvement and welfare technology in home care services. Experienced ethical aspects were also explored. This discussion elaborates on the results of the three sub-studies, thereby drawing on socio-technical system theory, ethics of care, principle-based biomedical ethics, and relevant research to discuss findings across the different user groups in the study.

In section 8.1, *factors affecting the adoption and use of welfare technology* are discussed. In the sub-studies, we found that factors such as the persons involved, access to and use of welfare technology as tools, how the technology was used to solve care tasks, the organisation of the service, environments, and infrastructure influence users' experiences. The mutual interactions between people and technology are highlighted.

Section 8.2 addresses *the complexity of user involvement* with regard to frail older patients, their relatives, and health professionals in the implementation and use of welfare technology. The sub-studies showed that the groups of patients, relatives, and health professionals were heterogeneous and had different expectations, needs, and prerequisites for user involvement. Barriers such as a lack of information and knowledge affected the users' attitudes and opportunities to be actively involved in care. The health professionals interviewed in this study had limited background knowledge to enable co-production in care. Furthermore, they experienced a heavy workload due to increased tasks and time pressures.

Section 8.3 highlights that *ethical aspects* are connected to relationships, recognition and respect for different knowledge and effort, trust, and conflicting values. Further, potential threats to autonomy, privacy and safety, transfer of responsibility and tasks without adequate mapping and cooperation were identified. Finally, the risk of inequality in services and access to welfare technology is discussed.

8.1 Factors affecting the adoption and use of welfare technology

My thesis has revealed that the expectations of increased involvement and the use of welfare technology entail new ways of providing care for health professionals and relatives and receiving care for patients (Glomsås et al., 2022; Glomsås et al., 2020, 2021). Welfare technology is not just a matter of "plug and play," as Stokke (2017) points out. Studies show that implementing welfare technology is a complex process involving many factors that translate the means and goals into practice (Ertner, 2019; Halvorsrud et al., 2021; Rydenfält et al., 2019).

To improve care quality and simultaneously take account of the extant resources and sustainable service requirements, there is a need for increased awareness of the different factors affecting the involvement and use of welfare technology. In line with socio-technical theory, experience with welfare technology is affected by human and technical factors such as people, tools, tasks, organisation, culture, infrastructure, and environmental factors (Holden et al., 2013; Leeds University Business School, 2021). When one factor in the system is affected, others are influenced. It is necessary to examine the whole system and not just a single element thereof (Institute of Medicine 2012). Welfare technology works differently in different contexts and for different people (Cozza et al., 2019).

8.1.1 The persons involved

For the successful experience of involvement in the implementation of welfare technology, it should be asked what is essential for patients and relatives and which technologies can best support their daily life (Olsen et al., 2020; Tsai et al., 2019). Furthermore, questions should be asked about how welfare technology can support and promote health professionals' work (Kamp et al., 2019; Majumder et al., 2017).

Sub-study one revealed that welfare technology could provide efficient planning and work strategies, thereby giving clearer overviews and streamlining health professionals' service provision (Glomsås et al., 2020). The findings of other studies support these findings (Kamp et al., 2019; Majumder et al., 2017; Rouleau et al., 2015). However, some of the health professionals in my study chose not to adopt new technological solutions, such as digital door locks. The results in sub-study one revealed that when a digital alarm was triggered, it took time for the health professionals to go to the office to collect the right key instead of going directly to the patient (Glomsås et al., 2020). The time used could affect the patient's safety and is an inefficient use of time. Further, there is a risk of not achieving the expected savings if both new and old solutions, such as physical keys and digital door locks, are simultaneously allowed. Based on the results, there seems to be a need for management to ensure that only new digital solutions are used. As Nilsen et al. (2016) point out, there can be several reasons for health professionals' resistance to new technological solutions and ways to perform health care. However, to reduce the resistance, my study found revised information and knowledge to be among the most decisive factors (Glomsås et al., 2020). Better access to competence can contribute to health professionals feeling safe and mastering the technology. Further, it can enable them to inform and answer questions from patients and relatives and train them in the proper use of the technology. This also shows that one group's assumptions and competence can affect those of another group.

Although reducing the number of visits from health professionals to save costs is one of the policy goals of introducing welfare technology, the effect of reducing the number of visits may be a challenge for some of the persons involved (Brewster et al., 2014; Karlsen et al., 2018; Mort et al., 2015). According to Sujan (2022), the consequences for the relationships involved must be considered with the increasing use of welfare technology. My study has revealed that there were concerns among the participants that reduced face-to-face interactions dehumanised care (Glomsås et al., 2022; Glomsås et al., 2020, 2021), a finding also coincides with other studies (Kim et al., 2017; Lynn et al., 2019; Mostaghel, 2016; Saborowski & Kollak, 2015). Moreover, health professionals may perceive reduced visits as a threat to their professional role and fear of losing power or control, as supported by Nilsen et al. (2016). It is a dilemma that reduced visits are desirable to save time but also provide fewer opportunities for professional assessments and identifying patients' health changes, such as impaired cognitive function and health deterioration. Wherein patients can no longer handle the technology, and health professionals do not detect this can represent a safety risk for the patient (Holthe & Wulff-Jacobsen, 2016). The relatives identified such an issue in sub-study three, where a relative said that the patient forgot how to use the technology due to increased cognitive impairment (Glomsås et al., 2022). Using technology in such a scenario will neither be effective nor serve its purpose. This also shows that it is not necessarily the welfare technology itself that is the problem. In such situations, healthcare professionals are expected to ensure that replacing care tasks with technology implies safe and improved care (Nakrem et al., 2018).

Even though most patients had positive experiences with welfare technology and the reduction of visits was desirable due to increased independence and empowerment, a few patients still wanted daily visits from health professionals if they could choose. However, this was more connected to loneliness and not the technology itself (Glomsås et al., 2021). This highlights the fact that different values among different people can be set against each other, and the use of technological solutions can create new needs. If these new needs are related to social contact, they can, in some situations, be taken care of by individuals other than health professionals. Involving volunteers is a significant part of Norwegian healthcare policy and has become a national and strategic priority for the government in the past decade (Meld. St. 15 (2017-2018); Ministry of Health and Care Services, 2015b). However, recruiting volunteers is not always easy. There may also be situations where some are not suitable for performing the actual tasks to be carried out. Further, a question arises of who will approve volunteers for service assignments if this takes place under the auspices of the healthcare services. Furthermore, the shortage of health professionals and the focus on efficiency also leads to the question of whether patients can choose between technology and receiving personal visits from health professionals in the future.

Some studies visualise that welfare technology has reduced some of the care burdens on relatives (Davies et al., 2020; Marasinghe, 2016). In my study, it was connected to freeing up personal time and reducing safety concerns (Glomsås et al., 2022). Nevertheless, the use of welfare technology also places demands on relatives since health professionals expect them to follow up on information and the patient’s use of the technology. My study indicates further that with reduced visits from health professionals, several patients depended on increased support from relatives (Glomsås et al., 2022; Glomsås et al., 2021). Close follow-ups and regular evaluations by relatives are even more important to ensure patient safety when technology takes over some of the daily tasks that health personnel used to perform.

8.1.2 Tasks, tools and technology

Healthcare tends to be squeezed between standard and tailored solutions and is often determined by economic factors (Kvæl et al., 2022; Nuti & Panero, 2013). If technology is not customised for patients, there is a risk that they may not use it or not use it as intended (Halvorsrud et al., 2021). For example, in sub-study one, the home care management decided to rent medicine dispensers that did not feature a digital voice telling the patients it was time for their medication and how the medicine should be taken. As a result, several patients with cognitive diseases could not use the dispenser, and the health professionals had to continue with the same frequency of visits as before in order to administer the medication (Glomsås et al., 2020). The medication dispensers without a digital voice were cheaper to rent. However, the total cost for the municipality was probably higher since fewer patients could use them and health professionals nevertheless had to continue their daily visits. The identification of who the users are and their prerequisites should form the basis for selecting and acquiring new technology.

A wide range of studies highlight problems with welfare technology design, especially with the insufficient involvement of patients in the design process (Bonner & Idris, 2012; Chadborn et al., 2019; Greenhalgh et al., 2015). My findings identified that material attributes of technologies, such as shape and size, can influence whether and how the technologies are used, which aligns with other studies (Greenhalgh et al., 2013; Nordang & Halvorsen, 2022). An example from sub-study two was a new type of safety alarm that several patients found too heavy to wear around their neck (Glomsås et al., 2021). As a result, they put the safety alarm in their handbag, laid it on the table or hung it on their walking frame. The patients did not reflect on the risk of being unable to access the alarm if they needed help. Technologies meant to be beneficial and enhance safety might not be suitable if the patient does not use them as intended, as also found in the study by Stokke (2017). This indicates that patients and relatives should also be part of the design process to ensure usability.

8.1.3 Organisation, environment and infrastructure

Health care management often controls the organisation of the service and the environmental factors without involving the health professionals who carry out the day-to-day care (Lipsky, 2010). For example, the health professionals in sub-study one experienced that the management controlled the general guidelines and resources, with limited opportunities for their involvement (Glomsås et al., 2020). They described a work situation that lacked personal choices regarding the time to perform care, the possibility of influencing the organisation, and what technology was acquired. The lack of time and opportunities for health professionals to customise the technology for patients shows that the system often prevents the optimisation of welfare technology. Health professionals' working conditions also affect their job satisfaction and thus the opportunities for patients' and relatives' involvement in their care. As Kvæl et al. (2022) point out, management must consider health professionals' opportunities to perform professionally sound and good care. This is also an important prerequisite for strengthening the empowerment of healthcare professionals, patients, and relatives alike (Dent & Pahor, 2015; Spreitzer, 2008).

Several healthcare professionals in my study expressed further fear of internet problems in rural areas and were sceptical of using technical solutions depending on it (Glomsås et al., 2020). Infrastructural issues such as poor internet connections can cause technical problems, affect use and satisfaction, and undermine trust in welfare technology. It could further lead to uncertainty, frustration and concern about healthcare quality. Trust in technology is thus an important influencing factor for accepting welfare technology (Berge, 2018; Hung et al., 2021; Nakrem et al., 2018). Cresswell (2013) supported this concern and noted that infrastructure is often not given sufficient attention when implementing welfare technology.

The health professionals in sub-study one argued that their units were unprepared for the changes following the implementation of the technology (Glomsås et al., 2020). An example was the increasing number of alarms triggered by faults in the medication dispensers, increased use of digital safety alarms, and alarms from window and door sensors. Plans for how and who will respond to the alarms should be clarified and followed up with adequate measures and changes to the organisation of this part of the service. In 2016, the Norwegian Directorate of Health (2016) issued recommendations for the municipalities to establish response centres to meet the need for better, faster and more coordinated responses to increased alarms from welfare technology solutions. These centres have health professionals who can take care of false alarms, respond orally to some of the alarms and prioritise further follow-up for the others. In this way, response centres relieve the health professionals in home care. Yet none of the participating municipalities in my study had implemented such response centres. Nevertheless, these centres cannot solve the psychological strain associated with worrying about dangerous situations for patients if help is not provided quickly enough due to alarms in real-time, as identified as a concern in sub-study one (Glomsås et al., 2020). Furthermore, the health professionals found that their managers had limited focus on this type of stress, which concerned them. This shows the necessity of discussion and exchange of knowledge about how health professionals also experience the daily use of the technology so that their needs can be met sensibly. It also highlights that the use of welfare technology affects but is also affected by other factors in the system, as supported by socio-technical system theory with the focus on the interaction between human factors and technological factors (Carayon et al., 2020; Holden et al., 2013; Wooldridge et al., 2017).

Since the welfare technologies discussed in this thesis are used in the patient's homes, the patient ultimately controls the internal environment. However, several patients from my study commented on the design of the most used medication dispensers. They felt the dispenser was "big and ugly. However, since they experienced it useful, they accepted them in their homes. Using the medication dispenser enabled them to take their medication at the right time, gave them freedom in not having to wait for health professionals, and gave them a feeling of empowerment in mastering the administration themselves (Glomsås et al., 2021). This shows that some values can be more important than others (Glomsås et al., 2021). Tsai et al. (2019) point out that availability and perceived usefulness for resolving tasks are important factors in accepting welfare technology. Still, awareness of the risk that if patients do not accept the design of welfare technology, it may mean some do not want to use it.

The external environment, including policy guidelines, procedures and factors such as financing and costs, is highly important to ensuring greater welfare technology involvement. It is also one of the driving factors behind the policy focus on increased welfare technology use (European Commission, 2021; Eurostat, 2020). However, there is a risk that economic considerations are experienced as the opposite of quality from the view of patients and relatives. This can be such as reduced physical visits and the municipalities' choice of the cheapest technology that is not adapted to most patients.

Some studies have pointed out that the most effective way of ensuring the successful implementation of new technologies is to involve and cooperate with groups who are expected to use them so as to enable an efficient information flow (Cresswell et al., 2013; Dixon-Woods et al., 2011). Other studies describe the minimal effect of involvement in implementing and using welfare technology (Cartwright et al., 2013; Davies et al., 2020). However, these studies fail to consider the complex interactions between technology, patients, relatives, and health professionals; they merely consider welfare technology to be a simple tool that is easy to implement and use (Greenhalgh et al., 2015; Greenhalgh et al., 2013).

8.2 The complexity of user involvement

User involvement is a generally accepted democratic principle in healthcare and is emphasised in the UN's outline of human rights (United Nations, 1948). Further, several countries, including Norway, have developed legislation and integrated the provision into policy documents to strengthen the influence of service users (Meld. St. 15 (2017-2018); Ministry of Health and Care Services, 2015a; Patient and User Rights Act, 1999). In health policy, there is further an expectation for more co-production in involvement, which entails a shift in responsibilities and tasks for patients and relatives and a transfer of power for health professionals (Batalden et al., 2016; Dent & Pahor, 2015). A co-production approach in involvement may improve service quality and satisfaction as well as reduce costs (Alm Andreassen, 2018; Ding et al., 2019; Omeni et al., 2014). A further challenge in this context is also that users tend to understand the concept of user involvement differently, which challenges the planning and performance of user involvement towards achieving common goals (Batalden et al., 2016; Coulter & Oldham, 2016; Hvitstein-Strøm, 2019).

By focusing on collaborations between the people involved in the care and being aware of their physical, mental, social, and behavioural conditions, one can better understand how different ways of involvement are experienced and can optimally fit individuals (Holden et al., 2013). Patients' and relatives' differences in needs, expectations and possibilities require an individual approach to the extent to which involvement is desirable (Bjørkquist et al., 2019; Kvæl et al., 2019; Nakrem et al., 2018). However, as Jenhaug (2018) points out, user involvement will not automatically increase satisfaction and a positive value for relatives and patients. Furthermore, co-production may not necessarily entail the right level of involvement for all patients and relatives and can, in some situations, be unrealistic and too ambitious.

Figure 1, presented in section 2.2.1, visualises how welfare technology fits at the different levels of involvement (Rolfe et al., 2021). At the lower level of involvement, patients and relatives are relayed certain “information” about welfare technology but have no say in its application. This can be the desired level for some, as identified in other studies (Ekdahl et al., 2010; Johannessen et al., 2018; Pearson et al., 2015). In my sub-study one, some of the patients expressed that they just wanted more information and did not have the knowledge or energy to be more actively involved. For that reason, they wanted healthcare professionals to make decisions on their behalf (Glomsås et al., 2021). This can indicate that patients have trust in health professionals, but the reluctance to be involved in the care may also be due to many older patients users are accustomed to the traditional, paternalistic and task-oriented care approach (Dyrstad et al., 2014; Hestevik et al., 2019; Johannessen et al., 2018; Olsen et al., 2019). If patients do not have the energy to be actively involved, the exception of co-production may be overwhelming and be too much to expect from frail older patients, as Paillaud et al. found (2017). Age-related issues such as cognitive impairment may further affect how patients can be involved in their care and the use of welfare technology (Bjørkquist et al., 2015; Halvorsrud et al., 2021; Holthe et al., 2018; Swarbrick et al., 2019). As some relatives described in sub-study thee, some patients did not remember the information they were given (Glomsås et al., 2022). This coincides with Lilleheie’s (2019) findings that older patients may struggle to understand and remember the information they are given. A concern is the unforeseen consequences of inviting frail old patients and their relatives to be more involved as co-producers of their care and whether this could lead to a feeling of negative mastery and disempowerment. Disempowerment can occur due to the inability to cope with the expected level of involvement and use of technology (Bennett, 2019). Consideration must thus be given to their decision-making capacity (Bennett, 2019; Wang et al., 2019).

It is first at the participating level in figure 1 we can begin to discuss user involvement in pursuing co-production of care. This level focuses on patients, relatives and health professionals working together to identify, implement and use the welfare technology (Rolfe et al., 2021). The co-production approach expects shared power and responsibility (Loeffler & Bovaird, 2017; The Co-production and Involvement Network for Wales, 2021). Health professionals must communicate with patients and relatives throughout the healthcare continuum. They should consider individual preferences, needs and values to optimise user involvement and encourage user involvement at a level that is adapted to the patients and their relatives (Berghout et al., 2015; Coulter & Oldham, 2016; Santana et al., 2018).

When relatives saw tracking technology gave patients more freedom and opportunities for an active life, some wanted to be actively involved and take responsibility for the follow-up. Further, using the GPS also gave them time for themselves and a feeling of safety in knowing where the patients were should they go out on their own (Glomsås et al., 2022). Such experiences strengthened these users' desire for involvement and increased use of other welfare technology. However, the early identification of relatives' needs and preferences for their involvement in the use of welfare technology and close follow-ups from health professionals are essential to reducing the potential burden of care (Plöthner et al., 2019). If not, there may be a risk that relatives feel the burden too high and got health issues like depression, anxiety and sleep disorders due to the excessive strain (S. Liu et al., 2017; Wulff et al., 2020). Furthermore, there is a risk that relatives may want to withdraw from the patient's care.

Health professionals are legally obliged to transfer the necessary information and knowledge to enable patients and relatives to become involved and make informed choices (The Health Personnel Act, 1999). However, when the health professionals perceive a lack of information and expertise about involvement and welfare technology, it affects how they can be involved in the development of the home service, but also how they involve patients and relatives (Berge, 2017; Guise & Wiig, 2017; Stokke et al., 2019). It is difficult for health professionals to inform and transmit knowledge to patients or relatives if they do not have the necessary information and knowledge themselves.

The perspectives of patients and relatives are affected by information, competence and the awareness of involvement and the availability of welfare technology (Kolkowska et al., 2016; Nilsen et al., 2016; Zander et al., 2021). Several participants stated they did not know what welfare technologies were available on the market, what they could apply for, and what the procurement process was (Glomsås et al., 2022; Glomsås et al., 2021). This led to frustration, especially for the relatives who applied for and acquired the technology from the municipalities on the patient's behalf, and the reduced opportunities for active involvement (Glomsås et al., 2022).

In paper three, a relative knew that the patient needed medication while she still was in bed. However, this specific knowledge was not taken into consideration as the health professionals first placed the medication dispenser in the patients' living rooms. As a result, the medication dispenser did not serve its purpose (Glomsås et al., 2022). Identifying challenges, where they are in the system, and close follow-ups are essential for professional care. This example also highlights the need for co-production and exchange of information about patient's health and other issues for optimal use of welfare technology (Greenhalgh et al., 2015; Staniszewska et al., 2022; Tønnessen et al., 2016).

Several challenges related to the user involvement of patients and relatives can be linked to health professionals. Attitudes and resistance to change, cultural perceptions of relations and cooperation where health professionals have traditionally made decisions, and the unwillingness to give up power are some of these barriers (Hestevik et al., 2019; Johannessen et al., 2018; Nilsen et al., 2016; Olsen et al., 2019). What patients see as important should be the guiding principle for services and interventions if genuine user involvement is to be taken seriously, a notion also supported by other studies (Dyrstad et al., 2014; Olsen et al., 2020; Vahdat et al., 2014). The Institute for Healthcare Improvement (2021) has primarily been responsible for one of the most used measures, spreading the question "What matters to you?" as a slogan and symbol for individualised involvement in care. In Norway, the question has become part of the political rhetoric to improve healthcare quality (Meld. St. 15 (2017-2018); Norwegian Institute of Public Health, 2021). The health professionals participating in this study were all familiar with the slogan and used it to justify that they were experienced in involving users in care since they asked this question. However, in the interviews, some of the health professionals’ statements indicated that they did not follow up on this question or failed to make patients’ or relatives’ wishes the main focus of their care (Glomsås et al., 2020). Several patients and relatives described paternalistic attitudes on the part of health professionals, such as deciding the conditions of their involvement and arriving at their homes with the welfare technology without any discussion thereof. The experiences expressed in this thesis indicate that health professionals need to develop how they think about their roles and involvement in care, as also described in the study by Hestevik et al. (2019). More than being performers in care, health professionals should act as facilitators and relinquish some of their power (Dugstad et al., 2019). The maintenance of power imbalances and stereotypical prejudices in the healthcare system thereby pose a challenge to co-production in care. To relinquish health professionals’ power, they need more knowledge of what power entails and how to establish themselves in equal relationships with patients and their relatives (Halvorsen et al., 2020). When the decision-making power is not balanced in reciprocal and caring relationships, one cannot discuss co-production in a sense defined in section 2.2.1.

A further issue is that health professionals are part of the healthcare system, which features several incumbent challenges. In many situations, they have limited influence over how the services they provide are organised and the resources allocated to the various tasks, as described by Lipsky (2010). The time available for observing patients and discussing their needs with them and their relatives was reduced due to the high number of tasks and patients they had, despite cooperation being essential for the relationship, sense of trust, and involvement between the parties (Glomsås et al., 2020). Involvement as a partnership in care requires regular meetings and time spent together, the importance of which other studies have also described (Dahl et al., 2014; Kvæl et al., 2019; van Dongen et al., 2017). Questions must also be asked about whether health professionals are able to work in a more involved way with patients and their relatives with the limited resources they have available.

8.3 Ethical aspects

There are two main drivers in the home care context: expectations of quality improvement and reduced healthcare costs (Rolfe et al., 2021). These two drivers often oppose each other and create tensions concerning priorities and values. Further, they also affect ethical aspects and underlying relations, autonomy, safety, trust, independence and equality of involvement in welfare technology in the current home care services context. The ethical focus can enable to highlight some of the tensions between the user groups and how different values and power dynamics influence practice and decision-making processes (Gheduzzi et al., 2021b; Hofmann, 2013; Mort et al., 2015).

From a human rights perspective, there are concerns about the ethics of introducing welfare technology without the full involvement of older people and their relatives (Ienca et al., 2018; Novitzky et al., 2015; Rolfe et al., 2021). The research has identified that when a person does not feel involved, respected, and heard, this gives rise to feelings of anxiety, an unwillingness to be involved further, and lower perceived empowerment (Spreitzer, 2008; Vahdat et al., 2014). It can result in a powerless position for the patients and relatives in relation to health professionals (Halvorsen et al., 2020; Knol & van Linge, 2009). In my study, it was some experiences of tasks and responsibilities merely transferred from the health professionals to patients and relatives without assessing if they had the necessary knowledge, capacity, or wish to engage in such a practice (Glomsås et al., 2022; Glomsås et al., 2021). When such situations occur, this does not promote user involvement respectfully nor reciprocally, which is a prerequisite for discussing involvement as a means of co-production of care (Beresford et al., 2015; Christensen & Fluge, 2016; Rolfe et al., 2021). To what extent and how patients and their relatives want to be involved in the decision-making process will differ and must be respected as part of their autonomy, as other studies have also pointed out (Dyrstad et al., 2015; Johannessen et al., 2018; Wiig et al., 2020). Respect is a moral value, and health professionals are expected to involve patients and relatives with an understanding of their whiches (Held, 2004). These findings underline that there has to be a balance between the expectation of active involvement and patients' wishes and capacities. Further, the choice of involvement must be made after patients and relatives have been given sufficient information about their options and the possibility to make informed choices, as cited in the Patient and User Rights Act (Patient and User Rights Act, 1999). It is concerning that some patients feel forced to use welfare technology when health professionals merely bring it to their homes (Glomsås et al., 2021). Patients' sense of autonomy is at stake when they do not get the option to choose, as the findings of other studies have also revealed (Dyrstad et al., 2015;

Johannessen et al., 2018). Moreover, there is also an ethical dilemma involved when patients are offered welfare technology, but it is unclear whether they are competent in their ability to accept and use it, especially those with cognitive impairment (Novitzky et al., 2015). This requires extra sensitivity from healthcare professionals to ensure patient safety. Health professionals should continue engaging and functioning as a safety net if patients make unhealthy choices (Batalden et al., 2016). Involving frail old patients and relatives can be demanding and requires time and effort from health professionals, especially for creating good relations (Fischer et al., 2019; Fjørtoft et al., 2020).

As a result of close and long-term relationships, relatives often feel attentive to and responsible for identifying and meeting the needs of patients (Tronto, 1994) Even though several of the relatives consider caring as an act of giving, they may also consider it as an obligation and a threat to autonomy (Glomsås et al., 2022). As human beings, we are dependent on each other and are never fully autonomous, a view that is in accordance with the ethics of care theory (Held, 2006; Tronto, 1994). This was especially true of relatives who did not feel they had a choice in providing more care to the patient when health professionals reduced their number of visits. Furthermore, this thesis further highlights the challenges faced when a patient and healthcare personnel's expectations do not match the relatives' ability to spend time or energy on their care. Emotional exhaustion on the part of relatives is further amplified when patients do not have insight into their health or are refused to accept care from either relative or health professionals (Glomsås et al., 2022), as found in other studies (Andrén & Elmståhl, 2008; Søvde et al., 2019). Such feelings are also described as a concern in the ethics of care theory (Held, 2004). Further, health professionals must pay more attention to the relatives' needs when they are partners in the patient's care, especially when increased co-production is expected, entailing more responsibility and increasing the number of care tasks.

Generally, health professionals do not intend to cause harm but merely want to focus on patients' and relatives' well-being and do the best for the patient (Beauchamp & Childress, 2013). However, healthcare professionals are bound by their management's frameworks and expectations (Fjørtoft et al., 2021). When health professionals have insufficient resources at hand, such as the necessary time to facilitate care co-production, this may lead to difficult choices about priorities and professional judgment. In line with the ethics of care, they may feel unable to offer adequate care to their patients, which can be experienced as excessively demanding considering their professional obligation to identify and follow up on their patient’s needs (Tronto, 1994).

Non-maleficence and beneficence can also conflict with the principle of autonomy. For example, health professionals are morally responsible for listening to patients’ wishes and preferences. However, this can pose problems when patients do not have the cognitive capacity to understand the correct use of welfare technology but still want to use it, as several relatives described in sub-study three (Glomsås et al., 2022). As suggested in the study by Ris et al. (2019), recognising the complementary forms of knowledge and expertise of relatives and health professionals is essential to cooperation and reducing the risks of harm. As ethics of care highlights, there is a need to avoid paternalistic domination from health professionals (Held, 2004). Health professionals must listen with interest to patients and relatives, recognising them as partners in care (Heaton et al., 2016; Wolff et al., 2020). However, different values can create conflicts concerning what the best is and for whom, as highlighted in my stub-studies (Glomsås et al., 2022; Glomsås et al., 2021). In such situations, health professionals must determine whether replacing care provided by people with technology is justifiable.

Some health professionals in my study expressed reservations about the impact of tracking devices on civil rights, patient’s need for privacy, and the threat to their autonomy (Glomsås et al., 2020), as also seen in other studies (Hofmann, 2013; Sánchez et al., 2017). The patients and relatives, however, did not consider the use of the technology as a means of insidious monitoring but rather as a safety measure that gave them peace of mind (Glomsås et al., 2021). This finding coincides with other studies (L. Liu et al., 2017; Olsson et al., 2016). However, we saw a change towards a more positive attitude from the first to the last interview among the health professionals who had gained more knowledge about the strict regulations governing the use of such technology (Glomsås et al., 2020). This strengthens the assumption that knowledge is an important prerequisite for attitudes surrounding the use of technology.

Another concern raised in my study was the possibility of reduced treatment quality and a threat to patient safety resulting from fewer face-to-face visits by health professionals. Relatives usually do not have the sufficient professional competence to take over tasks and professionally assess patient health changes (Glomsås et al., 2022), an issue also highlighted by Dugstad (2019). Further, frail older patients who do not have relatives to follow up on them will be particularly vulnerable when welfare technology replaces face-to-face interactions with health professionals. There is a question of where the limit is for what is professionally acceptable.

Respecting and recognising individual differences, knowledge, and needs and avoiding paternalistic domination from the health professionals are highlighted as a part of the ethics of care (Held, 2004). To become aware of the power that lies in dependency on healthcare services, health professionals need to reflect on the power dynamics involved in the relationship between patients and relatives (Halvorsen et al., 2020). It is not necessarily desirable to share power and responsibility equally between patients and professionals in all situations; it is more a question of respect and collaboration when needs are identified and when welfare technology is to be implemented and used.

Equality is a part of the principle of justice (Beauchamp & Childress, 2013). It is also a legal right (The Health and Care Services Act, 2011) and a moral principle enshrined in the Human Rights Declaration (United Nations, 1948). Additionally, it is an essential principle in modern welfare states (Dahl & Rasmussen, 2012). When inequality is experienced, it may affect individual and collective well-being and productivity and undermines trust in the healthcare system. Equality of services and thus also of access to welfare technology with fair distribution of benefits for all is a central principle of biomedical ethics (Beauchamp & Childress, 2013) and the ethics of care (Held, 2006; Tronto, 1994). Some relatives discussed the dynamics between the level of services patients received and how active they were in demanding and requesting the services (Glomsås et al., 2022). For several patients reporting a low income, the rental of safety alarms was a difficult issue to overcome (Glomsås et al., 2021). It is ethically problematic if differences in service access are due to relatives' knowledge or ability to stand up for the patient or their financial situation. The review by Kruse et al. (2018) and Deloitte's (2017) study identified that cost is one of the main barriers to adopting welfare technology. Wiborg and Hansen (2018) point out that inequality in health knowledge and finances in a given population can increase pressure on solidarity and democracy, as seen in Scandinavia and in other European countries.

Hofmann (2013) has expressed an ethical concern about who stands to primarily benefit from welfare technology. He is concerned that increasing use of welfare technologies will benefit health services more than those actually in need of care. Others are also concerned that user involvement and co-production are just political rhetoric for shifting tasks from health professionals onto relatives to cut costs more than it is in pursuance of quality improvements (Askheim, 2016; Batalden et al., 2016; Haukelien, 2020). Municipalities in this study exacerbate this concern by focusing more on financial savings than on patients' needs when procuring welfare technology (Glomsås et al., 2020), which coincides with the findings of Dyb et al. (2021).

9.0 CONCLUDING REMARKS

This PhD thesis provides new and relevant knowledge as well as a deeper understanding of patients', relatives', and health professionals' experiences of user involvement when welfare technology is implemented and used in home care services. The thesis also identifies and discusses the ethical aspects of user involvement in the pursuance of co-production and increased use of welfare technology. It has generated an enhanced understanding of the complexity of the changes in home care service for patients, relatives, and health professionals.

In the first section, 9.1, I present the conclusions of this thesis. Section 9.2 offers recommendations to enhance welfare technology and user involvement in home care services. Section 9.3 addresses a potential future research study.

9.1 Conclusion and thoughts for the road ahead

Home care is changing due to political expectations of the increasing use of welfare technology and user involvement as a response to expanded tasks and demographic changes. (European Commission, 2018; Eurostat, 2020). Different system factors affect individuals' experiences of welfare technology, and the individual characteristics of the persons involved in turn, affect the collaboration processes (Carayon et al., 2014; Holden et al., 2013).

My study has identified a call for building good relationships and trust between those collaborating in health care services that are in line with the ethics of care theory (Held, 2004; Tronto, 1994). However, this will require time and interest from patients, relatives, and healthcare professionals. Such arrangements should be put into regular practice and have significant potential for promoting patients' and relatives' involvement by giving voice to their needs. It could also prevent unfortunate consequences such as the incorrect use of the technology, which can lead to dire safety issues.

Healthcare professionals play a fundamental role when it comes to involvement, and their attitudes are of significant importance to the success of the co-production of care. Therefore, healthcare professionals should become more aware of their influence as providers of home care services. Access to the information and competence surrounding user involvement and welfare technology is necessary for health professionals to facilitate and transfer that competence to patients and relatives. However, it is also important that health professionals operate under reasonable conditions that allow them to fulfil their care obligations, such as having time to promote involvement and co-work with patients and relatives.

Involvement and respect for what is essential for patients can improve their autonomy and feeling of empowerment and increase the perception of high-quality services. Most patients in this study appreciated and wanted to use welfare technology more since it provided a sense of safety, independence, and the opportunity to live in their homes for longer. Further, the adequate dissemination of information and knowledge is necessary for increased involvement and the optimal use of the relevant technologies. Standardised technological solutions may not fit everyone, so individual adjustments must be made. This reinforces the need for end-users to be involved across all stages, from procurement to daily use.

The relatives in this study appreciated the use of welfare technology since they found that it enhanced patient safety, gave them more flexibility and time for themselves, and assured them that the patient would receive help when they could not be physically present. They called for early involvement to ensure successful and safe implementation and use. Relatives can be essential contributors to co-production. However, autonomy and their life situation must be taken into account when in the involvement process. Health professionals have a responsibility to facilitate conditions in which relatives feel respected, acknowledged, and empowered to become involved in the care of patients.

This thesis has revealed that human and technological factors influence how contemporary home care services are experienced. Information and knowledge were prerequisites for user involvement and optimal use of welfare technology. Individual approaches related to patients' and relatives' wishes, needs, and capacities can improve the experience and quality of the home care service. Among the issues raised were ethical concerns about autonomy, the risk of inequality in receiving services, and the availability and affordability of welfare technology. Home care service seemed unprepared for the changes involved in the greater use of welfare technology and the call for co-production in involvement.

9.2 Implications for practice

This study provides valuable insights into the complexity of user involvement and the use of welfare technology from the viewpoints of patients, relatives, and health professionals. It can create a basis for targeted efforts and measures in home care services to create a more inclusive environment in care provision. The new knowledge provided by this study may be used to guide the necessary assessments and interventions as well as to support municipal decisions when buying or renting welfare technology.

When planning for the involvement and use of welfare technology for frail older patients and their relatives, it is essential to consider their health and living situations and their individual needs for information, expectations, attitudes, and values. The co-production process should be characterised by respecting and acknowledging the resources and understanding of those involved.

This thesis also illustrates the necessity of respectful relationships based on trust and equality between health professionals, patients, and relatives. Regular meetings with patients and their relatives should be held, information and knowledge exchanges should be encouraged, sufficient time for cooperation must be allotted, and evaluations must be performed regularly and put into a system. There cannot merely be a transfer of responsibility and tasks; there must be a genuine partnership where power and responsibility are shared. Co-production may not be suitable for all patients and relatives. For that reason, individual assessments and mutual discussions may strengthen the possibility of discovering the most appropriate level of involvement for patients and relatives. Further, there is a need for a stronger focus on the working conditions of health professionals in home care services and available resources and knowledge for implementing the user involvement policy.

Attention should be directed towards a holistic approach with individual assessments of patients’ and relatives’ health and living situations to determine the support they need in using welfare technology. The findings may be relevant for researchers, policymakers, and professionals to facilitate user involvement and empowerment in home care and increase the use of welfare technology.

9.3 Future research

This study revealed the challenges in implementing and using welfare technology, such as the physical design of some technologies, unstable networks, and arrangements related to training, knowledge, and the priority of time and resources. All these challenges should be followed up with research and the further development of the services. However, the major challenge experienced by this study's participants was related to how the various users were involved in patients' care. Moreover, there is a great need for a specific focus on healthy relationships to reduce the risk of negative consequences for patients and relatives in pursuance of co-production in care. This thesis revealed that caring for patients involves an interaction between values, beliefs, and attitudes and is a far more complex activity than is often perceived. It thereby requires positive, intentional actions on the part of health professionals.

In the development of this study, I have become aware of the importance of further research on the person-centred approach and frameworks for proper care where health professionals work with patients and relatives to plan care and support to meet the individual's unique wishes and needs. McCormack and McCance (2006) offer a framework and theoretical model for person-centred nursing. They describe several core concepts and mutual relations that provide building blocks for realising reasonable care (McCance & McCormack, 2017a, 2017b; McCormack, 2020; McCormack & McCance, 2016; McCormack & McCance, 2006). Their framework is interwoven with a "transformational practice development" strategy and research methodologies that originate from the action research paradigm (McCormack and McCance, 2016). They argue that the framework is particularly suitable for empirical studies that aim to develop practical knowledge on the realization of person-centred care (McCormack & McCance, 2016). Further research to test this model for a closer examination of patient-centred care in the context of user involvement in the implementation and everyday use of welfare technology in home care services would be interesting as an extension of this PhD work.

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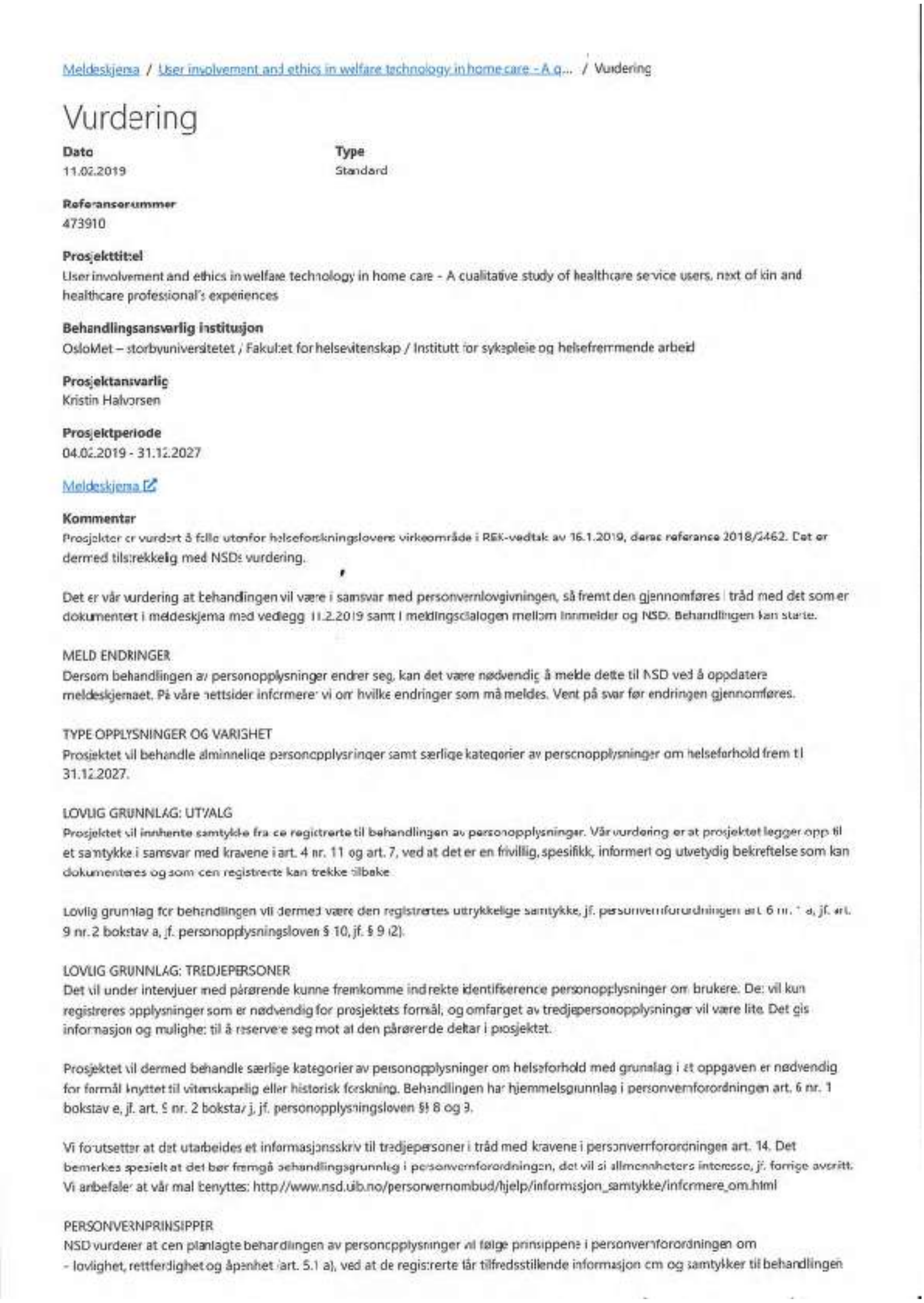
Appendix I



Meldeskjema / User involvement and ethics in welfare technology in home care - A q... / Vurdering

Vurdering

Dato
11.02.2019

Type
Standard

Referansenummer
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Prosjekttittel
User involvement and ethics in welfare technology in home care - A cualitative study of healthcare service users, next of kin and healthcare professional's experiences

Behandlingsansvarlig institusjon
OsloMet – storbyuniversitetet / Fakultet for helsevitenskap / Institutt for sykepleie og helsefremmende arbeid

Prosjektansvarlig
Kristin Halvorsen

Prosjektperiode
04.02.2019 - 31.12.2027

Meldeskjema

Kommentar
Prosjekter er vurdert å falle utenfor helseforskningslovens virkeområde i REK-vedtak av 16.1.2019, deres referanse 2018/2462. Det er dermed tilstrekkelig med NSDs vurdering.

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjema med vedlegg 11.2.2019 samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD ENDRINGER
Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle alminnelige personopplysninger samt særlige kategorier av personopplysninger om helseforhold frem til 31.12.2027.

LOVLIG GRUNNLAG: UTVALG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

LOVLIG GRUNNLAG: TREDJEPERSONER
Det vil under intervjuer med pårørende kunne fremkomme indirekte identifiserende personopplysninger om brukere. Det vil kun registreres opplysninger som er nødvendig for prosjektets formål, og omfanget av tredjepersonopplysninger vil være lite. Det gis informasjon og mulighet til å reservere seg mot at den pårørende deltar i prosjektet.

Prosjektet vil dermed behandle særlige kategorier av personopplysninger om helseforhold med grunnlag i at oppgaven er nødvendig for formål knyttet til vitenskapelig eller historisk forskning. Behandlingen har hjemmelsgrunnlag i personvernforordningen art. 6 nr. 1 bokstav e, jf. art. 9 nr. 2 bokstav j, jf. personopplysningsloven §§ 8 og 9.

Vi forutsetter at det utarbeides et informasjonsskriv til tredjepersoner i tråd med kravene i personvernforordningen art. 14. Det bemerkes spesielt at det bør fremgå behandlingsgrunnlag i personvernforordningen, det vil si allmennhetens interesse, jf. forrige avsnitt. Vi anbefaler at vår mal benyttes: http://www.nsd.uib.no/personvernombud/hjelp/informasjon_samtykke/informere_om.html

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om
- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen

- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

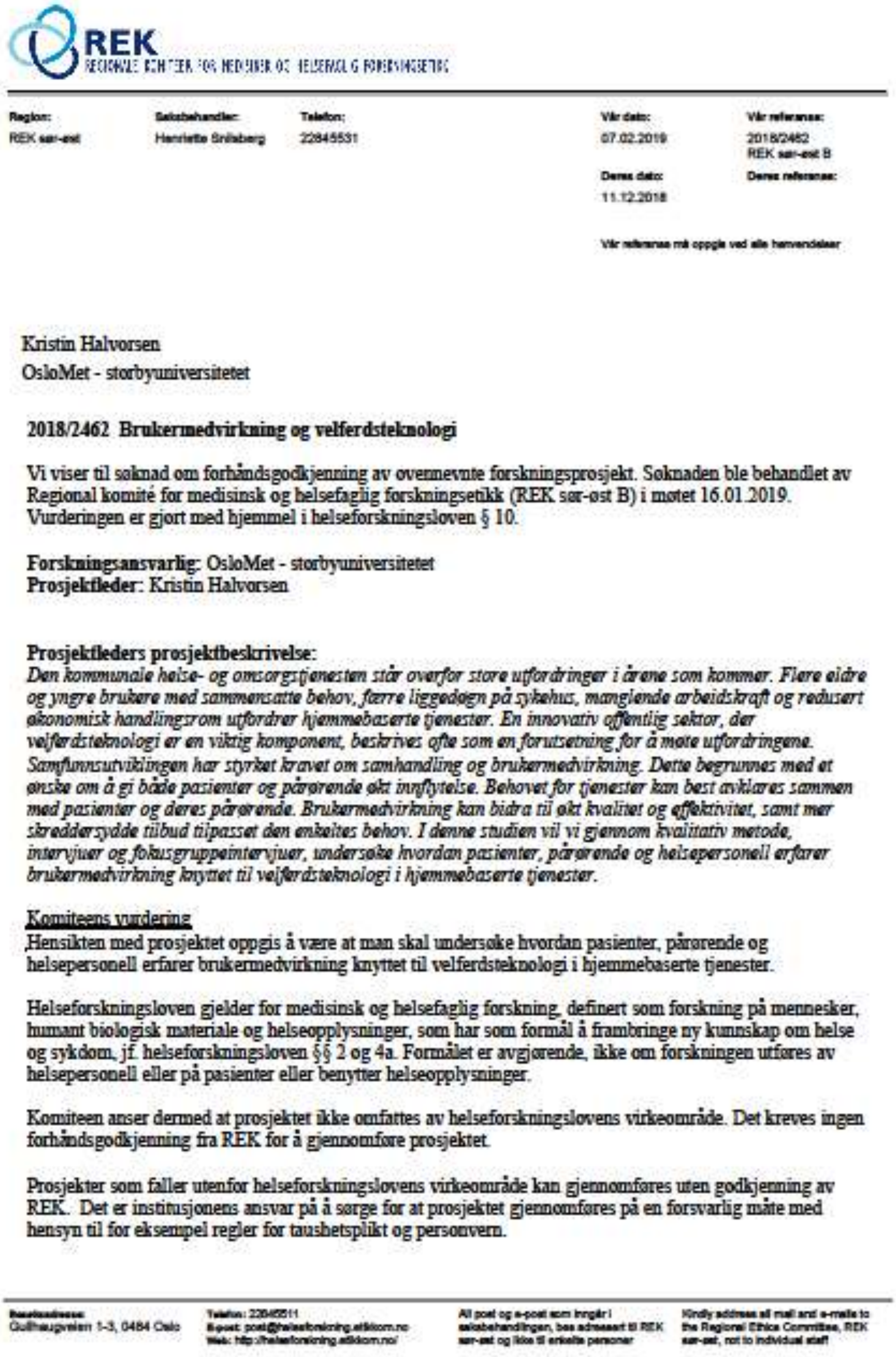
OPPFØLGING AV PROSJEKTET

NSD vil følge opp underveis og ved planlagt avslutning for å avklare status for behandlingen av personopplysninger.

Lykke til med prosjektet!

Kontaktperson hos NSD: Lasse Raa
Tlf. personverntjenester: 55 58 21 17 (tast 1)

Appendix II



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Henriette Snilsberg	22845531	07.02.2019	2018/2462 REK sør-øst B
			Deres dato:	**Deres referanse:**
			11.12.2018	

Vår referanse må oppgis ved alle henvendelser

Kristin Halvorsen
OsloMet - storbyuniversitetet

2018/2462 Brukermedvirkning og velferdsteknologi

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst B) i møtet 16.01.2019. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig: OsloMet - storbyuniversitetet
Prosjektleder: Kristin Halvorsen

Prosjektleders prosjektbeskrivelse:
Den kommunale helse- og omsorgstjenesten står overfor store utfordringer i årene som kommer. Flere eldre og yngre brukere med sammensatte behov, færre liggedøgn på sykehus, manglende arbeidskraft og redusert økonomisk handlingsrom utfordrer hjemmebaserte tjenester. En innovativ offentlig sektor, der velferdsteknologi er en viktig komponent, beskrives ofte som en forutsetning for å møte utfordringene. Samfunnsutviklingen har styrket kravet om samhandling og brukermedvirkning. Dette begrunnes med et ønske om å gi både pasienter og pårørende økt innflytelse. Behovet for tjenester kan best avklares sammen med pasienter og deres pårørende. Brukermedvirkning kan bidra til økt kvalitet og effektivitet, samt mer skreddersydde tilbud tilpasset den enkeltes behov. I denne studien vil vi gjennom kvalitativ metode, intervjuer og fokusgruppeintervjuer, undersøke hvordan pasienter, pårørende og helsepersonell erfarer brukermedvirkning knyttet til velferdsteknologi i hjemmebaserte tjenester.

Komiteens vurdering
,Hensikten med prosjektet oppgis å være at man skal undersøke hvordan pasienter, pårørende og helsepersonell erfarer brukermedvirkning knyttet til velferdsteknologi i hjemmebaserte tjenester.

Helseforskningsloven gjelder for medisinsk og helsefaglig forskning, definert som forskning på mennesker, humant biologisk materiale og helseopplysninger, som har som formål å frambringe ny kunnskap om helse og sykdom, jf. helseforskningsloven §§ 2 og 4a. Formålet er avgjørende, ikke om forskningen utføres av helsepersonell eller på pasienter eller benytter helseopplysninger.

Komiteen anser dermed at prosjektet ikke omfattes av helseforskningslovens virkeområde. Det kreves ingen forhåndsgodkjenning fra REK for å gjennomføre prosjektet.

Prosjekter som faller utenfor helseforskningslovens virkeområde kan gjennomføres uten godkjenning av REK. Det er institusjonens ansvar på å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff

Vedtak
Etter søknaden fremstår prosjektet ikke som medisinsk eller helsefaglig forskning, og det faller derfor utenfor helseforskningslovens virkeområde, jf. §§ 2 og 4 bokstav a.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Eventuell klage sendes til REK sør-øst B. Klagefristen er tre uker fra mottak av dette brevet.

Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering, jf. forskningsetikkloven § 10 og helseforskningsloven § 10.

Komiteens avgjørelse var enstemmig.

Med vennlig hilsen

Ragnhild Emblem
Professor, dr. med.
leder REK sør-øst B

Henriette Snilsberg
komitésekretær

Kopi til:fou-hf@oslomet.no
OsloMet ved øverste administrative ledelse post@oslomet.no

Appendix III

Brukermedvirkning og velferdsteknologi

Forespørsel om fornyet samtykke fra helsepersonell

User involvement and ethics in welfare technology in home care

- A qualitative study of healthcare service users, next of kin and healthcare professionals' experiences (brukermedvirkning og velferdsteknologi).

Denne henvendelsen gjelder fornyet samtykke fra deg som helsepersonell om bruk av data fra intervjuer foretatt vår 2017og/eller høst 2017. Intervjuene ble utført i forbindelse med forprosjektet «Muligheter og barrierer ved innføring av velferdsteknologi i hjemmebaserte tjenester - helsepersonell perspektiv». Prosjektet var en del av prosjektet SOL (Support quality Of Life).

Årsaken til at vi ber om nytt samtykke er at Norsk Senter for forskningsdata (NSD) har bedt om at vi innhenter fornyet samtykke, slik at det er klart for deltagerne at dataene fra forprosjektet også vil bli benyttet i dette doktorgradsprosjektet.

I dette skrivet gir vi deg informasjon om målet for prosjektet og hva fornyet samtykke innebærer for deg.

Formål

Denne studiens hovedmål er å møte noen av utfordringene i velferdssamfunnet, ved å bidra til kunnskap om en vellykket implementering og bruk av velferdsteknologi i helsetjenesten. Det overordnede målet er å få ny innsikt i brukeres erfaringer av brukermedvirkning, samt belyse etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologi. Brukere vil si pasienter, nærmeste pårørende og helsepersonell.

Hva innebærer prosjektet?

Du bes om fornyet samtykke, fordi vi ønsker å benytte dataene fra forprosjektet i denne doktorgrads studien.

Om du sier aksepterer at vi benytter dine data også i denne studien vil det ikke medføre noe ekstraarbeid for deg utover å returnere samtykkeerklæringen underskrevet.

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 Heidi Snoen Glomsås, telefon 45 20 80 61, e-post: hglomsas@oslomet.no , eller prosjektleder og hovedveileder Kristin Halvorsen, telefon 92 21 62 50, e-post: kristin.halvorsen@oslomet.no

Hva skjer med opplysningene om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. 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. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer, eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste som er kryptert og passordbeskyttet. Det er kun prosjektleder Kristin Halvorsen og stipendiat Heidi Snoen Glomsås som har tilgang til denne listen.

Prosjektet skal etter planen avsluttes 31.12.2021. Alle intervjuer både på papir og digitalt slettes etter at prosjektet er ferdig og senest 2027.

Deling av data

Ved å delta i prosjektet, samtykker du også til at opplysninger i anonyme intervjuutskrifter kan deles med medforfattere.

Heidi Snoen Glomsås, universitetslektor OsloMet – storbyuniversitetet, stipendiat

Kristin Halvorsen, førsteamanuensis OsloMet – storbyuniversitetet, hovedveileder

Ingrid Ruud Knutsen, førsteamanuensis OsloMet – storbyuniversitetet, medveileder.

Mariann Fossum, professor ved universitetet i Agder, medveileder.

Godkjenning

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har vurdert at prosjektet faller inn under helseforskninglovens virkeområde. Prosjektet er også i henhold til regelverk meldt Norsk Senter for forskningsdata (NSD), og har fått referansenummer 473910.

Etter ny personopplysningslov har behandlingsansvarlig OsloMet - storbyuniversitetet og prosjektleder ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning (GDPR), artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Kontaktopplysninger

Dersom du har spørsmål til prosjektet kan du ta kontakt med OsloMet- storbyuniversitetet ved:

- Heidi Snoen Glomsås, doktorgradsstipendiat, e-post: hglomsas@oslomet.no, telefon 45208061
- Kristin Halvorsen, prosjektleder, e-post: kristin.halvorsen@oslomet.no, telefon 9221625.
- Personvernombud ved institusjonen er Ingrid Jacobsen, e-post: ingrid.jacobsen@oslomet.no, telefon: 993 02 316
-

Jeg samtykker til at tidligere innhentede data i SOL prosjetet benyttes prosjektet brukermedvikning og velferdsteknologi

Jeg har mottatt og forstått informasjon om prosjektet “User involvement and ethics in welfare technology in home care - A qualitative study of healthcare service users, next of kin and healthcare professional’s experiences?” (Brukermedvirkning og velferdsteknologi)
Jeg har fått anledning til å stille spørsmål om prosjektet.

Jeg samtykker til at:

☐ Data innhentet i intervju våren 2017/høst 2017 i prosjektet «Muligheter og barrierer ved innføring av velferdsteknologi i hjemmebaserte tjenester - helsepersonell perspektiv» kan benyttes i dette doktorgradsprosjektet.

☐ Jeg samtykker til at mine opplysninger behandles frem til doktorgradsprosjektet er avsluttet, og senest 2027.

(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet:

Brukermedvirkning og velferdsteknlologi i hjemmebaserte tjenester

- En kvalitativ studie av brukere, pårørende og helsepersonell opplevelse.

Dette er en forespørsel til deg som er helsepersonell og som tidligere har deltatt i SOL prosjektet om du ønsker å delta i et oppfølgingsintervju.

I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltagelse innebærer for deg.

Formål

Studiens hovedmål er å møte noen av utfordringene i velferdssamfunnet, ved å bidra til kunnskap om en vellykket implementering og bruk av velferdsteknologi i helsetjenesten. Det overordnede målet er å få ny innsikt i brukeres erfaringer av brukermedvirkning, samt belyse etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologi. Brukere vil si pasienter, nærmeste pårørende og helsepersonell.

Hva innebærer prosjektet?

Du får spørsmål om å delta i denne studien, fordi vi ønsker oppfølgings intervju(er) av helsepersonell fra de 3 kommune som tidligere har deltatt et forprosjektet (Support Quality of Life – SOL). Deltagelse vil si å gi et til tre intervju i løpet av prosjektperioden. Avdelingsledere i hjemmebaserte tjenester i aktuelle kommuner har fått forespørsel om å finne frem til helsepersonell, som kan være aktuelle deltagere i denne studien.

Om du sier deg villig til å delta, vil du få informasjon fra din leder om dato og klokkeslett for intervjuet. Intervjuet vil foregå i OsloMet sine lokaler på Kjeller, og vil vare i ca. 1 time.

Du vil blant annet få spørsmål om:

- Bakgrunn for bruk av velferdsteknologi og hvilke løsninger kommunen du jobber i benytter.

- Dine erfaringer knyttet til hva du synes var bra eller utfordrende ved bruk av velferdsteknologi.
- Det vil være et særlig fokus på hvordan du opplevder mulighet for brukermedvirkning.
- Det vil være spørsmål om du tenker at det er noen etiske problemstillinger og utfordringer ved anskaffelse og bruk av velferdsteknologi.

Vi vil registrere alder, kjønn og hvor lenge du har jobbet i hjemmebaserte tjenester. Stipendiat Heidi Snoen Glomsås vil stille spørsmålene under intervjuet. En av hennes veiledere vil være tilstede på intervjuet. Intervjuet tas opp på en digital lydopptaker.

Frivilling 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. Dette vil ikke få konsekvenser for deg. 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 Heidi Snoen Glomsås, telefon 45 20 80 61, e-post: hglomsas@oslomet.no , eller prosjektleder og hovedveileder Kristin Halvorsen, telefon 92 21 62 50, e-post: kristin.halvorsen@oslomet.no

Hva skjer med opplysningene om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. 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. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer, eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste som er kryptert og passordbeskyttet. Det er kun prosjektleder Kristin Halvorsen og stipendiat Heidi Snoen Glomsås som har tilgang til denne listen.

Prosjektet skal etter planen avsluttes 31.12.2021. Alle intervjuer både på papir og digitalt slettes etter at prosjektet er ferdig og senest 2027.

Deling av data

Ved å delta i prosjektet, samtykker du også til at opplysninger i anonyme intervjuutskrifter kan deles med medforfattere.

- Kristin Halvorsen, førsteamanuensis OsloMet – storbyuniversitetet, hovedveileder
- Ingrid Ruud Knutsen, førsteamanuensis OsloMet – storbyuniversitetet, medveileder.

- Mariann Fossum, professor ved universitetet i Agder, medveileder.

Godkjenning

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet. I REK vedtak av 16.01.2019 er prosjektet vurdert til å falle utenfor helseforskningslovens virkeområde med referanse 2018/2462. Prosjektet er også i henhold til regelverk meldt Norsk Senter for forskningsdata (NSD) med referanse nummer 473910.

Etter ny personopplysningslov har behandlingsansvarlig OsloMet - storbyuniversitetet og prosjektleder Kristin Halvorsen et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning (GDPR), artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Kontaktopplysninger

Dersom du har spørsmål til prosjektet kan du ta kontakt med OsloMet- storbyuniversitetet ved:

- Heidi Snoen Glomsås, doktorgradsstipendiat, e-post: hglomsas@oslomet.no, telefon 45208061
- Kristin Halvorsen, prosjektleder, e-post: kristin.halvorsen@oslomet.no, telefon 9221625.
- Personvernombud ved institusjonen er Ingrid Jacobsen, e-post: ingrid.jacobsen@oslomet.no, telefon: 993 02 316

Jeg samtykker til å delta i prosjektet brukermedvikning og velferdsteknologi og til intervjuet brukes slik det er beskrevet

Jeg har mottatt og forstått informasjon om prosjektet "User involvement and ethics in welfare technology in home care - A qualitative study of healthcare service users, next of kin and healthcare professional's experiences?" (Brukermedvirkning og velferdsteknologi)
Jeg har fått anledning til å stille spørsmål om prosjektet.

Jeg samtykker til:

- ☐ Delta i oppfølgingsintervju
- ☐ Dataene kan benyttes i forbindelse med arbeid relatert til dette doktorgradsprosjektet
- ☐ Jeg samtykker til at mine opplysninger behandles frem til doktorgradsprosjektet er avsluttet, og senest 2027.

(Signert av prosjektdeltaker, dato)

Brukermedvirkning ved innføring og bruk av velferdsteknologi i hjemmebaserte tjenester – oppfølgingsintervjuer av helsepersonell

Demografiske data:

Profesjon: (sykepleier, hjelpepleier, omsorgsarbeider etc.):

Alder:

Kjønn:

Hvor lang erfaring har du i bruk av velferdsteknologiske løsninger? (mnd. / år)

Disse dataene legges inn under hver respondent.

Respondent 1:

Respondent 2:

Respondent 3:

Respondent 4:

Respondent 5:

Respondent 6:

Hva slags velferdsteknologi er tatt i bruk i din kommune?

Kommune1:

Kommune 2:

Kommune 3:

Intervjuspørsmål

1: Kan dere diskutere hva dere forstår med brukermedvirkning?

Hjelpespørsmål: Er dere opptatt av dette, og snakker dere om dette på jobben?

På hvilke måter jobber dere med brukermedvirkning i jobben?

2: Har det vært noen endringer i forhold til bruk av velferdsteknologi i deres kommune siden det første intervjuet og i så fall kan dere beskrive disse?

Hjelpespørsmål: Kan dere fortelle litt om dine erfaringer dette har det bragt med seg? (kunnskaper/holdninger)

3: Kan dere diskutere hvordan dere opplever informasjon, veiledning og oppfølging fra kommunens side i forhold til bruk av velferdsteknologi?

Hjelpespørsmål: Er det variasjoner mellom kommunene?

Hva tenkere dere hadde vært optimalt og hvordan kunne det gjøres?

4: Kan dere diskutere erfarte eller potensielle etiske problemstillinger ved bruk av velferdsteknologi?

Hjelpespørsmål: Overvåkning

Økonomi

Privat/offentlig anskaffelse og bruk

Pårørendes rolle og ansvar i forhold til daglig bruk

Selvbestemmelse

Trygghet

Utvisking av offentlig og privat sfære

Makt

5: Tenker dere at det er noen forskjell på de etiske aspekter sett fra deg som helsepersonell og hvordan pasienter og pårørende ser på dette?

Hjelpespørsmål: Interesser

Fokus

Behov

6: Kan dere diskutere hvilke muligheter for brukermedvirkning det er i deres kommune?

Hjelpespørsmål: For helsepersonell, pasienter og pårørende
Anskaffelse
Innføring
Daglig bruk

7: Har dere noen eksempler på hvordan dere jobber med brukerinvolvering av pasienter og pårørende?

8: Hvordan tenker dere at pasienter og pårørende bør involveres for at det skal bli best mulig bruk av teknologien og tjenenestene i hjemmebaserte tjenester?

Hjelpespørsmål: Hva tenker dere er viktig for å få dette til?
Informasjon og kunnskap

9: Får pasienter og pårørende velge om de vil ta velferdsteknologi i bruk, og i så fall hva er konsekvensene dersom de ikke velger teknologien med tradisjonell tjenesteutøvelse?

Hjelpespørsmål: Hva og hvordan får de være med å velge?
Autonomi
Trygghet
Sikkerhet

Er det andre ting dere tenker er viktig og som vi ikke har vært inne på?

Appendix VI

Brukermedvirkning og velferdsteknologi

Til leder i hjemmebaserte tjenester

Kjeller 01.04.2019

Doktorgrads studie: Brukermedvirkning og velferdsteknologi

I de neste tre årene skal vi forske på brukermedvirkning og velferdsteknologi i hjemmebaserte tjenester. I den forbindelse trenger vi godkjenning fra deg som leder, til å gjennomføre studien i din kommune.

Doktorgrads studien er en oppfølging av fra EU-prosjektet Support Quality of life (SOL). Et hovedmål i SOL, var å utvikle ny kunnskap og etablere bedre praksis for å introdusere og bruke velferdsteknologi i hjemmebaserte tjenester. Arbeidsforskningsinstituttet (AFI), SOL, Fet kommune og SHA samarbeidet om prosjektet. Ansatte i hjemmebaserte tjenester i tre kommuner deltok i fokusgruppe intervju. Funn i SOL prosjektet viste at det er behov for mer kunnskap om brukermedvirkning og velferdsteknologi.

Studiens hovedmål er å få ny kunnskap om erfaringer knyttet til brukermedvirkning, samt belyse etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologi. I denne sammenheng, ønsker vi å intervjue pasienter og pårørende fra 5 – 7 kommuner. Kunnskapen kan bidra til å møte noen av utfordringene i kommunene, ved å bidra til kunnskap om en vellykket implementering og bruk av velferdsteknologi.

Vi håper å få godkjenning fra deg som leder til å rekruttere pasienter og pårørende i din kommune utfra gitte inklusjonskriterier. Vi ønsker å intervjue 4-5 pasienter, og 4-5 pårørende. Om du godkjenner deltagelse, vil vi be om at en representant fra hjemmebaserte tjenester innhenter pasientens eller pårørendes samtykke til å delta. Pasienten eller den pårørende vil deretter få en telefon fra stipendiat Heidi Snoen Glomsås, for å avtale tid for intervjuet. Intervjuet vil bli foretatt i deres hjem, dersom det er i orden for pasienten/pårørende. Ønsker pasienten eller pårørende heller å bli intervjuet et annet sted, kan dette avtales. Intervjuet vil vare i ca. 1 time.

Intervjuene vil være knyttet til pasienter og pårørendes erfaringer om innføring og bruk av velferdsteknologiske løsninger og hvordan de opplever brukermedvirkning. Vi vil registrere alder, kjønn og relevante diagnoser i forhold til bruk av velferdsteknologi, samt tiden teknologien er benyttet.

Inklusjons kriterier for pasienter:

- Har hjemmebaserte tjenester
- Må ha brukt velferdsteknologi i minst 6 mnd.
- Fra 65 år og oppover
- Være samtykkekompetente

Inklusjons kriterier for pårørende:

- Være nærmeste pårørende til pasienter over 65 år som har hjemmebase tjenester, og som har brukt velferdsteknolog i minst 6 mnd.
- Være samtykkekompetente

Det er selvfølgelige frivillig å samtykke til deltagelse i prosjektet. Den som intervjues kan når som helst og uten å oppgi noen grunn trekke sitt samtykke. Dette vil ikke få konsekvenser for hverken pasienter eller pårørende. Dersom godkjenning trekkes tilbake kan den som er intervjuet kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Opplysningene som registreres skal kun brukes slik som beskrevet i hensikten med prosjektet. Alle opplysningene vil bli behandlet uten navn og fødselsnummer, eller andre direkte gjenkjennende opplysninger. Prosjektet skal etter planen avsluttes 31.12.2021. Alle intervjuer både på papir og digitalt slettes etter at prosjektet er ferdig og senest 2027. Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet. I REK vedtak av 16.01.2019 er prosjektet vurdert til å falle utenfor helseforskningslovens virkeområde med referanse 2018/2462. Prosjektet er også i henhold til regelverk meldt Norsk Senter for forskningsdata (NSD) med referanse nummer 473910.

Studien er et samarbeid med Nasjonalforeningen for folkehelsen.

Eventuell godkjenning fra deg som leder, samt navn og kontaktinfo på person i din tjeneste som kan være kontaktperson, kan sendes på mail til hglomsas@oslomet.no.

På forhånd takk, og ta gjerne kontakt om dere trenger mer info.

Vennlig hilsen

Heidi Snoen Glomsås	Kristin Halvorsen
PhD kandidat	Hovedveileder
Tlf: 45 20 80 61 /67236537	Tlf: 9221625
E-post: hglomsas@oslomet.no	E-post: kristin.halvorsen@oslomet.no

Appendix VII

Brukermedvirkning og velferdsteknologi

Forespørsel om deltakelse i forskningsprosjektet:

Brukermedvirkning og velferdsteknologi i hjemmebaserte tjenester
- en kvalitativ studie av helsepersonells, brukere og pårørendes opplevelser.

Dette er en forespørsel om du som bruker av velferdsteknologi og hjemmebaserte tjenester ønsker å delta i et doktorgradsprosjekt om brukerinvolvering og etiske problemstillinger relatert til implementering og bruk av velferdsteknologi i hjemmebaserte tjenester. Med velferdsteknologi forstår vi løsninger som er tilpasset brukeres behov knyttet til for eksempel overvåkning av sykdommer, digital kommunikasjon med tjenesteyter, trygghetssystemer, digitale dørlåser og ulike type roboter for hjelp i hjemmet.

I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltagelse innebærer for deg.

Formål

Studiens hovedmål er å møte noen av utfordringene i velferdssamfunnet, ved å bidra til kunnskap om en vellykket implementering og bruk av velferdsteknologi i helsetjenesten. Det overordnede målet er å få ny innsikt i brukeres erfaringer av brukermedvirkning, samt belyse etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologi. Brukere vil si pasienter, nærmeste pårørende og helsepersonell.

Hva innebærer prosjektet?

Du får spørsmål om å delta i denne studien, fordi vi ønsker brukere fra 5-7 kommuner på Østlandet som deltagere i denne studien, til sammen ca. 20 brukere. Deltagelse vil si å gi et intervju i løpet av prosjektperioden. Avdelingsledere i hjemmebaserte tjenester i aktuelle kommuner har fått forespørsel om å finne frem til brukere som benytter velferdsteknologi i deres kommune, som kan være aktuelle deltagere i denne studien. Informasjonen om at en du mottar hjemmebaserte tjenester og benytter velferdsteknologi er gitt fra leder i hjemmebaserte tjenester i din kommune.

Om du sier deg villig til å delta, vil du få en telefon fra stipendiat Heidi Snoen Glomsås, for å avtale tid for intervjuet. Intervjuet vil bli foretatt i ditt hjem, dersom det er i orden for deg. Ønsker du heller å bli intervjuet et annet sted, kan dette avtales. Intervjuet vil vare i ca. 1 time.

Temaer for intervjuet vil blant annet være:

- Bakgrunn for bruk av velferdsteknologi.
- Dine erfaringer knyttet til hva du synes var bra eller utfordrende ved å bruke velferdsteknologi.
- Det vil være et særlig søkelys på hvordan du opplever mulighet for brukermedvirkning.
- Det vil være temaer knyttet til etiske problemstillinger og utfordringer ved anskaffelse og bruk av velferdsteknologi.

Vi vil registrere hva slags velferdsteknologiske løsninger den du benytter for og bakgrunnen for at velferdsteknologiske løsninger er tatt i bruk. Hovedfokus i intervjuet med deg som pårørende er hvordan du erfarer medvirkning i prosessen ved implementering og bruk av velferdsteknologiske løsninger i hjemmet.

Stipendiat Heidi Snoen Glomsås er den som intervjuer deg. Intervjuene tas opp som lydopptak.

Frivilling 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. Dette vil ikke få konsekvenser for deg. 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 Heidi Snoen Glomsås, telefon 45 20 80 61, e-post: hglomsas@oslomet.no , eller prosjektleder og hovedveileder Kristin Halvorsen, telefon 92 21 62 50, e-post: kristin.halvorsen@oslomet.no

Hva skjer med opplysningene om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. 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. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer, eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste som er kryptert og passord-beskyttet. Det er kun prosjektleder Kristin Halvorsen og stipendiat Heidi Snoen Glomsås som har tilgang til denne listen.

Prosjektet skal etter planen avsluttes 31.12.2021. Alle intervjuer både på papir og digitalt slettes etter at prosjektet er ferdig og senest 2027.

Deling av data

Ved å delta i prosjektet, samtykker du også til at opplysninger i anonyme intervjuutskrifter kan deles med medforfattere (hovedveileder, medveiledere og samarbeidspartner).

- Heidi Snoen Glomsås, universitetslektor OsloMet – storbyuniversitetet, stipendiat
- Kristin Halvorsen, førsteamanuensis OsloMet – storbyuniversitetet, hovedveileder
- Ingrid Ruud Knutsen, førsteamanuensis OsloMet – storbyuniversitetet, medveileder.
- Mariann Fossum, professor ved universitetet i Agder, medveileder.

Godkjenning

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet. I REK vedtak av 16.01.2019 er prosjektet vurdert til å falle utenfor helseforskningslovens virkeområde med referanse 2018/2462. Prosjektet er også i henhold til regelverk meldt Norsk Senter for forskningsdata (NSD) med referanse nummer 473910.

Etter ny personopplysningslov har behandlingsansvarlig OsloMet - storbyuniversitetet og prosjektleder Kristin Halvorsen et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning (GDPR), artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Kontaktopplysninger

Dersom du har spørsmål til prosjektet, kan du ta kontakt med OsloMet- storbyuniversitetet ved:

- Heidi Snoen Glomsås, doktorgradsstipendiat, e-post: hglomsas@oslomet.no, telefon 45208061
- Kristin Halvorsen, prosjektleder, e-post: kristin.halvorsen@oslomet.no, telefon 9221625.
- Personvernombud ved institusjonen er Ingrid Jacobsen, e-post: ingrid.jacobsen@oslomet.no, telefon: 993 02 316

Jeg samtykker til å delta i prosjektet brukermedvirkning og velferdsteknologi og til intervjuet brukes slik det er beskrevet

Jeg har mottatt og forstått informasjon om prosjektet “User involvement and ethics in welfare technology in home care - A qualitative study of healthcare service users, next of kin and healthcare professional’s experiences.” (Brukermedvirkning og velferdsteknologi)
Jeg har fått anledning til å stille spørsmål om prosjektet.

Jeg samtykker til:
- ☐ Delta i intervju
- ☐ Dataene kan benyttes i forbindelse med arbeid relatert til dette doktorgradsprosjektet
- ☐ Jeg samtykker til at mine opplysninger behandles frem til doktorgradsprosjektet er avsluttet, og senest 2027.

Jeg kan kontaktes på telefonnummer________________________ om avtale for intervju.

____

Sted Deltager

Brukermedvirkning og velferdsteknologi

Forespørsel om deltakelse i forskningsprosjektet:

Brukermedvirkning og velferdsteknologi i hjemmebaserte tjenester - en kvalitativ studie av helsepersonells, brukere og pårørendes opplevelser.

Dette er en forespørsel om du som pårørende ønsker å delta i et doktorgradsprosjekt om brukerinvolvering og etiske problemstillinger relatert til implementering og bruk av velferdsteknologi i hjemmebaserte tjenester. Med velferdsteknologi forstår vi løsninger som er tilpasset brukeres behov knyttet til for eksempel overvåkning av sykdommer, digital kommunikasjon med tjenesteyter, trygghetssystemer, digitale dørlåser og ulike type roboter for hjelp i hjemmet.

I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltagelse innebærer for deg.

Formål

Studiens hovedmål er å møte noen av utfordringene i velferdssamfunnet, ved å bidra til kunnskap om en vellykket implementering og bruk av velferdsteknologi i helsetjenesten. Det overordnede målet er å få ny innsikt i brukeres erfaringer av brukermedvirkning, samt belyse etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologi. Brukere vil si pasienter, nærmeste pårørende og helsepersonell.

Hva innebærer prosjektet?

Du får spørsmål om å delta i denne studien, fordi vi ønsker brukere fra 5-7 kommuner på Østlandet som deltagere i denne studien, til sammen ca. 20 pårørende. Deltagelse vil si å gi et intervju i løpet av prosjektperioden. Avdelingsledere i hjemmebaserte tjenester i aktuelle kommuner har fått forespørsel om å finne frem til aktuelle brukere som benytter velferdsteknologi i deres kommune, som kan være aktuelle deltagere i denne studien. Informasjonen om at en du er bruker benytter velferdsteknologi er gitt fra leder i hjemmebaserte tjenester i din kommune.

Om du sier deg villig til å delta, vil du få en telefon fra stipendiat Heidi Snoen Glomsås, for å avtale tid for intervjuet. Intervjuet vil bli foretatt i ditt hjem, dersom det er i orden for deg. Ønsker du heller å bli intervjuet et annet sted, kan dette avtales. Intervjuet vil vare i ca. 1 time.

Temaer for intervjuet vil blant annet være:

- Bakgrunn for bruk av velferdsteknologien.
- Dine erfaringer knyttet til hva du synes var bra eller utfordrende ved prosessen når den du tok i bruk aktuell velferdsteknologi.
- Det vil være et særlig viktig for deg for at du skal opplevde brukermedvirkning.
- Det vil ogs¨være temaer knyttet til etiske problemstillinger og utfordringer ved anskaffelse og bruk av velferdsteknologi.

Vi vil registrere hva slags velferdsteknologiske løsninger du bruker og bakgrunnen for at velferdsteknologiske løsninger er tatt i bruk. Hovedfokus i intervjuet er hvordan du erfarer medvirkning i prosessen ved implementering og bruk av velferdsteknologiske løsninger i hjemmet.

Stipendiat Heidi Snoen Glomsås er den som intervjuer deg.

Det er nødvendig i prosjektet at den du er pårørende for er informert hvis du velger å delta. Vedlagte informasjonsskriv er til den du er pårørende for. Dersom vedkommende har innsigelser på at du skal delta, ber vi om at du tar hensyn til dette ved å ikke delta. Dersom den du er pårørende til av ulike årsaker ikke kan gi uttrykk for din deltagelse eller ikke, bestemmer du selv.

Frivilling 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. Dette vil ikke få konsekvenser for deg- eller den du er pårørende til. 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 Heidi Snoen Glomsås, telefon 45 20 80 61, e-post: hglomsas@oslomet.no , eller prosjektleder og hovedveileder Kristin Halvorsen, telefon 92 21 62 50, e-post: kristin.halvorsen@oslomet.no

Hva skjer med opplysningene om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. 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. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

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Prosjektet skal etter planen avsluttes 31.12.2021. Alle intervjuer både på papir og digitalt slettes etter at prosjektet er ferdig og senest 2027.

Deling av data

Ved å delta i prosjektet, samtykker du også til at opplysninger i anonyme intervjuutskrifter kan deles med medforfattere (hovedveileder, medveiledere og samarbeidspartner).

- Heidi Snoen Glomsås, universitetslektor OsloMet – storbyuniversitetet, stipendiat
- Kristin Halvorsen, førsteamanuensis OsloMet – storbyuniversitetet, hovedveileder
- Ingrid Ruud Knutsen, førsteamanuensis OsloMet – storbyuniversitetet, medveileder.
- Mariann Fossum, professor ved universitetet i Agder, medveileder. Karin Christiansen, dosent, Aarhus universitet (VIA), Danmark, samarbeidspartner og medforfatter.

Godkjenning

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet. I REK vedtak av 16.01.2019 er prosjektet vurdert til å falle utenfor helseforskningslovens virkeområde med referanse 2018/2462. Prosjektet er også i henhold til regelverk meldt Norsk Senter for forskningsdata (NSD) med referanse nummer 473910.

Etter ny personopplysningslov har behandlingsansvarlig OsloMet - storbyuniversitetet og prosjektleder Kristin Halvorsen et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning (GDPR), artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Kontaktopplysninger

Dersom du har spørsmål til prosjektet kan du ta kontakt med OsloMet- storbyuniversitetet ved:

- Heidi Snoen Glomsås, doktorgradsstipendiat, e-post: hglomsas@oslomet.no, telefon 45208061

- Kristin Halvorsen, prosjektleder, e-post: kristin.halvorsen@oslomet.no, telefon 9221625.
- Personvernombud ved institusjonen er Ingrid Jacobsen, e-post: ingrid.jacobsen@oslomet.no, telefon: 993 02 316

Jeg samtykker til å delta i prosjektet brukermedvikning og velferdsteknologi og at data fra intervjuet brukes slik det er beskrevet

Jeg har mottatt og forstått informasjon om prosjektet "User involvement and ethics in welfare technology in home care - A qualitative study of healthcare service users, next of kin and healthcare professional's experiences." (Brukermedvirkning og velferdsteknologi)
Jeg har fått anledning til å stille spørsmål om prosjektet.

Jeg samtykker til:
- ☐ Delta i intervju
- ☐ Dataene kan benyttes i forbindelse med arbeid relatert til dette doktorgradsprosjektet
- ☐ Jeg samtykker til at mine opplysninger behandles frem til doktorgradsprosjektet er avsluttet, og senest 2027.
- ☐ Jeg har informert den jeg er pårørende for at jeg deltar i dette prosjektet og de har bekreftet at dette er i orden.

Jeg kan kontaktes på telefonnummer_________________________ om avtale for intervju.

____

Sted Deltager

Informasjonsskriv til deg som har pårørende som blir invitert til å delta i doktorgradsprosjektet «Brukermedvirkning og velferdsteknologi»

Dette er en informasjon til deg som bruker av velferdsteknologi og hjemmebaserte tjenester, fordi vi ønsker å intervjue din nærmeste pårørende i forbindelse med et doktorgradsprosjekt.

Gjennom prosjektet ønsker vi å få økt kunnskap om hvordan pasienter, pårørende og helsepersonell opplever brukermedvirkning, samt etiske problemstillinger og utfordringer ved implementering og bruk av velferdsteknologiske løsninger i hjemmet, som for eksempel medisindispensere, elektronisk dørlås, trygghetsalarm eller lignende. Denne kunnskapen håper vi kan bidra til å gjøre hverdagen bedre for hjemmeboende brukere av velferdsteknologi og deres pårørende.

Vi ønsker å intervjue din nærmeste pårørende om hvordan han eller hun har opplevd å få ta del i prosessen omkring innføring av velferdsteknolgi for deg. Vi vil registrere hva slags velferdsteknologiske løsninger du har behov for og bakgrunnen for at disse er tatt i bruk. Det kan være at det fremkommer opplysninger som diagnose eller funksjonssvikt. I den forbindelse er det nødvendig at du er informert om intervjuet og ikke har noen innvendinger. Hvis du har innvendinger mot at din pårørende deltar, er det viktig at du sier ifra til din pårørende om dette.

Vennlig hilsen

Heidi Snoen Glomsås
Doktorgradsstipendiat ved OsloMet- storbyuniversitetet

Appendix X

Nasjonalforeningen for folkehelsen

EXTRA STIFTELSEN

OSLOMET

Brukermedvirkning og velferdsteknologi

Intervjuguide: Brukermedvirkning ved innføring og bruk av velferdsteknologi i hjemmebaserte tjenester – pasienter og pårørende

Demografiske data:

Alder:

Kjønn:

Hvor lang tid har du eller den du er pårørende til brukt velferdsteknologi?

Hvilken velferdsteknologi bruker du/den du er pårørende til?

Hvordan fikk du/den du er pårørede til denne teknlogien?

Årsak til at du/den du er pårørende til benytter velferdsteknologi (aktuell diagnose)?

Intervjuspørsmål

1: Kan du fortelle meg om dine erfaringer med velferdsteknologi?

Har bruk og holdninger av velferdsteknologi endret seg siden du/den du er pårørende til tok det i bruk?

Hvordan tenker du bruk av velferdsteknologi kan bidra til god og forsvarlig helsehjelp?

Hvordan oppleves brukervennlighet og utforming

2: Kan fortelle om hvordan du opplever informasjon, veiledning og oppfølging fra kommunens side i forhold til bruk av velferdsteknologi?

Hva hadde vært optimalt og hvordan kunne det gjøres bedre?

Hvordan opplevde du tidspunkt for når tjenesteapparatet kommer inn, eller behov identifiseres.
Var det nok informasjon om

Hva som finnes

Hvordan man kan få tak i dette

Opplæring

3: Kan du fortelle om hvordan du opplever helsepersonnellet har interesse for å høre om dine ønsker og hvordan du opplever å bruke teknologien?

Rutiner og organisering

4: Kan du fortelle om du erfarer at det er noen forskjell mellom dine ønsker og behov knyttet til bruk av velferdsteknologi og din(e) pårørende/den du er pårørende til

Bruker/pårørende vil noe og den andere vil ikke/ser ikke konsekvser av bruk.

5: Kan du fortelle hva du tenker på når vi snakker om brukermedvirkning?

Er du opptatt av dette, og er det noe du snakker med andre om?

Opplever du at det er noe som helsepersonell er opptatt av og på hvilken måte?

Har dere noen eksempler på brukerinvolvering av deg som bruker/pårørende?
Helsetjenesten mer tilpasset organisering enn brukers behov?

6: Kan du si noe om hvilke muligheter for brukermedvirkning det er i forhold til velferdsteknologi i din kommune?

Får bruker og pårørende være med på valgene kommunen gjør i forhold til:

Hva kommunen skal tilby, innføring og daglig bruk

Velge om du/dere vil ta velferdsteknologi i bruk, og i så fall hva er konsekvensene dersom de ikke velger teknologien

7: Hvordan tenker du at pasienter og pårørende bør involveres for at det skal bli best mulig bruk av teknologien og tjenenestene i hjemmebaserte tjenester?

Hva tenker du er viktig for å få dette til ?

Hvilken type informasjon trenger du?

Når trenger du den, og på hvilken måte?

8: Ser du eller har du erfart noen etiske problemstillinger ved bruk av velferdsteknologi og i så fall hvilke?

Overvåkning

Økonomi

Privat/offentlig anskaffelse og bruk

Pårørendes rolle og ansvar i forhold til daglig bruk

Selvbestemmelse

Trygghet

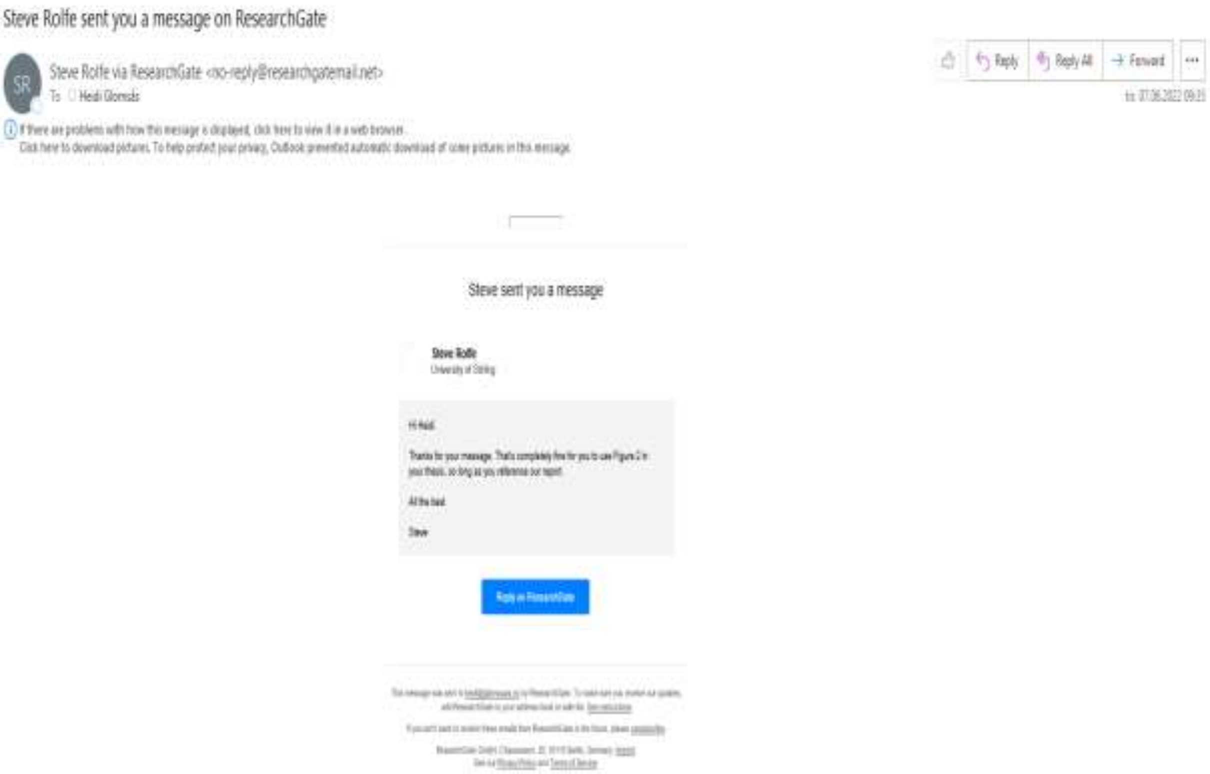
Utvisking av offentlig og privat sfære (for eksempel bruk av privat mobil)

Makt

Ansvaret den enkelte har selv i forhold til å forberede alderdommen

Har du noen andre tanker om brukermedvirkning og velferdsteknologi som du tenker er viktig og som vi ikke har snakket om?

Appendix XI



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Paper I

Glomsås, H. S., Knutsen, I. R., Fossum, M. & Halvorsen, K. (2020). User involvement in implementing welfare technology in home care services: The experience of health professionals - A qualitative study. *Journal of Clinical Nursing*, *29*(21-22), 4007-4019. https://doi.org/10.1111/jocn.15424

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ORIGINAL ARTICLE

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User involvement in the implementation of welfare technology in home care services: The experience of health professionals—A qualitative study

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Abstract

Aims and objectives: The aim of this study is to learn more about factors that promote or inhibit user involvement among health professionals when implementing welfare technology in home care services.

Background: It is a health policy goal to increase the use of welfare technology in order to address some of the challenges that healthcare services are facing. Health professionals' involvement is important for the successful implementation of welfare technology in home care services.

Design: The study has an explorative and descriptive longitudinal design based on a qualitative approach. Five focus group interviews were conducted with 16 nurses and assistant nurses from three different municipalities over a period of 2 years. The data were analysed using reflexive thematic analysis. The COREQ checklist was used.

Results: The analysis led to five main themes: competence a critical component, information and information lines, new ways of working, choice of welfare technology and change in patient services. From health professionals' perspective, there appeared to be a lack of preparedness for the change in the implementation of welfare technology entailed for home care services. The respondents experienced limited facilitation and opportunities for user involvement.

Conclusion: Health professionals want to be more involved but emphasised that competence, information and collaborative arenas are necessary factors if involvement in the process is to be increased. Competence affected some of the respondents' attitudes and willingness to use the technology. The respondents also experienced that the managements' focus on facilitation and interest in user involvement in addition to infrastructures that functioned in various ways had an impact on user involvement.

Relevance to clinical practice: The knowledge gained from this study about factors that promote or inhibit user involvement among health professionals could contribute to better preparedness for further implementation of welfare technology in the field of home care.

KEYWORDS
aged, e-health, home health care, innovation, nurse–patient relations, nursing, qualitative research, technology, telehealth

1 | INTRODUCTION

In Western societies, there is pressure on and growing demand for home care services due to the increasing number of older people, economic pressure and changes in health policies (Eurostat, 2019; Genet et al., 2011). It is a health policy goal to increase the use of technology that enables people to live longer at home (World Health Organization Regional Office for Europe, 2008). In Europe, 20% of citizens were over 65 years old in 2018, and this proportion is expected to reach a peak of around 29% in 2040 (Eurostat, 2019).

Statistics from Norway show that 31% of residents aged 80 years or older used home care services in 2018, and this percentage is expected to increase (Statistics Norway, 2019).

In the healthcare context, technological solutions in Scandinavian countries fall under the umbrella term welfare technology (Kamp, Obstfelder, & Andersson, 2019). Kamp et al. (2019) point out that the term is broad and loosely defined, covering a wide array of technologies. In international literature on healthcare technology, the term telecare is commonly used, but consensus on definitions is limited (Cook et al., 2016; Greenhalgh et al., 2013). Other commonly used terms are telehealth, telemedicine, assistive living technology and e-health, but the dividing lines between them seem to be blurred (Barrett, Thorpe, & Goodwin, 2014; Solli, Hvalvik, & Hellesø, 2012). In this study, we use the term welfare technology, understood as technological assistance used by both patients and next of kin to contribute to safety, security, wellness, mobility, social and cultural contact and participation, and treatment and care. Such technology can also provide useful information, overviews and logistical solutions in home care services for health professionals.

Providing opportunities for user involvement in the workplace is important for empowerment and a principle that promotes democratisation and job satisfaction among health professionals (Spreitzer, 2008). Health professionals' involvement, knowledge and ownership have been shown to be important success factors in innovation processes in the workplace (Framke et al., 2019). The context of home care is important for health professionals' experience in this study. Studies of combining user involvement, welfare technology and home care seem scarce. The focus of this study is on exploring different perspectives on user involvement among health professionals in the implementation of welfare technology in home care services.

What does this paper contribute to the wider global clinical community?

- Insight into health professionals' experiences of user involvement when implementing welfare technology in home care services.
- Identification of factors that promote or inhibit user involvement among health professionals when implementing welfare technology in home care services.
- Highlights user involvement as a prerequisite for successful implementation of welfare technology in home care services.

1.1 | Background

1.1.1 | Organisation of home care services

Home care services appear to differ between and within countries. In most countries, they include rehabilitative, therapeutic and assistive home care, in addition to nursing (Genet et al., 2011). In Norway, municipalities are responsible for providing primary health and social care, including home care. Home care is organised according to geographical areas, and it is an integrated part of the healthcare service. All Norwegians with health-related needs have a legal right to receive public home care services, in the municipality where they reside regardless of their age, gender, and socio-economic status (Ministry of Health and Care Services, 2011). This approach to health care is called the Scandinavian or Nordic Model (Kemp & Hvid, 2012). The Nordic healthcare model is based on solidarity and focuses on both universal civil rights and protection of minorities. The welfare state has the main responsibility for providing healthcare services to the entire population living in the Nordic countries. The municipalities primarily finance public home care services through taxes, and this care is publicly owned and operated (Magnussen, Vranbæk, & Saltman, 2009).

There are variations in the numbers of registered nurses (RNs), nursing assistants (NAs) and nursing aides employed in each municipality home care depending on its size, population, needs, finances and how municipalities organise their healthcare services (Holm, Mathisen, Sæterstrand, & Brinchmann, 2017). The high level of variation among municipalities makes it difficult to get exact figures about the number of employees who work in home care.

However, in Norway, and globally, there is a shortage of RNs. This may lead to a high workload and can affect the quality of the services (Rafferty, 2018; Statistics Norway, 2019; WHO, 2006).

1.1.2 | Implementation of welfare technology

Several municipalities in Western societies are carrying out projects of welfare technology in home care services (Barland & Lovett, 2014).

There is an expectation that increased use of welfare technology will have a positive effect to meet the changing situation resulting from the growing number of patients with complex needs, shorter hospital stays, the decreasing workforce of health professionals and a demanding financial situation, all of which are challenging healthcare services in the municipalities (Gaikwad & Warren, 2009; Kruse, Soma, Pulluri, Nemali, & Brooks, 2017). Welfare technology is envisioned as leading to new, smarter ways for health professionals to work, promising patients higher levels of empowerment, safety and quality (Kamp et al., 2019). For example, electronic patient record systems (EPRs) on tablets assist health professionals during their workday and help them find and provide information, administer the correct treatment, as well as document health care and make appropriate and effective individual plans. It is also expected to create efficient workflow and support decision-making (Rouleau, Gagnon, & Côté, 2015). Other technologies, for instance digital door locks, may provide health professionals easy access to the patients' home (Majumder et al., 2017). Digital safety alarms, sensors and medical robots primarily contribute to patients' safety, independence, quality of life and well-being in their own homes (Dugstad, Eide, Nilsen, & Eide, 2019; Holthe, Halvorsrud, Karterud, Hoel, & Lund, 2018; Stokke, 2017). Different welfare technologies have implications for RNs' and NAs' daily work in home care, and several factors influence patients' and health professionals' experiences and willingness to use these technologies (Barrett et al., 2014; Brewster, Mountain, Wessels, Kelly, & Hawley, 2014; Saborowski & Kollak, 2015).

To provide high-quality nursing competence is required, both for the technology itself and the new ways of working (Andersson, Lindholm, Pettersson, & Jonasson, 2017). Research shows that there are barriers to overcome when implementing welfare technology, including organisational, cultural, technological and ethical resistance (Nilsen, Dugstad, Eide, Gullslett, & Eide, 2016). Resistance arises from a variety of perceived threats, such as threats to stability, predictability and knowledge. Moreover, resistance develops from threats to health professionals' role and group identity, as well as threats to basic healthcare values and patient safety (Nilsen et al., 2016). The study by Brewster et al. (2014) indicates that competence and information flow influence the process of implementing welfare technology. Gjestsen, Wiig, and Testad (2017) identified management, workforce, motivation for change and maturity as important success factors in primary care when preparing the implementation of welfare technology. It has been pointed out that trust and partnership are prerequisites for the acceptance of welfare technology (Berge, 2018). In most of the studies of welfare technology, the focus is on the technology and its implementation, and not on how the health professionals are involved in the process, as is the case in this study.

1.1.3 | User involvement among health professionals

In this study, user involvement in the healthcare services is understood to refer to how those who are affected by a decision: patients, next of kin, health professionals or other users, can influence the decision-making processes and the design of home care services. Both "user" and "involvement" are terms that can be interpreted in several ways, and there are a number of suggestions for how user involvement can be encouraged, facilitated and increased (Dent & Pahor, 2015; Kaltoft, Nielsen, Salkeld, & Dowie, 2014). Focusing on user involvement can be seen as a step towards general democratisation and right to cooperate on the development of healthcare services (Barnes & Cotterell, 2012). The idea is that user involvement will contribute to better health services for both the individuals and communities and will result in greater respect for personal autonomy (Dent & Pahor, 2015).

Several studies have highlighted the need for user involvement in general in health care, although not relating to welfare technology. In addition, most studies focus on patients as users, while only a few focus on health professionals (Andreassen, 2017; Dent & Pahor, 2015). Decision-making skills, motivation and quality of health care were mentioned in a study by Omeni, Barnes, MacDonald, Crawford, and Rose (2014) as benefits of user involvement in health care. Cresswell's (Cresswell et al., 2013) article pointed out the importance of managers identifying needs together with everyone involved, including health professionals, to generate new insight and prepare the professions for changes. De Veer, Fleuren, Bekkema, and Francke (2011) offer insight into how a group of nurses perceived new technologies. They found that cooperative approaches may be the best way of achieving positive, sustainable implementation. Another study shows that improvement clearly depends on change, but that changes always generate new challenges (Dixon-Woods, Amalberti, Goodman, Bergman, & Glasziou, 2011). However, empirical studies of how user involvement best can be facilitated in the changing of home care services are scarce.

Health professionals' involvement may be important to the professional environment and quality of services, and the success of the implementation process. The impact of the changes on health professionals and the processes of facilitating implementation and user involvement has rarely been studied. Most of the studies focusing on user involvement in health service development focus on the patient as the user, and not on health professionals, and they are not linked to the use of welfare technology. There is thus a need to explore health professionals' experience of user involvement and welfare technology in the context of home care services.

1.2 | Aim of the study

This study will address and reflect on changes and preparedness for the process of implementation of welfare technology in home care services, and health professionals' experience of user involvement.

The aim is to learn more about factors that promote or inhibit user involvement among health professionals when implementing welfare technology in home care services.

2 | METHOD

To explore health professionals' experience, we decided to carry out a qualitative study with an explorative and descriptive longitudinal design, using focus group interviews. The design entails an opportunity to illuminate experiences and knowledge as part of a process of sharing and discussing experiences in a focus group interview and make sense of them. We gained insight and an understanding of the respondents' experiences, and through this, we could describe this study's complex context (Bowling, 2014; Morgan, 1997). For the analyses, we use reflexive thematic analysis as described by Braun, Clarke, Hayfield, and Terry (2019).

The COREQ checklist for reporting qualitative studies was used (Supplementary File 1).

This study is a part of a PhD project on welfare technology and user involvement in home healthcare services. It is the first of four sub-studies in the project.

2.1 | Design

In order to explore health professionals' experiences, attitudes and reflections on what inhibits and what promotes user involvement in implementing welfare technology in home care services, we used a phenomenological-hermeneutical approach to both grasp the essence of the respondents' everyday experiences and interpret these experiences from an understanding of user involvement (Bowling, 2014). Hence, we used focus group interviews with health professionals working in the home healthcare sector. In order to gain knowledge and an understanding of the everyday context and complexity of home health services, we searched for experiences of professionals with first-hand knowledge from working in the field. In focus groups, where people with different experiences meet and discuss the topics of the study, there is an opportunity to get complex perspectives through the participants' discussion and exchange of viewpoints (Morgan, 1997). It was for this reason that we wanted focus group respondents with different backgrounds, some with a great deal of experience and interest in welfare technology and others with a limited interest in it. We also wanted respondents from different municipalities that had different approaches to and experiences from the implementation process. The field of welfare technology is in rapid development, and there is reason to believe that this also impacts processes of involvement and health professionals' experiences. We wanted to conduct additional focus group interviews again after some time for these reasons. Accordingly, the design also has a longitudinal approach over a time period of 2 years.

2.2 | Data collection

During the planning stages for data collection, a joint information meeting was held for the management of the relevant municipalities. They were informed about the study's goals and research design. A written information consent form was also e-mailed to them after the meeting. The management of the home care services in three municipalities accepted the invitation to participate in the study, and they handed out invitations to the RNs and NAs in their department.

2.2.1 | Setting

The respondents were registered RNs' and NAs' working in home care services in three municipalities in Eastern Norway from 2017–2019. The smallest municipality had approximately 11,000 inhabitants, while the largest had approximately 18,000 inhabitants. In terms of land area, the size of the municipalities varied between 176 and 961 km^2 and they included both urban and rural areas.

Like all municipalities in Norway, the three municipalities were obliged to implement and use welfare technology in their day-to-day work in home care services. Although the implementation was started, the municipalities were at different stages in the process. In all three municipalities, health professionals had access to EPRs on digital tablets, and patients used medical robots and safety alarms. Most of the safety alarms were digital, having GPS tracking and the possibility of connecting to sensors. However, there were still some analogue alarms in use. Digital door locks were about to be installed in all three municipalities during the study period.

2.2.2 | Sampling and recruitment

A purposive sampling procedure was chosen due to the aim of the study. The inclusion criteria were that RNs' or NAs' had worked in home care services for at least 6 months, in at least at 50% position. Representation for both genders was requested along with a variety of ages and work experience. In order to be included in the follow-up interviews, respondents must have had participated in one of the three initial interviews. One RN and one NA from each municipality, a total of six, were invited to attend the two follow-up interviews. It was the management of each of the three municipalities who recruited the respondents for all five interviews and gave out the consent forms and collected the signed forms. In all the interviews, the first author agreed with the managements about time and place for the interviews. The management informed the respondents.

2.2.3 | Respondents

A total of 16 respondents, 9 RNs' and 7 NAs' agreed to participate. There were 3 men and 13 women, and their age ranged from 33–62 years, with a median age of 45. Their work experience in their municipalities ranged from 8 months to 13 years, with a median of 10 years.

2.2.4 | Focus group interviews

Focus groups are particularly suitable when the objective is to learn more about people's experiences, attitudes and views in the environment where they usually interact (Morgan, 1997). The respondents were invited to discuss and comment on each other's opinions and experiences (Morgan, 1997). We wanted to shed light on a variety of experiences, views and attitudes to welfare technology.

A moderator (first author) and a secretary (last author) conducted the focus group interviews, as recommended by Morgan (1997). They held the same position during all five interviews. The moderator led the interviews, while the secretary took notes and regularly summed up to validate the discussions. The moderator was attentive to the respondents' discussions and stories and sensitive to surprises and/or topics and opinions that might challenge preconceptions. The first author and secretary met the respondents for the first time at the first three interviews. Both the moderator and the secretary are RNs' and have previous experience of focus group interviews and qualitative methods. The moderator is a PhD student, while the secretary is an experienced researcher.

2.2.5 | Conducting the focus group interviews

Five focus group interviews were held. Three interviews were conducted in spring 2017, at the respondents' workplace. One follow-up interview in autumn 2017 and one in spring 2019 were conducted at the first authors' workplace.

A flexible interview guide was used for the first three interviews, focusing on experiences of being introduced to welfare technology in home care services. The interview guide was based on the research questions and focused on what characterises an effective process for implementing welfare technology, and what barriers and facilitators were experienced in the implementation process and daily use of existing welfare technology. For the follow-up interviews, the interview guide was slightly modified to focus more on how the implementation process in the municipality developed, and how this influenced user involvement. The purpose of the fourth and fifth interviews was to examine changes in the processes of implementing welfare technology, and whether or how user involvement was affected. In addition, we wanted to obtain a more saturated description from respondents of user involvement than had emerged in the first three interviews. The interviews lasted for 90 min on average, and they were recorded digitally and transcribed verbatim.

2.3 | Data analyses

The data were analysed using reflexive thematic analysis, as described by Braun et al. (2019). In reflexive thematic analyses, the themes are described as meaning-based patterns in the data that are evident in either explicit or conceptual ways. The analysis process was done manually, and all the researchers played an active role in the process.

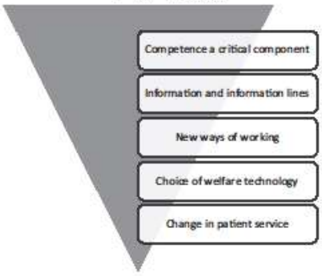


FIGURE 1 Main themes. Visualisation of the main themes relating to user involvement in the implementation of welfare technology in home care services

As recommended by Braun et al. (2019, pp. 852–857), the six phases in the data analyses were followed, starting with phase one, *familiarisation* with the data material. Both during and after the interviews, the secretary took notes about impressions and possible interpretations. After transcription, all the interviews were read and reread by all the authors. The data material was discussed, and intuitive codes elaborated. In phase two, we carried out more detailed and systematic work on the data *to generate codes*. Each transcript was explored using open thematic coding. In this process, we extracted the meaning content from the data, which were organised around similar codes and meanings. In phase three, *themes were constructed*, built and moulded across the data, based on the research questions and the researchers' interpretations. An overview of tentative themes and sub-themes was created based on the patterns and statements in the text. In this phase, some statements were categorised under more than one theme, as they were still perceived as overlapping and difficult to place. After the initial coding, sorting and thematising, we agreed on the codes and themes that were necessary to proceed to the next analytical level. Themes *were revised* in phase four, and we reflected on and discussed themes back and forth. All the themes were discussed and revised to avoid overlaps and to gain a clear sense of how each of the themes was related to the others, and they were checked across the whole data set. In phase five, the themes *were defined and given more clarified names* to convey the essence of the empirical data. (Figure 1). The analytical work was wrapped up in the sixth phase, *producing this article*, which involved checking how well the themes worked, together and individually.

Tables 1 and 2 visualise how we have arrived at selected themes through coding and analysis.

TABLE 1 Examples from the coding procedure

Quotes about health professionals' involvement	Code	Group	Initial themes
"I have experienced poor training. I suddenly stood there and an alarm went off and the medicine roll had jammed, and I did not know what to do."(5)	A feeling of not knowing what to do	Lack of training	Insecurity
"We have long distances. I normally have to go back to the office to pick up a key. Then I realised that the patient had gotten a digital door lock. So I spent 5 min instead of 25 min getting to the patient." (4)	Technology saved time	Routine change	Change of work
"The last time I was interviewed I was very negative about the use of GPS, but now I am very positive. So I turned around. It's about learning more about how strict the law is in relation to this." (4)	Knowledge changed attitudes	Factors influence attitudes	Attitudes

In the follow-up interviews, the respondents were invited to check the analysis of the previous interviews. We presented the results from the previous interviews at the start of both follow-up interviews. We asked if the respondents had any comments, objections or additions to the results of our preliminary analysis. They confirmed our results.

The results from all five interviews were also presented to the advisory group of the PhD project, of which this study is a part. Participants in this group were recruited from two Pensioners Associations, and one was recruited from a next of kin group from the National Association for Public Health. The group consists of one person receiving home care, two next of kin, of whom one was also a NA. The group's role was to be a discussion partner during the interpretation of the findings. The advisory group introduced new perspectives from their point of view, for instance how to interpret the quotes from the interviews.

2.4 | Research ethics

The study complies with the Helsinki Declaration's principles for medical research (The World Medical Association, 2017). All respondents in the study were given oral and written information about the project and signed written informed consent. They were informed that they could withdraw from the project if and whenever they wished, but that the data already in the analysis could not be shredded. Furthermore, they were informed that all data are unidentified and that their confidentiality was safeguarded. They were informed that the data were stored in accordance with applicable rules and guidelines for storing research material.

The study has been reported and approved by the National Centre for Research Data.

3 | RESULTS

In the interviews, the respondents showed great commitment to discussing user involvement and the implementation of welfare technology in home care services. All of them were active in the focus groups and engaged with the use of welfare technology. However, they had a somewhat different understanding of the concept of user involvement, and there were different user experiences of technologies.

TABLE 2 Results of the analysis

Initial themes	Sub-themes	Main themes
1: Changed way of working	New ways of working	New ways of working
2: Getting information	Information lines	Information and information lines
3: Network challenges	Infrastructural challenges	Information and information lines
4: Time and areas	Facilitating competence enhancement	Competence
5: Insecurity	Facilitating competence enhancement	Competence
6: Resources and economy	Deciding which technology to choose	Choice of welfare technology
7: Limited information	Need for information	Information and information lines
8: Competence is needed	Need for competence	Competence
9: Attitudes	Need for competence	Competence
10: Resistance to change	Need for competence	Competence
11: Limited ownership	Involvement and responsibility	Competence
12: Concern for patients	Professionalism and concern for patients	Change in patient service

In this study, we found that health professionals experienced that, when welfare technology was implemented in home care services, there were several factors that inhibited user involvement and a few that promoted it. One overall result from the perspective of the health professionals appeared to be an experience of unpreparedness for the change that would follow the implementation of welfare technology in home care services at all levels. The health professionals also experienced limited opportunities for user involvement.

In this section, we have added the number of the health professional (HP) respondent in front of the quotation, and the interview number they are associated with, in parentheses.

3.1 | Competence a critical component

Implementation of welfare technology requires competence in the sense of being prepared for change, seeing opportunities and using welfare technology as intended. Most of the respondents stated that competence was the most important prerequisite for user involvement. Competence was associated with confidence and concern about the quality of home care, like it appeared in interview three.

HP 17: It is necessary to have good information and competence, first and foremost about the products to be used.
HP 20 followed this up: We must learn enough about it (welfare technology), have confidence about it, talk positively about it… Then it'll be easier to speak to the next of kin and patients about it.

Several respondents expressed that they did not have enough competence in relation to welfare technology, and few opportunities to acquire this. There were differences in competence levels even within the same municipality, as appeared in interview one:

HP 2: There are some digital safety alarms in use
HP 6: Yes, but they've probably been bought on the private market because I don't think we have any
HP 4: What do you mean by digital? What do they look like?

The respondents stated that their manager only to a small extent, provided competence-enhancement measures enabling them to learn about welfare technology. Some managers expected the health professionals to familiarise themselves with this new competence during their free time, which was experienced as challenging. There were variations between the three municipalities, but the tendencies revealed a convincing pattern of not involving health professionals in competence-enhancement measures.

By the time of the last follow-up interview, competence-enhancement programmes had become more common and were offered within the framework of ordinary working hours. After some rounds in which different technology was tried out, some managers recognised the importance of competence in relation to involvement and managing the technology.

Nevertheless, there were still some problems with organising the competence-enhancement measures so that they reached all health professionals since most of them worked shifts.

The respondents realised that not all of them could decide in the implementation of the technology and supported the idea of using resource groups in such processes. However, they emphasised the importance of having a basic understanding and knowledge of the different technologies, in addition to playing an active role in the implementation process and dialogue with the patients, next of kin and their colleagues. They were concerned that limited competence might have negative consequences for patient care.

HP 5 (Interview five): We have experienced that patients have received incorrect information and training because of limited competence among health professionals.

On the other hand, some of the respondents stated that having increased competence inspired them to use technology. They were more positive, eager, and more actively involved and became more aware of patients' opportunities and needs. The quotation below is an example of how patients might be at risk if the management does not provide competence-enhancement measures.

HP 2 (Interview four): We had a research and development nurse who came from the management staff who taught us how to use electronic patient records on the digital tablets. That helped us a lot because we can plan our workdays better. Previously, many forgot to give the medication because they did not know where to find the information.

The fact that the technology was often introduced before adequate training was given may have caused operational problems, as well as resistance to the use of the technology. Health professionals felt uncomfortable in front of the patients and next of kin because they were not familiar with the functionality of the welfare technology. The consequence was a feeling of inadequacy, and some chose not to use welfare technology.

HP 6 (Interview five): I suddenly stood there, and an alarm went off, and the medicine roll had jammed in the medicine robot, I did not know what to do.

We found that health professionals' attitudes to taking initiatives or responsibility for improving their competence varied. Some of the respondents wanted to see more involvement and responsibility from their colleagues. While most of the respondents wanted to acquire more competence, a few were sceptical and did not want to use the technology or learn more about it than they needed to.

HP 7 (Interview one): I'm not very good and uncertain about how to use the technology. I will soon retire, so I am not very interested in learning more or being involved more than I need to.

3.2 | Information and information lines

To be involved as users, the respondents stated that it was important to have the necessary information in all parts of the process, from planning to day-to-day use. A general need for information was mentioned in all interviews, but there did not seem to have been any progress or improvement as regards information and information lines from the first to the last interview. The results indicate that health professionals wanted more involvement, and information and collaboration were highlighted as important factors in this context. There were some expectations of information that they did not experience were met.

HP 3 (Interview one): We get too little information. When we started to use welfare technology, I thought we should know what is on the market and what kind of technology we can actually get. I think we know too little about it.

Although there was a general need for increased information, there were also differences in how the health professionals in the same municipality experienced receiving information, especially between those who were in resource groups and those who were not.

HP3 (Interview four): (talking about what was new since the last interviews) We've had some door locks fitted. Otherwise, I have no idea.
HP 4 (Interview four): I know a lot because I'm in the resource group, and we've talked about it.

Another obstacle experienced by the health professionals was that managers were hesitant to provide information and feedback. An example of this was that the health professionals were aware of unstable or lack of network access in some areas in the municipalities, but experienced that no action was taken as a result of their feedback. They found that the management failed to note that important patient care information could be missing because of the unstable or missing network access, even though this was reported because of concern for patients' safety. The respondents described how such examples of not being heard led to a loss of motivation for user involvement.

New services involving welfare technology can present challenges relating to the exchange of information with all involved partners, such as IT departments and suppliers of the technology, as the results from this study indicate. The results show that the municipalities do not seem to have ensured adequately functioning procedures for information exchange between all parties involved. In the quote below, the respondent refers to a situation where they had not been informed about a necessary software update, which meant that updating was not completed and, as a consequence, the welfare technology did not work.

HP 1 (Interview one): We received an SMS containing a.com address for the system with a link for updating. It did not come from the municipality's address. It would have been nice to get a message from the IT department or the management about updating. I thought it was SPAM and deleted the message.

Nonfunctioning welfare technology impacted on respondents' interest in and motivation for user involvement and reported that this kind of situations led to frustration and a feeling that welfare technology was unavailable and not trustworthy. Respondents stated that, when the technology did not work, one consequence could be that they resisted using it.

On the other hand, when the technology worked as expected, and the respondents had enough information and competence to use it, they felt this contributed to a better overview and access to information wherever they were; time was saved for this reason.

HP 3 (Interview one): If I have to call the emergency room when I'm with a patient, I don't have to run to the office. If you have EPR on your tablet, you can read about their medication and who their GP (General Practitioner) is. You can also read their old reports, and there's easy access to all the user information.

3.3 | Changing services and new ways of working

For all the respondents, the implementation of welfare technology led to continuous changes in the services and new ways of working with patients. The respondents felt, however, that the management did not require involvement, and few took responsibility for discussing opportunities and challenges with them as users during the change process and their concern about the patients. The limited involvement meant that respondents were worried about how the changes would affect their workdays in practice, and they argued that their unit was not prepared for changes following the implementation of the technology. An example was the increasing number of alarms from technologies, and how this impacted on their day-to-day work, as well as the concern they experienced about how to handle and follow-up the alarms.

HP 18 (Interview three): I think that the more alarms we get, this must be followed up by someone to take care of them. Who should that be? Should we reach out to even more patients?

Another example they gave was about the response time for safety alarms. Long response times could lead to a dangerous situation for the patient if help were not provided quickly enough. Alarms could also be stressful for health professionals due to the risk of not arriving on time, and they experienced that their managers had limited focus on the stress; this could cause them as health professionals.

> HP 5 (Interview five): We have one person who has a door sensor. There is a risk that the person will go out onto a busy road before we arrive. If you are with someone else and have a long distance to travel, this causes employees discomfort as there is a risk of not arriving on time.

Despite challenges arising from technology, several respondents stated that it was important to be able to see the benefits of using welfare technology. That insight into the positive sides could influence their attitude and desire for further user involvement. The technology also involved opportunities to make their workdays easier.

> HP 1 (Interview four): We have long distances. I normally have to go back to the office to pick up a key. Then I realised that the patient had a digital door lock. So I used 5 min instead of 25 min to get to the patient.

3.4 | User involvement in the choice of welfare technology

Our results showed that there were different levels of involvement throughout the implementation process relating to welfare technology. Before the technology's acquisition, the respondents' experience was that some RNs' and NAs' in one municipality took part in a resource group and were involved and listened to in the process. In the end, however, for financial reasons, the management of the municipality did not follow their recommendation. The health professionals who took part in this group felt ignored, disappointed and not heard. This feeling was painful because their involvement was motivated by a wish for rational choices, which was about the quality of the services provided for older people living in their own homes.

> HP 3 (Interview five): The management chose the medical robot that does not speak; it just beeps like an alarm clock. Patients who suffer some cognitive failure would not understand what that beeping means. The management of the municipality said that our choices should weigh most, but in the end, costs were what counted.

After implementation, however, some health professionals experienced involvement in the process of deciding which patients should be offered the available technology. They were also involved in an evaluation of welfare technology together with the patient after it had been in use for some time. Health professionals saw themselves as valuable sources of knowledge, as they knew the patients and the services well, and experienced more acceptance and desire for involvement at this stage of the process.

> HP 2 (Interview four): We look at potential users, and then we score them based on different parameters, to see which candidate will benefit most from the technology (medical robots). It is also important to evaluate regularly because they can normally only use it for a period of time.

3.5 | Concerns about the changes, and implications for services and patients

A feeling of not being involved in the process of implementing welfare technology led to concerns among the respondents about the implications the change in services had for the patients. One example was patients who had services replaced by technology such as medical robots. The respondents were concerned that the number of visits to some patients would decrease and that the importance of observation and follow-up of other needs was underestimated. The tension between the patients' freedom and social contact and its possible impact on the quality of nursing was discussed. Respondents reported that their concern about the quality of nursing was an important factor in relation to attitudes to the use of welfare technology.

> HP 4 (Interview one): We don't catch up if there's something wrong, do we? If there's a patient who is ill… we only come when we bring them medication. There are many times we find other things wrong that we must pass on, or report or call the doctor about. But then we lose that opportunity, and that's what scared us when the robot is used.

The health professionals experienced that incentives to use welfare technology were primarily driven by a desire for efficiency among the management. Due to what seemed to be a lack of user involvement of health professionals, the respondents experienced that possible undesirable consequences, particularly related to safety and the quality of the patient services, were not clearly presented.

Another aspect of concern for patients reported by the respondents was that, if they became uncertain or sceptical about some of the technology, they were afraid that their concern would spread to the patients. They stated that competent and confident health professionals were important for high-quality services and for the patients to experience a feeling of safety.

> HP 19 (Interview four): I have experienced that a consequence of my being too questioning and uncertain in connection the introduction of the technology is that the patients do not want to use it. We must have solid competence to reassure patients who are sceptical about it.

4 | DISCUSSION

We have explored what inhibits and promotes user involvement among health professionals in the implementation of welfare technology in home health care and found a series of factors that might have an impact on it.

The results indicate that the organisations were not prepared for the changes that were needed for the successful implementation of welfare technology. Furthermore, there appeared to be a top-down process in the organisation, whereby the health professionals were told what technology it had been decided to introduce, rather than being fully involved in the processes. There is reason to believe that the limited involvement of health professionals might hinder opportunities for the development of the services and use of resources, which Brewster et al. (2014) also found in their study.

Our findings indicate that, for a successful implementation process, managers should ask the health professionals about what information and competence they need. This is in line with the findings in a study by Dugstad et al. (2019). Unfortunately, our findings indicate little involvement among managers. Our results show that health professionals experienced not having enough competence in welfare technology, which was repeatedly mentioned in the interviews as the most important factor for acceptance and use. The importance of competence is in line with results from other studies (Dugstad et al., 2019; Saborowski & Kollak, 2015). One risk resulting from low competence could be that health professionals do not have sufficient insight and expertise to be active partners in the implementation process. Limited competence can also lead to uncertainty, which, in turn, can lead to workarounds, whereby the new systems are used in unintended ways or completely avoided, as we saw in our study. Some of the respondents felt uncomfortable about not mastering the technology in their day-to-day work. As a result, some continued to use old solutions as their private way of dealing with the challenges, which might have a negative impact on further implementation and use.

On the other hand, competent users tend to be more confident and more satisfied. The results indicate that satisfaction can lead to positive attitudes and a desire to increase the use of technology, as supported by Guise and Wiig (2017), who found that training created confidence and changed attitudes. The study by Berge (2016) revealed that acceptance is related to the systems being operational and used so that people experience improved job performance when using technology. Using information from, for example, EPR on digital tablets enabled health professionals to optimise and schedule work lists and driving routes, as well as to switch assignments between employees when they receive alarms. However, health professionals must be more flexible than before in terms of what tasks they perform. Requiring flexibility may create resistance.

Managers at all levels of the organisation only asked the health professionals for their opinions or suggestions to a limited extent, and nor did they ask for feedback on reported needs and suggestions for changes. When health professionals were asked, and their recommendation was not followed up, they were disappointed and felt that democracy and involvement only existed in theory. This could inhibit further involvement and collaboration. As other studies have pointed out, the most effective way of ensuring successful implementation of new technologies is to cooperate with the groups that are expected to engage in implementing it, and secure the information flow (Cresswell et al., 2013; Dixon-Woods et al., 2011). Lack of involvement from the management may be perceived as passive resistance to user involvement.

As Cresswell et al. (2013) pointed out, infrastructure is often not given sufficient attention when welfare technology is implemented. As found in this study, network instability can undermine trust in welfare technology. It can lead to a feeling of uncertainty, frustration and concern about the quality of care. As pointed out by Berge (2018), trust is important for the acceptance of welfare technology. This, in turn, can affect attitudes and resistance to the use of such technology, as found in our study and in the study by Nilsen et al. (2016). The technology should, therefore, be properly tested and piloted in the organisation before being put into regular use (de Veer et al., 2011). User involvement throughout the process is likely to help to uncover challenges at an early stage so that resistance and infrastructure challenges can be taken seriously and interventions can be implemented where possible, as Kujala (2003) also points out. If this is not done, the result could be that health professionals do not use technology, as we found. This can lead to inefficient services and to technology not being used in an optimal way.

Health professionals do not always know of or acknowledge the opportunities welfare technology can provide. This may be due to limited competence, but also because of a lack of opportunities for involvement in the implementation process. This may lead to resistance to change, which has been found in other studies (Lapointe & Rivard, 2005; Nilsen et al., 2016). Nilsen et al. (2016) point out that it is important to address resistance and not underestimate it. Despite initial resistance to digital tablets, our study showed that, after some time, the health professionals found digital tablets useful. They experienced that EPR on the tablets contributed to a better quality of care because the health professionals had better access to necessary information and a better overview of the tasks to be performed. They also documented their assignments and assessments directly. This is in line with Nilsen et al. (2016), who found that resistance changed over time when welfare technology was implemented. This underlines the importance of user involvement throughout the implementation process and the need for competence. However, the results from this study show that some respondents did not actively take part or become involved in processes, even when they were given an opportunity to do so. This is a challenge for managers, and it sheds light on the challenging process of changing practice.

The findings from our study, like the results from Anderson et al. (2017), show that health professionals had a strong desire to do their best for patients, which may have an impact on choices and recommendations relating to welfare technology. In-depth knowledge of patients and their needs can be crucial in terms of assigning the right service to the right patient. It can also be important, for example, to identify increased cognitive failure and evaluate when patients are no longer able to handle the technology, as pointed out in this study, as well as by Morley and Floridi (2019), and Holte and Wulff-Jacobsen (2016). Technologies that are thought to be beneficial and to enhance safety might, in fact, not be suitable if the patient is not getting the help he or she needs, as demonstrated by Stokke (2017). In these processes, a greater degree of user involvement by health professionals will be essential when planning safe home care, as well as providing input on the technology that is to be procured.

Although one of the main goals of introducing welfare technology is to reduce the number of visits, this can be a challenge for the health professionals, as shown in our study and by Brewster et al. (2014). Despite being positive about resources being freed up through the implementation of welfare technology where resources that can be used by others who cannot use welfare technology for different reasons, it can be challenging not seeing patients face-to-face daily (Saborowski & Kollak, 2015). Several of the respondents were concerned about patient safety, as well as reduced social contact, especially as regards patients with small social networks. This is an example of how the implementation of welfare technology often creates new needs. User involvement by patients, next of kin and health professionals is needed to meet the challenges and make suggestions for how to address them.

4.1 | Further research

User involvement is still a relatively new field of research, and much research remains to be done using different methods and perspectives. From our study, it seems that user involvement varies and that health professionals have many and complex experiences. Further studies of the process of implementing welfare technology should be carried out, with the focus on how health professionals are inspired by user involvement to change services and increase the use of welfare technology. Involvement in the development of the welfare technology itself, to ensure that the technology is better adapted to the services, is another field that should be explored further. Studies of what promotes user involvement could provide important input and help to make home nursing services more prepared for further innovation processes when new technology is implemented.

4.2 | Limitations of the study

The results provide a limited picture of the factors that promote or inhibit user involvement in the implementation of welfare technology, based on a sample of 16 health professionals from three municipalities. Home care services are undergoing development and changes, and experiences can, therefore, change quickly. We nonetheless believe that this study identifies some important prerequisites for user involvement and the further implementation of welfare technology.

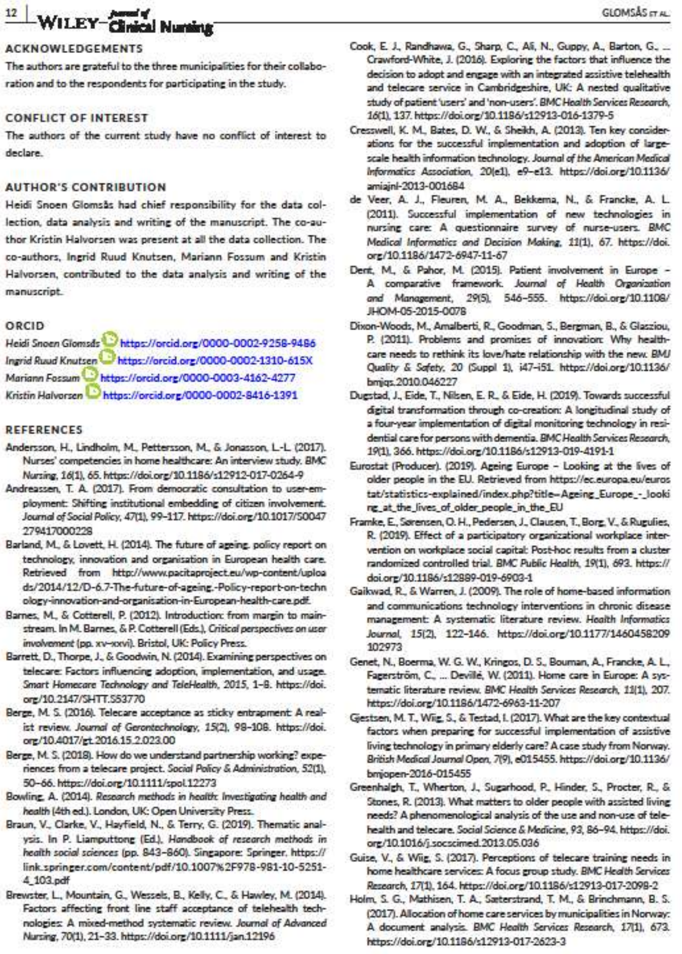
The authors' preconceptions can affect the interpretation of data, and the results can be coloured by this. The first author of this article has good knowledge of home care and thereby an understanding of the field. To ensure credibility through ongoing reflexivity, all steps in the analysis were discussed with all the authors and tentatively presented with clarity, as Morse (2015) recommends.

5 | CONCLUSION

From the perspective of the health professionals, there appeared to be unpreparedness for the changes that the implementation of welfare technology would lead to in the home care services. In the interviews, the respondents described management who seemed to want to implement welfare technology before the health professionals were ready and had enough competence to take advantage of it. The management had a limited focus on facilitation and the need for user involvement. The findings show that most of the health professionals wanted more involvement, but emphasised that more competence, information and collaborative arenas were necessary for involvement in the process. Limited competence also affected their attitudes and willingness to use the technology. The respondents underlined that they felt that the management wanted to see a quick financial gain when implementing new technology and that this could be at the expense of the quality of the service. They were also left with an impression of a quasi-democratic process when their professional recommendations were not followed. Without user involvement among health professionals, respondents were concerned about how the implementation of new technology would affect patient services and their work situation. Better facilitation and a stronger focus on user involvement among managers at all stages of the process of procuring and using welfare technology were identified as important, but demanding factors.

6 | RELEVANCE TO CLINICAL PRACTICE

The knowledge of factors that promote or inhibit user involvement, as experienced by health professionals and gained from this study, may contribute to the refinement of services and increase focus on providing opportunities for user involvement in the home care service. Our findings indicate that health professionals would like to be involved in the implementation processes of welfare technology to a higher degree. Our findings also indicate a need for increased attention on user involvement of health professionals when implementing welfare technology in municipal home health care. This may have a positive impact on reaching the health policy goal of increasing the use of welfare technology in home care services.



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CONFLICT OF INTEREST

The authors of the current study have no conflict of interest to declare.

AUTHOR'S CONTRIBUTION

Heidi Snoen Glomsås had chief responsibility for the data collection, data analysis and writing of the manuscript. The co-author Kristin Halvorsen was present at all the data collection. The co-authors, Ingrid Ruud Knutsen, Mariann Fossum and Kristin Halvorsen, contributed to the data analysis and writing of the manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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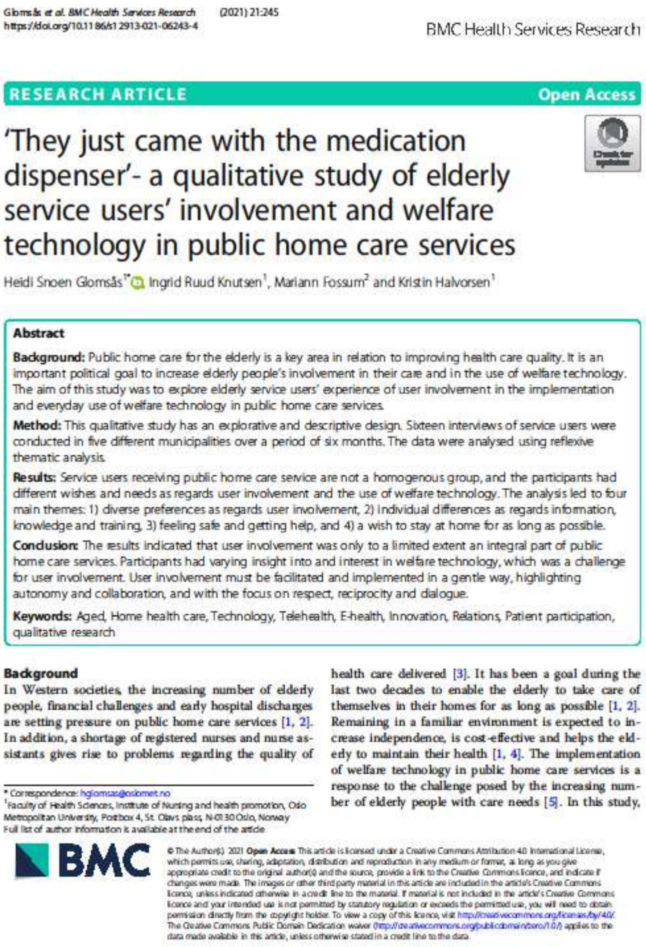

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‘They just came with the medication dispenser’- a qualitative study of elderly service users’ involvement and welfare technology in public home care services

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Abstract

Background: Public home care for the elderly is a key area in relation to improving health care quality. It is an important political goal to increase elderly people’s involvement in their care and in the use of welfare technology. The aim of this study was to explore elderly service users’ experience of user involvement in the implementation and everyday use of welfare technology in public home care services.

Method: This qualitative study has an explorative and descriptive design. Sixteen interviews of service users were conducted in five different municipalities over a period of six months. The data were analysed using reflexive thematic analysis.

Results: Service users receiving public home care service are not a homogenous group, and the participants had different wishes and needs as regards user involvement and the use of welfare technology. The analysis led to four main themes: 1) diverse preferences as regards user involvement, 2) individual differences as regards information, knowledge and training, 3) feeling safe and getting help, and 4) a wish to stay at home for as long as possible.

Conclusion: The results indicated that user involvement was only to a limited extent an integral part of public home care services. Participants had varying insight into and interest in welfare technology, which was a challenge for user involvement. User involvement must be facilitated and implemented in a gentle way, highlighting autonomy and collaboration, and with the focus on respect, reciprocity and dialogue.

Keywords: Aged, Home health care, Technology, Telehealth, E-health, Innovation, Relations, Patient participation, qualitative research

Background

In Western societies, the increasing number of elderly people, financial challenges and early hospital discharges are setting pressure on public home care services [1, 2]. In addition, a shortage of registered nurses and nurse assistants gives rise to problems regarding the quality of health care delivered [3]. It has been a goal during the last two decades to enable the elderly to take care of themselves in their homes for as long as possible [1, 2]. Remaining in a familiar environment is expected to increase independence, is cost-effective and helps the elderly to maintain their health [1, 4]. The implementation of welfare technology in public home care services is a response to the challenge posed by the increasing number of elderly people with care needs [5]. In this study,

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we rely on one of the most used definitions of welfare technology in Norway:

> *'Technology that can contribute to increased security, safety, social participation, mobility and physical and cultural activity, and that strengthens individuals' ability to manage for themselves in everyday life despite illness and social, mental or physical disability. Welfare technology can also function as technological support for next of kin and otherwise help to improve accessibility, resource utilisation and the quality of service provision. Welfare technology solutions can in many cases prevent the need for services or hospitalisation'* [6]:99).

Most European countries have also adopted a policy for user involvement and empowerment that creates expectations of quality improvement in public services [1, 2, 7, 8]. Despite increased awareness of user involvement, municipalities struggle to overcome the challenges associated withs translating the rhetoric of involvement into practice [9, 10].

New knowledge of elderly service users' experiences of involvement in the implementation and use of welfare technology in public home care services is needed and is the purpose of this study.

Public home care services

Public home care services appear to differ between and within countries. In most countries, they include rehabilitative, therapeutic and assistive home care, in addition to nursing [11]. In Norway, all citizens with health-related needs have a legal right to receive public home care services free of charge [12]. Public home care is organised by geographic area, and it is an integral part of the municipal health care services that are primarily financed through taxes [13]. Although some service users or next of kin acquire welfare technology privately, the most common situation in Norway is that the municipal service acquires, offers and operates the welfare technology, as is the case in this study.

Welfare technology

In Scandinavian countries, the term welfare technology is commonly used to describe technological solutions used in home care to support and improve services [14]. In the international literature, terms such as telecare, telehealth, telemedicine, assistive living technology and e-health are often used synonymously with welfare technology [15, 16]. There appears to be no consensus on the boundaries between the terms and their content [17, 18].

The goal of using welfare technology is to strengthen individuals' ability to manage for themselves in everyday life and cope with their life situation, preferably in their own homes [19–21]. Moreover, the use of welfare technology comes with an assumption of increased safety for service users and their next of kin [4, 22]. Welfare technology is expected to contribute to innovation in health care services, with the focus on improved quality and reduced costs [2]. Financial savings associated with the use of welfare technology are primarily related to a reduction in the number of visits from the home care service, fewer hospital admissions and service users being able to stay longer in their homes [23]. There may be discrepancies between expectations and the complex reality these technologies are part of [21]. Previous studies have shown that the introduction of welfare technology can be beneficial, but also have problematic implications and barriers. Not all technology is suitable for service users [4, 24]. Examples of barriers to the implementation and use of welfare technology include attitudes and resistance from users [4, 25], limited knowledge, competence and information [26–28], instability of internet access and the cost of software [26, 29]. These barriers can have an impact on how use is experienced and affect user involvement.

User involvement

In contemporary Western societies, user involvement is a widely accepted democratic principle, and several countries, including Norway, have developed legislation to strengthen service users' influence [7, 30]. There are political expectations that user involvement will contribute to increased quality and efficiency, and reduce health care costs [31–33]. However, user involvement is in many ways a vague concept that covers many different approaches [8, 34]. Historically, user involvement is linked to individuals' right to be able to influence their own lives [35]. User involvement has subsequently been seen as an expression of a consumer and individual orientation, where the focus on freedom of choice is central [8]. In recent years, user involvement has been associated with the terms 'co-creation' or 'co-production', where users of welfare services are seen as equal and competent co-producers with expertise and a right to influence and improve the services they need [8, 33, 36].

User involvement is about creating opportunities for service users to express their opinions about the service, including sharing information and feelings. The service users' goals, needs, and capabilities should be the guiding principle for services and interventions if genuine user involvement is to be achieved [33, 37]. For this reason, this study should also be seen in light of the increased focus on patient-centred care in health services [38, 39]. Furthermore, user involvement is also about the relationship between health professionals and service users [40]. Studies and reports have highlighted that service users who are actively engaged in their health and care can experience better health outcomes and care experiences [7, 33, 41]. However, research shows that, in many situations, user involvement is inadequately integrated into health care for elderly [34, 42]. There are several studies from hospitals and discharge processes to home care or mental health, but few empirical studies on user involvement are from public home care services [34, 42–44].

Perceptions of user involvement differ among elderly service users. Some service users believe that user involvement is about receiving information and only have a limited wish to participate in decision-making about the services they receive [45]. Others perceive user involvement as the ability to become involved as co-producers and to be able to decide for themselves [46]. The study by Bjørkquist et al. [5] indicates that involving elderly service users in the process of implementing welfare technology is challenging due to a lack of competence and information about what technology is available and what service users might benefit from. Another study found that elderly service users reported that they often struggled to understand and remember the information they were given about welfare technology, which is a challenge for user involvement [42]. Bennett [19] argues that consideration must be given to patients' decision-making capability and human rights in connection with user involvement.

Several studies have addressed questions concerning user involvement among the elderly and the use of welfare technology separately, but few studies have looked at public home care from the perspective of service users. We believe that greater insight into factors affecting user involvement in this context will benefit all stakeholders, especially those interested in improving care for elderly service users.

Method

Aim and study design

The aim of this study is to explore elderly service users' experience of user involvement in the implementation and everyday use of welfare technology in public home care services.

A qualitative study with an explorative and descriptive design was chosen. This design offers an opportunity to illuminate experiences and obtain in-depth knowledge of the participants' experience of user involvement through individual interviews, and to make sense of this knowledge [47]. To explore participants' experiences, attitudes and reflections on what inhibits and what promotes user involvement, we used a phenomenological-hermeneutical approach [47]. This approach was used in order to capture the essence of the participants' everyday experiences and to interpret them from a user involvement perspective. By inviting participants with varied backgrounds in terms of gender, age, experience and interest in welfare technology, we gained first-hand insight, knowledge and an understanding of the everyday context and complexity of home health services. This was further strengthened by inviting participants from different municipalities that had taken different approaches to the implementation process, and everyday use of welfare technology.

Context

Service users of public home care services from five municipalities in Eastern Norway participated. The smallest municipality had approximately 5000 inhabitants, while the largest had approximately 87,500 inhabitants. In terms of land area, the municipalities varied between 176 sq. km and 961 sq. km, and both urban and rural municipalities were included.

The five Norwegian municipalities were obliged to implement and use welfare technology in their day-to-day provision of home care services. The implementation had started, but the municipalities were at different stages of the process in terms of what they were able to offer their inhabitants.

Recruitment and participants

During planning of the data collection, a joint information meeting was held for the management of some of the municipalities that Oslo Metropolitan University had a cooperation agreement with. They were informed about the objective and the planned research design of the study. Managers of home care services in three municipalities accepted the invitation to participate. To ensure enough participants, two more municipalities were invited.

The inclusion criteria for taking part in the present study were that the service users were capable of giving consent, had used some kind of welfare technology for at least six months, were 65 years old or older, and able to sign an informed consent. It was requested that participants have varied backgrounds in terms of gender, age, experience of and interest in welfare technology.

The management of home care services asked the health professionals who were in daily contact with service users to give potential participants an information form containing information about the study and the written informed consent that was to be signed. As soon as the home care service received the written consent and delivered it to the first author, the participants were contacted by phone, and interviews were scheduled. Initially, 18 participants consented to take part in an interview, but two withdrew before the interviews took place.

A total of 16 participants, five men and 11 women, ranging in age from 65 to 95 years, participated in the study. Some had used welfare technology, such as safety alarms, for a few months and others for many years, while a few respondents did not remember exactly how long they had used welfare technology. Digital safety alarms, medication dispensers and digital door locks were the most used welfare technologies in these municipalities.

Data collection

A semi-structured interview guide was developed by the authors for this study (Additional File 1). The interview guide was designed to explore participants' experiences systematically and comprehensively, and it kept the interviews focused on the desired line of action. Nonetheless, as Bowling [47] recommends, it allowed the interviewer to probe and enabled the participants to raise other relevant issues. The questions in the interview guide comprised core questions and many associated questions, which, in turn, were further improved through one pilot test in line with Cresswell's recommendations [48]. The main questions in the interview guide were whether participants could tell the interviewer about: how they obtained the technology, how they used it, whether, in their experience, health professionals from the municipal health services were attentive to their needs and wishes, whether they experienced being involved in processes, and what challenges or needs they believed had to be addressed to ensure more user involvement. The interviews took place between March and September 2019.

The first author conducted the individual interviews and met the participants for the first time at the interviews. The first author assessed the participants' competence to consent and decided whether it was appropriate to conduct the interviews. Only the participants and the first author were present during the interviews. The first author is an RN/PhD student and has previous experience of individual interviews and qualitative methods. In the interviews, it was desirable to be attentive to the participants' experiences and stories and to be sensitive to surprises, topics and opinions that might challenge preconceptions. A few participants had some problems expressing themselves during the interviews, after e.g. stroke or mild cognitive impairment. This meant that it was necessary to make adjustments during some of the interviews in order to specify and explain some questions. Simple verbal prompts were provided to improve the communication. Moreover, some answers were very brief, with the result that some of the data were of low quality, while others provided rich data. Both during and after the interviews, the first author took notes for the analysis. When the 16 interviews were completed and a preliminary analysis had been carried out, the authors agreed that satisfactory saturation had been achieved.

Three interviews took place at a day activity centre for the elderly, and the rest in the participants' homes. The interviews lasted between 30 and 90 min; they were recorded digitally and transcribed verbatim and unidentified. The first author transcribed eight of the interviews, and a professional transcriber the rest.

Data analysis

The coding in the data analysis was performed using NVivo 12 software. After the coding, manual analyses were carried out. All authors were involved in the analyses.

Reflexive thematic analysis was used, as described by Braun et al. [49]. In the first phase, the objective was familiarisation with the data. All the interviews were read and reread by all the authors, and possible interpretations of the material were discussed. In phase two, more detailed and systematic work was carried out. We extracted the meaning content from the data and generated codes, using open thematic coding for each transcript. The NVivo12 software provided an overview and helped us to organise and manage the data in the process. In phase three, we grouped codes and manually constructed initial themes. Themes were identified and discussed across the data and in line with the research questions and our interpretations. Some statements were categorised under more than one theme. In phase four, we revised initial themes and discussed themes back and forth to avoid overlaps. We discussed how the themes were related to each other across the whole data set. In phase five, the themes were revised and given more clarified names that conveyed their essence. It was a goal that the final themes should reflect the results. The analytical work was wrapped up in the sixth phase, which involved checking how well the themes worked, together and individually, and preparing the article. Throughout the analysis, the authors went back and forth in the data material.

The results were presented to an external project advisory group for the PhD project of which this study is a part. Participants in this group were recruited from two Pensioners Associations, and one from a next of kin group of the National Association for Public Health. The group consisted of one person receiving home care and two next of kin, one of whom was also a retired nurse assistant. The participants in this group acted as discussion partners in the interpretation of the findings. The responses did not produce any immediate changes but confirmed that the analytical reflections were in line with their experience.

The Consolidated Criteria for Reporting Qualitative research (COREQ) checklist for reporting qualitative studies was used [50].

Research ethics

The Helsinki Declaration's principles for medical research [51] were complied with. All respondents in the study were given oral and written information about the project and signed a written informed consent. Information was also provided about the possibility of withdrawing from the study if they wished before the data were analysed. Since the participants were a vulnerable group of frail elderly, competence to consent was assessed before the interviews were conducted. All data were anonymised, and the confidentiality of the respondents was safeguarded. The data were stored in accordance with the applicable rules and guidelines for storing research material. The project was approved by the Norwegian Centre for Research Data (NSD), reference number 473910.

Results

The participants had varied backgrounds as regards their health, social and economic status, and they had different needs and experiences. Most of them lived alone, and there were significant variations in housing standards. While some lived relatively isolated, far from their nearest neighbour and in simple living conditions, others had moved to modern, practical apartments or to an independent living facility with services in the city centre area. Some of the participants had problems remembering or expressing themselves orally, for example after having had a stroke. In contrast, others had no problem at all and eagerly kept up with the news and were socially engaged. Some participants expressed that they were active users of Skype, Facebook and other types of social media, while others were not on the internet and had neither a mobile phone nor a computer.

Four main themes emerged during the analysis. There were challenges related to involvement in the decision-making process because of the different preferences among the participants as regards user involvement. Moreover, individual differences in information, knowledge and training affected the participants' ability to ask for welfare technology and become involved in the decision-making process. A third theme concerned how the experience of safety affected attitudes to and the use of welfare technology. Participants' experience of welfare technology as a tool that could enable them to stay as long as possible in the home was the final main theme.

Diverse preferences for user involvement

The results showed differences between the participants as regards to what extent and in what way they wanted to participate and be involved when welfare technology was implemented and used. Some participants' attitude was that health professionals knew best and made the correct choices on their behalf when the municipality acquired welfare technology. Other participants said that they did not want to decide because they lacked energy or knowledge. They expressed gratitude for the help they received and said that other service users should also be grateful and not complain or argue when health professionals came up with ideas for new technology. It was a challenge that some of the participants did not remember whether they had been asked if they wished to use welfare technology.

> *'Oh, no, I don't want to decide. I don't have enough energy, so the health professionals must choose (the type of welfare technology).'*

Some of the participants felt that they coped well with everyday life themselves, but reported that their family or health professionals argued that they needed to use welfare technology. In some situations, participants felt that others decided for them. For some, this was okay, while, for others, it was not because they wished to make their own decisions. Nonetheless, most of the participants said that they accepted what the health professionals and next of kin thought they needed because they did not have enough knowledge or did not want any conflicts.

> *'No, that's... it's the family. They want me to have such a safety alarm, but I do not think I need it.'*

On several other occasions, participants stated that they wanted to be involved when health professionals suggested or brought welfare technology with them. They wanted to discuss the available opportunities with the health professionals and be given a chance to accept or reject the new technology. To be able to make individual choices and having the feeling of being in charge of their own lives were perceived as important.

> *'..they just came with it (medication dispenser). They are a bit.. what can I say ... they are a bit controlling. It would have been nice if they had asked.'*

In procurement processes for welfare technology, the municipalities frequently bought or rented just one model to cover the services in their municipality, and the service users were not invited to participate in the process. The result indicates that the technology was not tailored to the individual service users' health challenges. In some cases, the result was that some participants could not use the model offered by the municipality, at least not in the expected way. An example from this study was a new type of safety alarm. Several of the participants found it too heavy to wear around their necks. For that reason, they put the safety alarm in their handbag, laid it on the table or hung it on their walking frame. The participants did not reflect on the risk of being unable to access the alarm if they were in need of help. This example also indicates that not all development is necessarily positive.

> *'... it doesn't work with me. I never wear it on me. I can't wear anything heavy around my neck. I am very sore in all my muscles and body ... in my skin.'*

Individual preconditions for knowledge, information and training

Participants' prior knowledge of welfare technology varied from not knowing what the term meant to having a good overview of what it is, what kind of welfare technology exists and what the municipality can offer. For most of the participants, it was important to be given information about welfare technology in general, and what the municipality could offer in particular.

> *'We need more information because there is a lot that I do not know. What you can apply for, what you are entitled to, such important things.'*

Other participants said that they did not need such information now, but that, if they got worse and some technology could help them in their everyday lives, they would like to be given such information. Based on the results, it also seems that what is known and what is unknown about welfare technology influenced whether service users themselves take the initiative to apply for it. For example, most of the participants stated that they or their next of kin had applied for safety alarms. As regards medication dispensers and digital door locks these were aids that health professionals suggested when they thought it would help service users to cope with everyday life and continue to live at home.

Only to a limited extent did health professionals ask the participants about how they experienced using the technology and what knowledge they felt was lacking. Most participants were satisfied with the use of welfare technology and felt that it was easy to use, even though several of them had only been given limited training. Our results indicate, however, that, in some situations, participants had a limited understanding of how to use the equipment, which may have led to incorrect use.

> *'Because I didn't know how to ... Because I thought it was just a case of pressing the button, but it was not. You have to touch it and hold it for a few seconds or so. Then you have contact with the home care (safety alarm).'*

Feeling safe and getting help

The participants expressed that the use of several welfare technologies gave them an experience of safety, and that this was essential if they were to have a positive attitude to using such technology. For example, using safety alarms made the participants feel safer, and this feeling was further enhanced for those who had safety alarms with Global Positioning System (GPS) tracking. None of the participants experienced GPS tracking as intrusive monitoring, only as providing increased safety. This indicates that participants were more concerned about getting help than about the possibility of being monitored. Another positive aspect emphasised by the participants was that if they forgot to charge for example the safety alarm, the health care professionals were notified digitally about the low battery. In such case, the health professionals contacted the participants and asked them to charge it. The home care service was also notified if the service user forgot to take the medication from the medication dispenser, or if there was something wrong with the dispenser, for example, if the medication inside the dispenser had jammed.

> *'It is the safety that makes it okay to have one (safety alarm), so you can get hold of someone if you should fall.'*

The results indicated that, for some participants, the conditions for involvement and understanding information were challenging. It emerged from our findings that some participants' insight into their own cognitive capacity was limited. For example, some of them stated that they did not understand why the medication dispenser repeated that they had to take their medicine. They said they sometimes became irritated and thought that the dispenser was being 'fussy'. Experiences also differed as regards whether health professionals observed that they mastered the use of welfare technology. Most of the participants said that it was reassuring that the health professionals checked how they used it, while, for others, it was perceived as rather controlling and indicated a lack of confidence in them.

> *'Now, they do not check. In the beginning, they did, but then they realised that I could remember how to do it myself.'*

Some of the participants had experienced some start-up problems with the technology, for example related to an unstable network or software issues. When the welfare technology had faults or did not work, this could represent a safety risk for the service users, for example if the health professionals could not open the digital door lock when service users were in need of help. The participants did not emphasise such challenges. Instead, they found pragmatic approaches until the problem was solved. For example, participant 18 stated: *‘It still happens a few times that the door lock does not work, but I keep the balcony door open and the health professionals can enter by it, so it is not a problem.’* The participants did not perceive an unlocked balcony door as a security problem and seemed to be less afraid of uninvited guests than of not getting help when needed.

A wish to stay at home as long as possible

Several of the participants stated that welfare technology was a prerequisite for continuing to stay at home. They were positive about making more use of welfare technology if that would enable them to cope with their everyday. When they experienced, for example, that technology helped them to remember to take their medicine, this gave them a feeling of mastery.

> *‘I think you can say that everyone should try a medication dispenser. They will become so fond of them. In the morning when I get up, the dispenser says, "it's time for medicine" and then I manage to take it myself.’*

None of the participants reported that they had been asked whether they would prefer a visit from a health professional to administer their medication instead of using the medication dispenser. However, most participants said that they preferred the medication dispenser. One argument that was mentioned several times in the interviews was the importance of taking medication at the right time, instead of waiting for the health professionals to come, which had previously been a problem. Managing the administration of medication gave the participants a feeling of independence and increased freedom, which illustrates that, for some service users, technology can be experienced as better than the services provided by health professionals.

> *‘The home care service came up with this idea, and I thought it was a gift package (medication dispenser). It is a lot easier because, if people come here every day, then I have to ... then I am very tied up.’*

However, some participants preferred physical visits for the administration of medication but were not given this option. For them, health professionals represented social contact in a situation where they struggled with loneliness.

> *‘If I had the choice, I would have chosen someone to come. I am alone a lot. I think it is nice when someone comes here and talks to me.’*

Discussion

When we started the study, our objective was to explore participants' experience of involvement in the implementation and everyday use of welfare technology in public home care services. After our analysis, the results showed that we could not refer to elderly people living at home as a homogeneous group. They are a group of individuals with very different knowledge, needs and preferences as regards user involvement and how to use welfare technology.

The results illustrate various aspects of involvement, engagement and dialogue about the implementation and use of welfare technology. Based on the results from this study, we would argue that user involvement seems to be more of an ideal than normal practice in home care services, even though it has been a legal requirement and a political goal for some time [1, 2, 7, 8].

Conditions and challenges for involvement and decision making

The results, which are in line with other studies [34, 37], show that some participants felt that they were not involved, which may lead to a feeling of disempowerment and resignation. This can especially be the case if the service user gets the feeling that health professionals have made up their minds before discussing with them, which is supported by the study by Rydeman and Törnkvist [52]. Health professionals' attitudes and whether they focus on users' needs and goals in their contact with service users may have an impact on the service users' feeling of involvement. Hestevik et al. [53] argue that a paternalistic attitude on the part of health professionals in relation to how service users are included in the process and allowed to share their wishes and experiences can be a barrier to user involvement. In line with Olsen et al. [39], a more patient-centred focus can contribute to user involvement in relation to service users' health-related needs and goals.

The study revealed differences between the participants as regards to what extent and in what way they wanted to be involved in decision making, which other studies also support [34, 54]. It is pertinent to ask what is realistic to expect of elderly service users, especially in relation to see them as equal and competent partners, as in co-production, since many of them have multimorbidity and experience low energy. As Bennet [19] pointed out, it is necessary to consider the consequences of inviting frail service users to be more involved, and whether this could lead to a feeling of negative mastery. Our results indicate that involvement and democratic ideals may be overwhelming and too much to expect from frail service users, as also Paillaud et al. found [55]. In line with our findings and Pearson et al. (2015), service users sometimes want health professionals or their next of kin to make choices for them. This indicates that service users have trust in health professionals, but it could also be because many elderly service users are accustomed to the traditional, paternalistic and task-oriented care approach [34, 53, 56, 57]. However, when service users do not want to be involved, their autonomy should be respected. Choosing not to be involved can also be seen as a form of user involvement.

Cozza et al. [58] point out that welfare technology works differently in different contexts and for different people, something our results also indicate. The material attributes of technologies, such as shape, colour, durability and size, can influence whether and how the technologies are used [18]. Technologies that are meant to be beneficial and to enhance safety might not be suitable if the service user does not use them as intended, as was the case for some of the use of safety alarms in this study, and as also found in the study by Stokke [22]. This highlights the need for user involvement by end-users in the procurement process if the home care service is to acquire new technology that actually meets service users' needs. Furthermore, other studies [4, 39] point out that health professionals have a responsibility to follow-up on what service users experience as important.

Health care decision-making is complex and requires efficient and explicit processes to ensure transparency and consistency of criteria considered [59]. Health decision-making frameworks provide policymakers with evidence to inform decision-making [60]. Weights on criteria in frameworks vary widely, reflecting the diverse perspectives of involved participants [61]. In this process, service users' involvement and reflections about social, economic, organisational, and ethical criteria can enrich the framework. In situations where information and involvement from frail service users can be challenging, alternative data collection should be considered. If data from one essential group is missing, decisions of criteria can be made on an inadequate basis, and there is a risk that quality work will fail.

The need for knowledge, information and training

Knowledge, information and training is a prerequisite for exercising the right to be involved, and it must be adapted to the individual's needs, as enshrined in the Norwegian Patients' Rights Act [30]. Our study found shortcomings in this area, and we also found that limited knowledge and training led to uncertainty and resistance to the use of welfare technology, which is in line with the study by Nilsen et al. [25]. Sufficient knowledge and information are also necessary for service users to be able to look after their health, self-manage their own lives and provide input that can increase the quality of the services [22, 33, 62–64]. Our results show that the participants asked for technologies they were familiar with, such as safety alarms. Safety alarms have been well established and much used since the late 1970s in health care services in Western societies [22]. For the other welfare technologies, such as medication dispensers, it was the health professionals who suggested using them. This highlights the need to improve information about what exists and how to obtain it. However, information and communication do not automatically enable service users to influence decisions about the introduction of welfare technology in home care services.

Welfare technologies' impact and consequences for safety, independence and the ability to stay at home

Overall, the participants in our study were positive to welfare technology and wanted to use it more because of the feeling of safety it gave them and because it could help them to continue to live an independent life at home, as supported by findings from other studies [4, 19, 20]. For example use of safety alarms enabled participants to keep doing daily activities without worrying about falling, which is in line with a finding from a study by Stokke [22]. Another point of agreement with other studies [21, 65], was the initial scepticism we found about using the technology. After a while, participants felt that welfare technology contributed to their feeling of safety. Such initial scepticism highlights the need for friendly nudging when welfare technology is introduced, and for close cooperation and follow-up to keep users feeling safe.

One consequence of using welfare technology was a reduction in the number of physical visits by health professionals to some participants. Even though this is a desired development from the authorities and some service users' perspective. Bennet [19] points out that it is essential to consider the impact such changes have on service users. As the results from several studies indicate, it is important to acknowledge that technology in elderly care cannot be seen as a neutral tool, and it is essential to consider the impact its use has on service users [19, 22, 66]. For example, one of the participants was happy about using a medication dispenser but said that, if she had the choice, she would still prefer to have a person come with the medication, because of loneliness. Reduced visits can also be challenging for health professionals as regards identifying whether, for example, a service user's cognitive function is decreasing, and evaluating whether service users can no longer handle the technology, as pointed out in another study [67].

In some studies, health professionals have expressed some reservations about the impact on civil rights of using GPS tracking [26, 68]. The findings from our study show that the participants did not experience the use of GPS as monitoring, but as a safety measure. What service users see as important should be the guiding principle for services and interventions if genuine user involvement is to be achieved, rather than the attitude of the health professionals, as also supported by other studies [33, 39, 56]. A feeling of being heard and listened to was seen as important by the participants in our study. In line with Kuipers et al. [38], we found that user involvement with the focus on patient-centred care and co-creation of care can have a positive effect on service users' well-being and satisfaction. Olsen el al [39]. pointed out that patient-centred care is essential for trust and cooperation, as well as for optimising health care. Making patient-centred user involvement the standard way of working among healthcare professionals is a matter of urgency in relation to putting the service user in focus. If this is not done, there is a risk that user involvement will end up as mere rhetoric and not a realistic approach for the public home care service.

Limitations of the study

This study is based on a sample of 16 participants and the welfare technologies they use, which means that it has a somewhat limited knowledge base. The municipalities were at different stages of implementation which may have affected participants' experiences and reflections. The participants were frail elderly, which may have had an impact on the responses we received. Nonetheless, the results highlighted challenges for user involvement and everyday use of welfare technology. The authors' preconceptions and experience could also have influenced the results. To ensure credibility through ongoing reflexivity, all steps in the analysis were discussed with all the authors and tentatively presented in a clear manner.

Relevance to clinical practice

This study provides valuable knowledge and will increase awareness of different needs and preferences for user involvement among elderly service users. It also highlights the importance of individual assessments, and adds to our knowledge and understanding of the complex nature of public home care. The results show that information, knowledge and training must be facilitated, preferably in a more patient-centred way, if user involvement is to become a reality. The participants were not concerned about monitoring, but about feeling safe, getting help when they needed it, and staying at home for as long as possible. The municipalities must keep this in mind in their further implementation of welfare technology. To further improve the quality of home care services, user involvement should be facilitated and implemented in a gentle and patient-centred way, where the focus is on autonomy and collaboration, as well as on respect, reciprocity and dialogue about the service users' situation.

Conclusion

The results indicate that user involvement is only to a limited extent an integral part of public home care services for the service users. Most of the participants called for more knowledge, information, training and opportunities to play an active part in decisions on the use of welfare technology. However, some of them preferred health professionals taking decisions on their behalf. Service users' autonomy should be respected even when they do not want to be involved. Standard offers of welfare technology and limited dialogue between the home care services and the participants result in limited opportunities for individual adaptation. In some cases, this led to non-optimal use of the technology. Nevertheless, the welfare technology that was already introduced made participants' feel safer and enabled them to continue to live at home, which was very important and in accordance with political recommendations and goals.

As regards user involvement, our results highlight the challenges of involving frail elderly in the implementation and everyday use of welfare technology in public home care services. A relevant topic for future research would be to look more closely at interventions that can encourage patient-centred user involvement and test it, for example, in a randomised controlled trial.

Abbreviations

COREQ checklist: The Consolidated Criteria for Reporting Qualitative research checklist; RN: Registered nurse; PhD project: Doctoral project; PhD student: Doctoral student; NSD: The Norwegian Centre for Research Data; REK: The Norwegian Regional Committees for Medical and Health Research

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-021-06243-4.

Additional file 1: User involvement in the introduction and daily use of welfare technology in home care services. Interview guide.

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Authors' contributions

HSG, IRK, MF and KH designed the project. HSG collected the data. HSG, IRK, MF and KH analysed the data and developed the manuscript. HSG, IRK, MF and KH read and approved the final manuscript. The authors read and approved the final manuscript.

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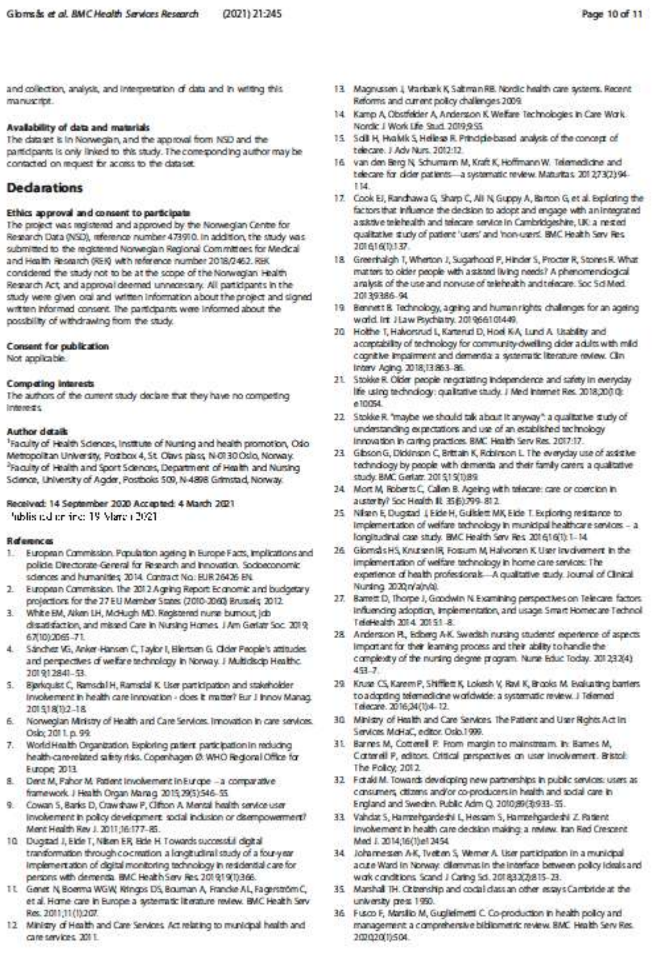

and collection, analysis, and interpretation of data and in writing this manuscript.

Availability of data and materials
The dataset is in Norwegian, and the approval from NSD and the participants is only linked to this study. The corresponding author may be contacted on request for access to the dataset.

Declarations

Ethics approval and consent to participate
The project was registered and approved by the Norwegian Centre for Research Data (NSD), reference number 473910. In addition, the study was submitted to the registered Norwegian Regional Committees for Medical and Health Research (REK) with reference number 2018/2462. REK considered the study not to be at the scope of the Norwegian Health Research Act, and approval deemed unnecessary. All participants in the study were given oral and written information about the project and signed written informed consent. The participants were informed about the possibility of withdrawing from the study.

Consent for publication
Not applicable.

Competing interests
The authors of the current study declare that they have no competing interests.

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Paper III

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RESEARCH Open Access

Family caregivers' involvement in caring for frail older family members using welfare technology: a qualitative study of home care in transition

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Abstract

Background: Demographic, economic and organisational changes challenge home care services. Increased use of welfare technology and involvement of family members as co-producers of care are political initiatives to meet these challenges. However, these initiatives also involve ethical aspects.

Method: The aim of this qualitative study was to explore family caregivers' experience of involvement and possible ethical aspects of caring for frail older family members receiving home care services supported by welfare technology.

This study used a qualitative explorative and descriptive design within a phenomenological-hermeneutical approach. Sixteen interviews with eighteen family caregivers were conducted. The participants were sons, daughters, siblings and spouses of frail older people receiving home care services with the support of welfare technology. Data were analysed using reflexive thematic analysis. The COREQ checklist was used.

Results: The analysis led to five main themes. First, the family caregivers' experienced caring as meaningful but increasingly demanding concerning the changes in home care services. Second, they experienced a change in relationships, roles, tasks, and responsibilities related to more family involvement and the use of welfare technology. This also challenged their sense of autonomy. However, welfare technology helped them deal with responsibilities, especially safety. The family caregivers requested early involvement, dialogue for care decisions, more cooperation and support from health professionals. Third, the participants experienced that health professionals decided the conditions for co-production without discussion. Their need for information and knowledge about welfare technology were not met. Fourth, the family caregivers felt that the health professionals did not adequately recognise their unique knowledge of the care receiver and did not use this knowledge for customising the welfare technology to the care receiver and their families. Fifth, the family caregivers expressed concern about service and welfare technology inequality in home care services.

Conclusions: Co-production in the involvement of family caregivers in care is still not an integral part of home care service. Welfare technology was appreciated, but the family caregivers called for early involvement to ensure

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successful and safe implementation and use. More attention needs to be given to ethical concerns about the change in relations, transfer of tasks and responsibility, and risk of inequality.

Keywords: Caregiver, Elderly, Ethics, Home care, Involvement, Qualitative research, Technology

Introduction

During the past two decades, healthcare services have changed due to increasingly ageing populations, a shortage of health professionals and a transfer of specialised healthcare services to primary care [1–3]. The rationing potential of older people living longer in their homes receiving home care services is emphasised in health policy documents [4, 5]. To support services for older people, the importance of using welfare technology is underlined. Furthermore, health policy calls for family caregivers to co-produce care [2, 4, 6].

With the transformation of health care, home care is changing the service for older care receivers through increased use of welfare technology. More knowledge is needed about family caregivers' experiences as co-producers of care using these technologies and their collaboration with the services. Investigation of ethical aspects of this complex interaction and co-production is underexplored and requires attention if the quality of care is to be ensured.

Background

Older people living at home are often frail and need support from their family [2]. A central challenge in home care services seems to be that welfare technology is often introduced without involving the care receivers and their families in the process [7, 8]. Increased expectations of co-production of care and the use of welfare technology raise ethical concerns about how to balance responsibility and proper care, maintain trust and mutual respect for individuals' autonomy, and secure equal access to welfare services.

The role of family members

In Norway and the rest of Europe, there has been increasing awareness in health policy of family members' vital contribution to the care of frail older people living at home [2, 4, 9]. Data from Europe show that 5.4% of women and 2.2% of men aged 18-64 have reduced their working hours or taken breaks from work of more than a month to take care of ill and older family members with disabilities [10].

Many family members wish to be involved in decision making and care planning in a collaborative practice with health professionals [11]. They can bring invaluable knowledge about the care receivers' values, resources and needs [12, 13]. Their knowledge of the care receivers can improve home care services if used wisely [14, 15]. The ethics of care theory underlines family caregivers' ability to recognise and respond to care receivers' well-being and needs [16, 17]. However, numerous studies stress that the feeling of duty and responsibility for practical and psychological support can be challenging [14, 15, 18]. Family caregivers often perceive their role as lonely, exhausting and burdensome [18]. Challenges related to the power asymmetry between health professionals, family caregivers and care receivers, in terms of communicative strategies, have been identified [18, 19].

User involvement and co-production

The trend towards more user involvement is expected to result in a demand for increased co-production. Co-production is receiving broad attention worldwide in healthcare. It can be seen as a step towards increased democratisation and the right to improve healthcare services [6, 20, 21].

The Co-production Network for Wales describes the term co-production as: 'an asset-based approach to public services that enables people providing and people receiving services to share power and responsibility and work together in equal, reciprocal and caring relationships' [22].

The public sector has embraced this involvement approach because of its potential to improve service quality and user satisfaction and reduce costs [6, 23]. Co-production occurs when people individually or collectively engage actively in delivering and designing the services they or their family members receive. Valuing knowledge from all parties involved while acknowledging each persons' strengths are core principles in co-production and are inspired by common ethical values and principles [24, 25]. The emphasis is on peoples' lives, not on the systems [22]. A positive attitude towards co-production and trust between family caregivers and health professionals are considered requirements for co-production of care [16, 26, 27]. However, there are ongoing debates about its definition and impact [28].

Public home care services and implementation of welfare technology

There are differences in the availability and practical organisation of home care services for older people in Europe [29, 30]. In Norway, municipalities provide primary health and social care, including home care services. The home care service is organised by geographical areas and is an integral part of the healthcare service [31]. Taxes primarily finance the services, which are free of charge. All inhabitants of Norway have a legal right to receive healthcare regardless of age, gender and socio-economic status [32]. Equal access to health services is an essential ethical principle [33]. The Norwegian healthcare model is based on solidarity, focuses on universal civil rights, and is part of the Scandinavian or Nordic welfare model. However, the ageing population, immigration, globalisation and limited resources challenge the model [9]. Despite the basic premise of equal access to services, we see in Norway and Europe that access to and use of healthcare services vary among population groups and are related to income and education level [34–36].

We have chosen the Scandinavian umbrella term 'welfare technology' to describe and name technological solutions used to support older people living at home [37]. Welfare technology can also function as a support for family caregivers [38]. One of the most used definition of welfare technology in Norway is:

> *'Welfare technology is primarily technological assistance that improves the safety, security, social participation, mobility and physical and cultural activity, and strengthens the ability of individuals to fend for themselves in everyday life despite illness and social, mental or physical disability. Welfare technology can also act as support to their families and otherwise help to improve availability, resource utilisation and quality of service provision. Welfare technological solutions in many cases can prevent the need for services or institutionalisation' ([39], p 99). Translation by Hole [40].*

Kamp et al. [37] point out that the term is broad and loosely defined, covering a wide array of technologies. In international literature on healthcare technology, terms like assistive technology, telecare, telehealth and e-health are used, but the dividing lines between them seem to be blurred [41, 42]. To increase quality, save time and cut costs, welfare technology is expected to be an integral part of primary healthcare in Norway [43]. However, welfare technology affects the lives of care receivers and family caregivers and therefore involves empirical, practical, and ethical issues related to the introduction of welfare technology.

Many frail older people want to live at home for as long as possible, supported by home care services and family caregivers. Welfare technology can help to make this possible [8, 44]. Welfare technology solutions are being implemented to improve safety and care quality for care receivers and family caregivers [2, 37]. They may reduce the stress and strain experienced by some family caregivers [38]. However, family caregivers' views and experiences of welfare technology and their involvement in implementation and daily use have been poorly documented [45].

Ethical aspects of family caregivers' involvement and welfare technology

Involvement and the increased use of welfare technology include ethical aspects for care receivers and their families [46, 47]. Some ethical implications of welfare technologies have been examined and discussed, such as implications for privacy, freedom and autonomy of care receivers [46, 48, 49]. However, little consideration has been given to the implications for the involvement of family caregivers when the use of welfare technology is increased.

To understand family caregivers' experience and the values at stake, we examine the importance of personal relationships and responsibility inspired by the ethics of care theory [16, 17]. The values of responsibility, concern and attachment forming care are based on personal relationships. Personal attitudes, such as respect for the other and the desire to provide care, are central [16]. Still, family members can also perceive care as an obligation and an added burden in their daily lives [16]. Hence, the feeling of obligation and added responsibility can challenge the family caregivers sense of autonomy and feeling of agency. According to Beauchamp and Childress [33], we ought to have the freedom to plan and live our lives according to our desires, beliefs and preferences. However, as Tronto [17] points out, people are not fully autonomous since we are interdependent, social beings relying on others for advice and support. There can be a tension between respecting a persons' autonomy and the principle of benevolence and care for the vulnerable other. This dilemma might not only be apparent in the care for the frail family member but might also characterise the relationship between the family carers and the health professionals as well.

Another essential aspect of relationships between people is trust. Trust is based on the understanding that another person or persons will have honourable intentions with their actions. For there to be trust between people, such understanding must be mutual. Care is both a value and a practice and must be based on mutual concern, respect and trust [17].

Methods

Aim

The aim of this qualitative study was to explore family caregivers' experience of involvement and possible ethical aspects of caring for frail older family members receiving home care services supported by welfare technology.

Research design and philosophical approach

This study used a qualitative explorative and descriptive design. A qualitative design entails gathering data related to the participants' perceptions and reflections [50]. The study was based on individual interviews of family caregivers, which were recorded and transcribed, thus producing texts that we could interpret [51, 52]. We were particularly interested in family caregivers' experiences of changes in relationships, roles, responsibilities and tasks and ethical aspects of their involvement in caring for their older family member using welfare technology.

A phenomenological-hermeneutical approach was chosen to capture and understand the richness, complexity and individuality of the participants' experiences [50, 51]. We focused on the family caregivers' experiences in real-life circumstances regarding actions, attitudes and relationships. We were inspired by van Manen's phenomenology when exploring and attempting to understand the essential meaning of the phenomena when the family caregivers' expressed their lived experiences and ethically difficult situations in home care [53]. However, the research method is also hermeneutical since it is based on text interpretation [54]. Our pre-understanding of the parts of the text emerged and led to new understandings in a circular process.

Research context

Family caregivers in six municipalities in south-eastern Norway participated in the study. It included both urban and rural areas. The municipality with the smallest population has approximately 1800 inhabitants and covers $500\,\text{km}^2$, while the largest has about 86,000 inhabitants and covers $410\,\text{km}^2$ [55].

The municipalities were obliged by the national authorities to implement welfare technology in their daily home care services but were at different stages. Digital door locks, digital medicine dispensers, patient alarms (both analogue and digital) with and without an integrated global positioning system (GPS), watches with GPS, stove guard, window and door sensors and digital calendars and planners supported the frail older family members received care in this study.

Recruitment

The management of the home care service had knowledge of the family caregivers who were actively involved in caring for their family members where different types of welfare technology were used. The management contacted, informed, and recruited potential participants by combining their knowledge of the family caregivers with the inclusion criteria and our request for both genders to be represented, different ages and relation to the caregiver. The management did not state how many family members were asked and if any refused to participate; they only informed about the number of participants that accepted the invitation. The management collected signed informed consent forms and passed them to the first author before the interviews. When the management invited potential participants, they told the family members that the study focused on their experiences of user involvement and the care receivers use of welfare technology. A definition of welfare technology was included in the consent form: 'With welfare technology, we think of technical solutions that are adapted to users' needs, for example, safety alarms, door and windows sensors, GPS trackers, digital door locks and various types of robots such as medication dispensers.' The family caregivers also received an information letter about the study to give to the care receiver and asked for their oral consent before the interviews. The caregivers were asked to withdraw if the care receiver did not want them to participate in the study. The first author contacted the participants by phone to schedule the interviews.

To be included in the study as a family caregiver, a person had to be mentioned as the closest family member in the care receivers' electronic medical record. In addition, the caregivers' family members who received home care services had to have used welfare technology for at least six months and be over 65 years old. Eighteen family caregivers participated: eight men and ten women aged 54 to 77 years (average 64). The participants consisted of two spouses, six sons, nine daughters and one sibling.

Interviews

The authors developed a qualitative semi-structured interview guide (Table 1). An essential prerequisite for the successful introduction and use of welfare technology is mutual respect and collaboration with care receivers and their families. To gain a deeper understanding of the family caregivers real-life experiences, some questions focused especially on involvement, relations, information, and knowledge exchange with the health professionals since this may indirectly impact the use of welfare technology.

Sixteen individual interviews were planned and arranged. However, two extra siblings asked to participate in two of the interviews. For that reason, eighteen family caregivers participated in the study. The first author conducted all the interviews. She met the participants for the first time and were the only person present besides the participants in the interviews. The first author is a registered nurse and doctoral student and has previous experience in individual interviews and qualitative methods.

Table 1 Questions in the interview guide for family caregivers

	Questions
1	Could you tell me how your mother/father/sister/brother/husband/wife got the welfare technology? - Could you describe your involvement in the process?
2	Could you describe how your mother/father /sister/brother/husband/wife uses the welfare technology and whether you give him/her assistance in any way?
3	Could you describe how you find health professionals' interest in your experiences and wishes for your mother/father/sister/brother/husband/wife?
4	Could you describe your experience of information exchange with the home care services?
5	Could you describe your experience of cooperating with home care services?
6	Could you describe how you feel about giving care and whether it has affected your relationship with the care receiver?
7	Do you have any concerns about your family member using welfare technology? -If so, could you describe them?
8	What are your thoughts on how your involvement in the care could be improved?
9	Can you describe what you think could improve the quality of home care services in general?

A semi-structured interview guide was used (Table 1). Notes were taken for the analysis both during and after the interviews, as Brinkmann and Kvale (2015) recommend. During all the interviews, attention was paid to the participants' experiences and how these were expressed. Information that emerged during the interviews was regularly summed up to validate or clarify the participants' meaning. After 16 interviews, the first author stopped collecting data since the authors agreed that satisfactory saturation had been achieved.

The family members chose the time and place of the interviews. Nine interviews were conducted by telephone. Seven were conducted face-to-face, two in private homes, and the remaining five in quiet public places. The interviews lasted 20-62 min (average 35 min). They were recorded digitally and transcribed verbatim but de-identified. The first author transcribed five of the interviews and a professional transcriber eleven.

Data analysis

Thematic analysis inspired by Braun, Clarke, Hayfield, and Terry [52] was employed to analyse themes and patterns in the dataset, as shown in Table 2.

The analyses were manually carried out. All the authors were involved in all parts of the analysis. Table 3 svisualise how three different quotes were condensed to the same main theme.

The results were presented and discussed in an external advisory group for the PhD project of which this study is a part. One caregiver and one care receiver in this group were recruited from two pensioners associations. One caregiver was recruited from a group of patients and next of kin via the National Association for Public Health. Reflections that emerged during meetings in the advisory group did not produce any immediate changes to the analysis but rather confirmed the analytical reflections.

Table 2 The six phases of thematic analysis [52]

Phase	Description of the process
1 Familiarisation	We read and re-read the dataset and took notes through a curious approach to what was interesting in the data and to notice possibilities, connections, and quirks, which may add depth and nuance to our later coding.
2 Generating codes	Essential characteristics of the data that might be relevant to answering the aim of the study were identified. We organised data around similar meanings. By generating codes, we got a sense of the participants' experiences of involvement, welfare technology and ethical aspects.
3 Searching and construction themes	We examined the codes systematically and identified patterns of meaning, developing potential themes from the analytical work and 'tested it out' concerning the aim.
4 Reviewing themes	All the themes were discussed and revised to avoid overlaps and to understand how each of the themes was related to each other. They were checked across the whole data set to determine if they reflected the data and the aim.
5 Defining and naming themes	We explored how well the themes worked together and separately and finished by defining and naming the final themes.
6 Producing the report	The last step was the selection of examples, preparing and writing this article.

Table 3 Example of the coding- and analyse process

Main theme	Preliminary themes	Examples of codes	Examples of quotes
Recognising complementary forms of knowledge.	Recognise the family caregivers' knowledge and information needs of welfare technology. Recognise family caregivers' knowledge of the caregivers. Access to health personnels' knowledge of welfare technology.	Not know what to ask about. Know the challenges in everyday life. Need information and knowledge of welfare technology.	*We do not know what we can ask about…and maybe the missing link is. Because we can see how complicated things are in everyday life… we do not know if there is any technology that can help our mother* [7]
		Have in-depth knowledge about the care receiver. Health professionals do not have time to get to know the care receiver.	*No one knows our mother well except us then. No one from the home care service has been with her for so long that they know her* [2].
		Health professionals know what kind of welfare technology is available. Welfare technology as support to administering of medication.	*The nurse in home care service asked if we would try a medicine dispenser because my wife uses many pills, and I have to make sure she gets it* [10].

The Consolidated Criteria for Reporting Qualitative research (COREQ) checklist for reporting qualitative studies was used (Additional file 1).

Ethical considerations

The principles for medical research stated in the Declaration of Helsinki [56] were followed. All participants received verbal and written information about the study and signed an informed consent form before the interviews. Information was provided about the possibility to withdraw from the study before the data were analysed. Confidentiality and anonymity were assured and safeguarded. Guidelines for storing research material were followed. Participation was voluntary, and no financial compensation was given. The study was registered with the Norwegian Centre for Research Data (NSD), reference number 473910. The Norwegian Regional Committee for Medical and Health Research Ethics, South-Eastern Norway (REK south-east), considered the study. They waived the ethical approval, reference number 2018/2462, in view of the procedures during the data collection and the nature of the study.

Results

Eighteen adult family caregivers with close and long-term relations with their frail older family members participated. The participants had varied backgrounds regarding their health, social and economic status. The family caregivers had different needs, knowledge and experiences of involvement and welfare technology. The two spouses lived with their wives and were retired from work. Most of the daughters, sons and the sister lived with their own families, and several worked full-time.

Five main themes were identified in the analysis. First, the family caregivers' experience of caring as meaningful but demanding. Support and discussion with the health professions were expressed as important for caregiving. Second is the experience of changing roles, tasks, and responsibilities to follow up the care receivers and how the welfare technology worked. Third, the family caregivers' experience of health professionals decided the conditions for collaboration without dialogue. The health professionals did not explore whether the family caregiver had sufficient information and knowledge to follow up on the care receivers' use of technology. Fourth, the need to recognise complementary forms of knowledge. The family caregivers pointed out that they ought to be involved early to adapt the technology to care receivers. Fifth and finally, the family caregivers' concern about inequality related to their knowledge and the care receivers' finances concerning the access to services and welfare technology.

In this section, we have added the interview number of the participants in parentheses at the end of the quotation.

Caring is perceived as meaningful but also demanding

The family caregivers' close relationship and emotional attachment to the care receiver contributed to their wish to give care and perceive it as meaningful. Several family members spent most of their spare time assisting the care receiver. Family carers responded very positively to situations where health professionals discussed their perception of the conditions for care and offered increased services and welfare technology in times of need. Although this happened rarely, it provided the family caregivers with a sense of safety and renewed energy for continuing the care.

> *'I am very concerned about whether I can manage to handle my wife at home. ...... we were invited to a meeting where they said they could offer her a place at the day centre three days a week. Getting that offer before I even started to ask for it was a nice gesture' [1].*

Nevertheless, most participants found caregiving to be demanding and exhausting. These feelings were particularly strong among those who did not lived with the care receiver and worked full-time. When the family caregivers could not spend sufficient time with their older family members to care for them properly, various emotions such as pain and guilt transpired. The participants expressed frustration and tension building up when health professionals did not understand the constraints they were working under. This often resulted in feelings of anger, sadness and helplessness. Several family caregivers said that most health professionals did not seem to care about those feelings and showed no particular interest or empathy with their situation.

> *'When we are not there enough, it feels like we are not caring for our mother properly. It hurts to feel like that. My mother thinks she does not need any help from home care services because she has six children. She relies on us. Now it is our turn' [9].*

Changed roles, tasks and responsibilities

The family caregivers felt a high degree of responsibility for the well-being and safety of their parents, siblings or spouses. They also said that using welfare technology freed up time and supported them in creating a safe environment and dealing with the anxiety of not being available 24 h a day.

> *'It was a relief when mother got that medication dispenser and that she has the safety alarm. It's crucial to relax a little and know that mother ... that someone will come and help her if we're not close by. It's crucial that we feel safe then'* [10].

Most of the family caregivers wanted to be involved in the care and the care receivers' use of welfare technology. The results indicated only a few established routines and wide variations in how the home care services informed caregivers and followed up general needs and special needs connected to welfare technology. There were no regular collaboration meetings, although these were requested by many participants. Family caregivers usually took the initiative to contact home care services to discuss the care receivers' situation, the need for care and how welfare technology could support them and the care receivers.

> *'I would like to get involved. I always try to make it possible for my mother to have a good life in her flat for as long as possible. So, I want to get as much information as I can'* [10].

The family caregivers respected the family members' desire for autonomy and to live relatively independently in their own homes for as long as possible. However, the participants had to assess and respond to signs of frailty such as cognitive decline. They stressed the importance of having a close dialogue with health professionals about changes in the health status of care receivers requiring adjustments to the use of welfare technology. There were examples of care receivers who no longer remembered that they had a particular technology or had forgotten how to handle it properly. Hence, new safety concerns arose and had to be addressed regularly.

> *'She has a safety alarm but does not know how to use it. She does not understand... she no longer thinks about the fact that she might need help'* [9].

The participants expressed concern about the rationalisation of home care services, such as fewer visits due to increased allocation and implementation of welfare technology for the older care receivers. One example was a care receiver who only received help in administering medication. When the care receiver got a medication dispenser, the number of visits from health professionals was reduced from daily visits to only once every fortnight. In these situations, the family caregivers felt more responsibility was added to their normal duties regarding follow-up and reporting back on the patients' needs, health changes and potential health issues.

Health professionals decided the conditions for collaboration

In several situations, the participants found that health professionals decided the conditions for their collaboration and took their contribution and efforts for granted. They, therefore, felt that the power relationship was asymmetrical.

> *'I had to take time off from work because I had to come at a time that suited the health professionals. It was completely wrong for me. I have already spent so much time there to assist the home care service'* [11].

Several family caregivers expressed frustration that changes in home care services primarily seemed to transfer tasks and responsibilities from health professionals to them. They felt they did not receive the necessary information and had no dialogue and discussion before tasks and responsibilities were transferred. As the quote below shows, one family caregiver was not even consulted by the health professional before she was responsible for explaining and repeating information to her mother about the use of welfare technology.

> *'They just said to her that it would be a lot of information, but I would explain to her after they had left'* [2].

Recognising complementary forms of knowledge

The long-term personal relationship between family carers and care receivers gave a unique insight into the care receivers' specific values, needs and demands. This knowledge could be essential for the wise implementation of welfare technology in a particular context. Several participants felt that the health professionals showed little respect for this kind of knowledge and did not ask for it.

> *'No one knows our mother well, except us then. No one from the home care service has been with her for so long that they know her'* [2].

The availability of a named contact person in the home care service, whom one could easily reach and communicate with, was considered highly important for co-production. One participant emphasised that it was much easier to find suitable technological solutions quickly and meet the care receivers' needs if the health personnel knew the caregivers and care receiver.

Several participants found it frustrating not knowing what welfare technologies were available on the market, what they could apply for, and the procurement process.

> *'We do not know what we can ask about...and that's maybe where the missing link is. Because we can see how problematic things are in everyday life ... we do not know if there is any technology that can help our mother'* [7].

The participants emphasised the importance of receiving information and becoming more actively involved early in the process concerning proper allocation and implementation of welfare technology to ensure that it met the care receivers' needs. Home care services implementing welfare technology without dialogue with care receivers and family caregivers about material circumstances and daily practices and routines could decrease the likelihood of appropriate use and raise safety concerns.

> *'The medication dispenser was initially put in my mother's living room by the healthcare professionals. But she needs to reach the medication while she is still in bed'* [11].

An important factor for mutual understanding and cooperation is trust. When information from home care services about welfare technologies or services was considered unclear, inconsistent or unreliable, it created frustration and distrust among family caregivers. One example was two daughters who had received different information from separate health professionals about the services available. This made it impossible to navigate appropriately between the information and arguments provided to reach reasonable and well-informed decisions.

Concerns about inequality

Several participants reflected on the close relationship between the level of services received, the number of follow-up visits from home care service, the availability of welfare technology and well-educated family members with insights or interests in welfare technology advocating for the care receiver.

> *'I am an engineer by education, so I am all for implementing welfare technology. I read up on everything about it. I always like to ask, and I think that is the reason why we got the technology'* [1].

The participants mentioned that in some situations the home care services did not offer the requested technology. Instead, the health professionals recommended the care receiver or the family caregiver to buy or rent it themselves. However, this was not possible for all families; the cost of buying or renting technology devices was a matter of concern. Since home care services are financed through taxes in Norway, some participants felt that such additional costs placed an unfair burden on them or the care receivers.

Discussion

The family members' experience of involvement and welfare technology was influenced by various factors such as knowledge, background, living conditions, and the health status of those involved. Involvement as co-production implies practical and moral acts, where people must relate to each other and work together in equal, reciprocal and caring relationships. The consequences and ethical aspects of the changes in home care service and what is considered essential for family caregivers in this context will be discussed.

Caring as meaningful but also demanding

The ethics of care theory assumes that we are relational, dependent and vulnerable beings, relying on each other for care and support. Familial, social and historical contexts are essential in care [16, 17]. This can partly explain why long-term relationships and emotional ties play a crucial role in family members' wishes and sense of responsibility to care for parents, siblings and spouses. The close relationship provides an experience of caring as valuable to the family caregiver, as emphasised by Held [57]. Family caregivers are, in principle, autonomous and free to live their lives according to their desires, beliefs and preferences [33]. However, they are dependent on and shaped by their relationships with and expectations of care receivers, which affect the feeling of autonomy. Held [57] supports the notion that family caregivers can never be fully autonomous but understand themselves as acting in relation to care receivers and health policy requirements.

An integral part of health professionals' work is the ethical focus on doing right for care receivers and family caregivers [33]. However, it may be questioned whether family caregivers perceive the attitudes and practices of health professionals as the best practice.

for the family caregiver. There is no doubt that the participants in the present study found that their care burden could be overwhelming when tasks and responsibilities were transferred from health professionals without considering their strengths, weaknesses and life situations. Ethical concerns are raised when responsibility and tasks are transferred to family members without considering their ability to take responsibility and risk potential adverse health consequences. Previous studies have shown an increased risk of depression, anxiety and sleep disorders due to excessive strain on family caregivers [58, 59]. Although the participants in this study did not report such health problems, several reported high levels of stress and exhaustion.

In general, the family caregivers appreciated welfare technology since it contributed to security and independence for the care receivers and themselves. For that reason, it reduced some of the care burdens, which other studies also support [38, 60]. Nevertheless, welfare technology was also experienced demanding since health professionals expected family caregivers to follow up information and the care receivers use. This shows some of the double-sidedness of using welfare technology. It both eases and add to the burdens of the family caregivers.

Even though providing good care is essential for many family caregivers, they pointed out the importance of balancing responsibility for the care receiver with taking care of themselves. Self-care is now more important with the expectation of increased involvement and responsibility. Plöthner [61] recommends focusing on early identification of caregivers' needs and preferences and close follow-up from health professionals to reduce the care burden and enable caregivers to bear the responsibility over time.

Changed roles, tasks and responsibilities

As supported by other studies, welfare technology can decrease family caregivers' burden and make it easier to deal with the responsibility, especially in terms of safety and freedom [62, 63]. However, family caregivers' close attention and ability to follow up on any problems is essential to identify how well the welfare technology works for the care receiver and make changes if needed. It is also essential to identify changes in cognitive functioning and assess whether the care receiver can no longer handle the technology, as pointed out in our study and other studies [64, 65]. The family caregivers found it demanding to make such assessments independently, with limited support from health professionals. This again highlights the urgency of developing a sustainable co-production approach.

When health professionals expect family caregivers to act on information, this means an extra task and responsibility, which may be felt like a forced order and limit family caregivers' autonomy. There is also an increased risk of misunderstandings and misinformation if the information must go through several channels before reaching the care receiver. Studies of health professionals have shown that lack of competence could lead to incorrect use of welfare technology [66] and uncertainty and resistance [67]. This could clearly also apply to many family caregivers. Therefore, health professionals should be very careful about the types of information and responsibility to be transferred to family caregivers, especially if the results could have adverse consequences for the care receiver.

While some family caregivers would have been happy to take on more responsibilities and perform additional tasks and roles, this was not true of all of them. An important fact that all parties must take seriously is that some family caregivers are frail themselves and do not have the capacity to perform the expected tasks, especially not when the tasks and responsibilities increase. Younger family caregivers might also have particular needs and wishes that have to be addressed. Many have full-time work besides caring for young children. They may not be able to be involved as much as health professionals or the care receiver request. If there is no proper exchange of information and clarification of the nature and scope of caregivers' involvement, this can create serious tensions between the parties.

If family caregivers' needs and capacity to be involved are ignored, and tasks and responsibilities are just transferred without dialogue about individual family caregivers' health and life situation, the caregivers might find the care burden excessive and withdraw from the caregiving role. In line with Plöthner et al. [61] and Tønnessen et al. [14], we recommend regularly discussing tasks and experiences to ensure that family members have the necessary skills and knowledge about welfare technology and time and energy to provide care.

Health professionals decided the conditions for collaboration

Health professionals' attitudes and willingness to share power and responsibility with family caregivers and give them a voice are among the most important factors for successful co-production [26]. When health professionals stipulate conditions for collaboration with family caregivers, this indicates an unequal and non-mutual relationship. The participants seemed to agree that involvement should take place through partnership, and develop and mature through mutual dialogue and negotiation of power between health professionals and family caregivers, as suggested by Gheduzzi et al. [68]. This way of working and thinking enhances care receivers' satisfaction and quality of health [28].

Since older care receivers depend on help from others, they transfer power and trust to family caregivers or health professionals to provide satisfactory care. Trust is a mutual understanding of intentions and expectations [16]. It is an example of a value inherent in an ethics of care since good caring relationships depend on it. Trust is also essential for optimal use of welfare technology and co-production of care. Health professionals show their values, attitudes and desires to involve family caregivers through their actions. Our study shows that several family caregivers felt vulnerable and relied on support, information, acknowledgement and close follow-up from health professionals to cope with the challenges of caregiving. However, they felt health professionals did not show them respect and recognised their unique knowledge or efforts. In several situations, the participants felt their responsibility for the care receivers use of welfare technology was taken for granted by the health professionals.

The participants provided examples of situations where they did not feel adequately acknowledged and respected as caregivers. Unfortunately, the combination of low trust and lack of mutual respect between the parties might lead to low satisfaction with the healthcare service, thus threatening the continuity of care and co-production. In line with Gheduzzi et al. [68], we recommend that health professionals change their attitude and work towards co-production in care.

Recognising complementary forms of knowledge

One of the main purposes of co-production is to recognise the value of multiple kinds of knowledge and use this to improve the organisation of health care services and provide optimal care to care receivers [26]. Family caregivers know the care receivers far better than health professionals, at least in terms of their preferences, values and goals. However, health professionals hold invaluable medical knowledge developed through training, education and clinical practice. Ris et al. [11] suggested that recognising the complementary forms of knowledge and expertise between family caregivers and health professionals is essential for family caregivers' involvement. It is also vital to use family caregivers' knowledge to select welfare technology and adapt it to the individual users' needs and coping capacity. Respect for the family caregivers' knowledge requires recognising different knowledge and avoiding paternalistic domination from the health professionals, as the ethics of care highlight [57]. Health professionals need to listen with interest to family caregivers, recognise them as partners in care, and show respect for their knowledge. Insight into each other's specific competencies is required [69, 70]. Further, co-production also requires sufficient time to cooperate and insight into the philosophy and methodology of co-production [20]. The importance of working within a co-production framework was addressed indirectly by the participants when they reflected on the benefits and challenges of implementing welfare technology. The participants agreed that welfare technology must be tailored to the individual user to be used as intended [64, 71]. Much will be gained if family caregivers, who know the needs and interests of the care receiver, are invited into a dialogue with health professionals about identifying and allocating suitable technology. This is particularly important if the care receiver is technologically illiterate or suffering from cognitive decline. If the health professional is open and responsive to the unique insights and contributions of the family caregivers, the utilisation of welfare technology and quality of care is likely to improve.

Inequality in care

Equality as a moral principle enshrined in human rights [72] and is an essential tenet of the modern welfare state. The Norwegian Patient Rights Act states that all patients have an equal right to health care [32]. The fact that some family caregivers found a close association between their knowledge and engagement with the home care received and the availability of welfare technology suggests vulnerability and inequality. It is legally and ethically problematic if access to welfare technology and various services depends on the care receivers' financial situation and on family caregivers' knowledge or ability to stand up for the care receiver. There is a risk that the most vulnerable people and those without a family will receive lower service quality.

A review by Scott Kruse et al. [73] identified cost as one of the main barriers to adopting welfare technology. If some people cannot afford to buy or rent the equipment, there is a risk of inequality. It also makes it less likely that the technology will be used by many families to maximum benefit. Fewer users of the technology may threaten the policy initiatives to meet challenges in home care with increased use of welfare technology [37].

Limitations and methodological concerns

With 18 participants, the results provide a limited picture of family caregivers' experiences of involvement, welfare technology and possible ethical aspects. Further, our participants may have had a higher socio-economic status than average since they agreed to participate in the study. For these reasons, the results cannot be generalised.

Moreover, we are aware that results of interviews can differ according to whether they are conducted in peoples' homes or public places, and with or without other people nearby [51]. The two interviews where two siblings asked to be present affected the interview situation and challenged our plan of using only individual interviews. However, with their presence, the data in those two interviews were more nuanced.

Further, individual face-to-face interviews often become more personal and deeper than telephone interviews [51]. Additionally, telephone interviews do not allow us to observe body language. The duration of the interviews and some of the participants' short answers may have resulted in less substantial content than desirable. Nevertheless, the qualitative data provided a rich picture of family caregivers' experiences.

Conclusions

The family caregivers felt that they had a moral responsibility to observe and respond to care receivers' needs and use of welfare technology. The feeling of obligation to provide care to family members and health professionals' expectation of increased involvement challenged the family caregivers' autonomy. However, welfare technology supported the participants in creating a safe environment and freeing up time. Still, welfare technology also made new tasks and responsibilities for information and followed up of the care receiver.

Equal and fair access to healthcare service is a democratic ideal, which means equal access to services and welfare technology for all people. It seems essential that the transfer of tasks, roles and responsibilities is clarified and adapted to family caregivers' capacity and opportunity for co-production in care for their older family members. Health professionals' must give attention to family caregivers' living situations and provide adequate support to reduce the care burden and enable them to bear the responsibility of care over time. Reliable information and trust are vital for family caregivers to co-produce care in a close relationship with home care services. Sharing power and responsibility and respecting mutual knowledge must be paramount when the goal is to improve the quality of home care service. However, the family caregivers experienced that home care services were not prepared for their involvement as active and equal partners in co-production when implementing and using welfare technology.

Abbreviations

COREQ checklist: The Consolidated Criteria for Reporting Qualitative research checklist; PhD project: Doctoral project; NSD: The Norwegian Centre for Research Data; REK: The Norwegian Regional Committees for Medical and Health Research; GPS: Global positioning system.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12877-022-02890-2.

Additional file 1. COREQ (Consolidated Criteria for Reporting Qualitative Studies) checklist.

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Authors' contributions

HSG had the main responsibility for all parts of the study in close cooperation with the last author. IRK, MF, and KH designed the project together with the first author. HSG collected the data. HSG, IRK, MF, KC and KH analysed the data and developed the manuscript. HSG, IRK, MF, KC and KH read and approved the final manuscript.

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Availability of data and materials

Data can be available from the corresponding author for an appropriate purpose within the study framework. The data is in Norwegian. Permission from NSD and the participants have only been granted to use data for this current study.

Declarations

Ethics approval and consent to participate

The study was registered with the Norwegian Centre for Research Data (NSD), reference number 473910. The Norwegian Regional Committee for Medical and Health Research Ethics, South-Eastern Norway (REK south-east), considered the study. They waived the ethical approval, reference number 2018/2462, in view of the procedures during the data collection and the nature of the study. The principles for medical research stated in the Declaration of Helsinki [54] were followed. Participation was voluntary, and all participants received oral and written information about the study and signed an informed consent form before the interviews. Information was provided about the possibility of withdrawing from the study before the data were analysed. Confidentiality, the anonymity of the participants and storage of research material were ensured and safeguarded.

Consent for publication

Not applicable.

Competing interests

The authors of the current study declare that they have no competing interests.

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