# Implementing welfare technology in palliative home care

## A study exploring the experiences of patients with cancer and health care professionals

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# ABSTRACT

**Background:** The number of people living longer with cancer is growing globally, and the demand for palliative care is concurrently increasing. The increasing shortage of health care professionals (HCPs) challenges the health care system. To meet these challenges, there is a need for innovation. In Norway, current health policies aim to facilitate patients in palliative care receiving care and staying in their homes for as long as possible. Welfare technology and remote patient monitoring are highlighted as some of the measures to enable patients to spend time at home by remotely supporting their individual palliative care needs, such as symptoms and illness deterioration. Such care necessitates a person-centered approach. Despite increasing evidence of benefits with technological interventions in palliative home care, the uptake has been slow, which reveals a knowledge gap in leveraging technology for improved patient outcomes in palliative care. The overall aim of the study was to elicit the experience with and viability of a welfare technology service called "remote home care" (RHC) in palliative home care for patients with cancer.

**Methods:** A descriptive-explorative, qualitative research design was employed. Data were generated from two focus groups (N = 8), individual interviews (n = 6) with interdisciplinary HCPs (Paper I), and repeated individual interviews with patients diagnosed with cancer in the palliative phase living at home (N = 11) (Paper II). All participants were experienced RHC users. Data for Paper I and II were analyzed using qualitative content analyses. Paper III was based on a secondary analysis of the data material collected for Papers I and II using the "Reach, Effectiveness, Adoption, Implementation, and Maintenance Framework" (RE-AIM). Data were analyzed using deductive reflexive thematic analysis.

**Results**: RHC provided enhanced routines, control, and safety in patients' daily lives which strengthened their ability to manage their illness at home. Personal relationships and close connections with HCPs were considered fundamental for illness management. Over time, patients felt responsible for informing HCPs about symptom development. Although patients found safety in RHC, HCPs felt anxious and nervous about receiving reports from patients, particularly because they lacked experience and training in palliative care and cancer care. Contrasting results in patients and HCPs regarding RHC utility identified a communication gap between HCPs and patients regarding RHC scope and follow-up. RHC was not suitable for addressing the patient's spiritual and existential needs, which is in striking contrast to person-centered, palliative care. In addition, the introduction of RHC may have increased patients' perception of a fragmented health care system, indicating the lack of a necessary digital infrastructure to support palliative RHC. Perceived vulnerability in patients among HCPs led to gatekeeping in recruitment, which may have excluded eligible patients from receiving RHC.

**Conclusions:** RHC comes with the potential to support patients' symptom control and improve routines at home, which may support their self-image and facilitate self-determination and autonomy. Furthermore, RHC may function as a supportive tool, allowing patients to stay at home and maintain their social relationships. However, HCPs have an important role of helping patients uphold social relations and providing support to those patients identify as being closest to them. Person-centered care depends on a tailored approach where patients' changing needs must be considered when RHC care is planned and delivered. Thus, preservation of patient autonomy and self-determination is of outmost importance. The lack of viable systems for transferring patient information poses a risk of an unintended autonomy where patients bear the responsibility for conveying information crucial for further care. Consideration of the complexity of the RHC intervention is fundamental, particularly when implemented for individuals in vulnerable life situations, such as patients with cancer in the palliative phase. Applying the RE-AIM framework during the planning stages of implementation may ensure that HCPs and policymakers can more effectively understand how new technologies such as the RHC can be adapted from one context to another, promoting person-centered care and ensuring its viability within the concepts presented in the 6S model.

# ABSTRACT IN NORWEGIAN

**Bakgrunn:** Antallet personer som lever lenger med kreft øker globalt, og behovet for palliativ omsorg øker tilsvarende. Kombinert med stadig større mangel på kvalifisert helsepersonell, skaper dette betydelige utfordringer for helsetjenesten. For å imøtekomme disse utfordringene er det nødvendig med innovasjon. Norske helsepolitiske målsetninger understreker at pasienter i palliativ fase skal kunne motta omsorg og bo hjemme så lenge som mulig. Velferdsteknologi og digital hjemmeoppfølging fremheves som mulige løsninger som kan legge til rette for mer hjemmetid ved å ivareta pasientenes palliative behov på avstand, inkludert symptomovervåking og tidlig identifisering av forverring av helsetilstanden. For å tilby en palliativ omsorg der pasientens individuelle preferanser, behov og verdier ivaretas, bør en personsentrert tilnærming vektlegges. Til tross for økt dokumentasjon av fordelene med teknologiske intervensjoner i hjemmebasert palliativ omsorg, har implementeringen vært treg. Dette indikerer et kunnskapshull hva gjelder utnyttelsen av teknologi for å forbedre pasientresultater i palliativ omsorg. Den overordnede hensikten med studien er å innhente erfaringer og undersøke bærekraftighet av en velferdsteknologisk tjeneste kalt “remote home care” (RHC) i palliativ hjemmeomsorg til pasienter med kreft.

**Metode:** Et beskrivende, utforskende, kvalitativt forskningsdesign ble benyttet. Data ble samlet gjennom to fokusgrupper (N = 8) og individuelle intervjuer (n = 6) med tverrfaglig helsepersonell (Paper I), samt gjentatte individuelle intervjuer med pasienter diagnostisert med kreft i palliativ fase som bor hjemme (N = 11) (Paper II). Både helsepersonellet og pasientene hadde erfaring fra bruk av RHC. Data for Paper I og II ble analysert ved kvalitativ innholdsanalyse. Paper III er basert på en sekundær analyse av data samlet for Paper I og II. Her ble rammeverket «Reach, Effectiveness, Adoption, Implementation, and Maintenance» (RE-AIM) benyttet i en deduktiv refleksiv tematisk analyse.

**Resultater:** RHC førte til bedre rutiner, økt kontroll og opplevelse av trygghet hos pasientene, og styrket deres evne til å håndtere sykdommen hjemme. Personlige og tett kontakt med helsepersonellet ble fremhevet som avgjørende for sykdomshåndteringen. Ettersom tiden gikk opplevde pasientene et økt ansvar for å holde helsepersonellet informert om utviklingen av symptomer. Selv om pasientene opplevde trygghet, uttrykte helsepersonellet engstelse og usikkerhet, spesielt fordi de manglet erfaring og opplæring i kreft- og palliativ omsorg. RHC egnet seg ikke for å adressere pasientens åndelige og eksistensielle behov, noe som står i sterk kontrast til personsentrert, palliativ omsorg. Pasienter og helsepersonell hadde motstridende resultater hva gjaldt nytteverdien i RHC, noe som illustrerer manglende kommunikasjon med hensyn til hensikten og oppfølgingen av tjenesten. RHC kan ha øket pasienters opplevelse av fragmenterte helsetjenester noe som indikerer at den digitale infrastrukturen ikke fungerer tilfredsstillende. Helsepersonellets egne opplevelser av pasientenes sårbarhet førte til "gatekeeping" i rekrutteringen, noe som kan ha forhindret pasienter i å motta RHC.

**Konklusjon:** RHC har potensiale til å bedre symptomkontroll og pasienters rutiner hjemme, noe som kan styrke deres selvoppfatning og legge til rette for selvbestemmelse og autonomi. Videre kan RHC fungere som et støttende verktøy som muliggjør for pasienter å bo hjemme og opprettholde sosiale relasjoner. Samtidig har helsepersonell en viktig rolle i å hjelpe pasienter med å ivareta og støtte dem pasientene identifiserer som sine nærmeste. En skreddersydd tilpasning av RHC der pasientens skiftende behov tas i betraktning er avgjørende for å tilby en personsentrert omsorg. I tillegg må pasientens autonomi og selvbestemmelse vektlegges. Mangelfull digital infrastruktur for overføring av pasientinformasjon utgjør en risiko for en utilsiktet autonomi der pasientene får ansvaret for å formidle informasjon avgjørende for omsorgen som skal gis. Kompleksiteten i RHC-intervensjonen må vektlegges, spesielt når den implementeres for individer i sårbare livssituasjoner, som pasienter med kreft i palliativ fase. Ved å anvende RE-AIM-rammeverket under planleggingsstadiene av implementeringen kan helsepersonell og beslutningstakere mer effektivt forstå hvordan nye teknologier som RHC kan tilpasses fra én kontekst til en annen, og samtidig legge til rette for bærekraftig og personsentrert omsorg med utgangspunkt i konseptene presentert i 6S-modellen.

# LIST OF PAPERS

I. Oelschlägel, L., Dihle, A., Christensen, V. L., Heggdal, K., Moen, A., Österlind, J., & Steindal, S. A. (2021). Implementing welfare technology in palliative homecare for patients with cancer: a qualitative study of health-care professionals' experiences. *BMC Palliative Care*, *20*(1), 146. https://doi.org/10.1186/s12904-021-00844-w

II. Oelschlägel, L., Christensen, V. L., Moen, A., Heggdal, K., Osterlind, J., Dihle, A., & Steindal, S. A. (2023). Patients' experiences with a welfare technology application for remote home care: A longitudinal study. *Journal of Clinical Nursing*, *32*(17-18), 6545-6558. https://doi.org/10.1111/jocn.16592

III. Oelschlägel, L., Moen, A., Christensen, V. L., Heggdal, K., Österlind, J., & Steindal, S. A. Implementation of Remote Home Care – assessment guided by the RE-AIM framework.
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The papers will be referred to in the text by their Roman numerals I, II, and III.

# SIGNIFICANT TERMS AND DEFINITIONS

| | |
|---|---|
| **EAPC** | The European Association for Palliative Care |
| **HCPs** | Health care professionals<br>To preserve privacy and confidentiality in the presentation of results, the various health professions included in the study are not differentiated. Thus, the term HCPs refers to the multidisciplinary HCPs recruited for this study in the presentation of the Methods, Results, and Discussion of this thesis. |
| **RE-AIM framework** | An acronym for the Reach, Effectiveness, Adoption, Implementation, and Maintenance framework |
| **RHC** | Remote home care<br>The term remote home care was chosen after several attempts to place the intervention under study within one of the more common umbrella terms frequently appearing in the international literature covering remote patient monitoring, such as telecare or telemonitoring. However, after several assessments, a more direct translation of the Norwegian term “digital hjemmeoppfølging” (formerly “medisinsk avstandsoppfølging”) was chosen. The term “remote” elucidates that HCPs are situated in a different geographic location from that of the patient. The term “home care” refers to the service being available in the patient’s own home. |
| **Reflexive TA** | Reflexive thematic analysis |
| **Welfare technology** | Welfare technology can be broadly categorized into four categories: safety and security technology, compensation and well-being technology, technology for social contact and communication, and technology for treatment and care (Thygesen, 2019). This study and Papers I, II, and III focus on the last-mentioned category, technology for treatment and care. |

# 1 INTRODUCTION

Due to an aging population with increasing complexity and comorbidity, combined with a significant shortage of qualified health care professionals (HCPs), future health care services are facing significant challenges. Both nationally and internationally, there is a need for innovation in health care to meet these challenges in a sustainable manner and to ensure good health care services for all (The Norwegian Directorate of Health, 2021; World Health Organization, 2016, 2021). Furthermore, the global increase in cancer cases and improved survival has amplified the demand for palliative care (Etkind et al., 2017). Palliative care services are designed to maintain the quality of life of individuals living with severe, life-limiting illnesses, such as cancer, by alleviating physical, psychosocial, spiritual, and existential suffering (World Health Organization, 2020). Palliative care is to be delivered according to patients' personal preferences, necessitating a person-centered approach from the HCPs involved in their care (Radbruch et al., 2020). The majority of patients requiring palliative care prefer to stay in their homes as long as possible, with some opting to die at home; consequently, health policies aim to facilitate at-home long-term treatment including palliative care (Radbruch et al., 2020; Sandsdalen et al., 2015; Skorstengaard et al., 2017; World Health Organization, 2018).

Welfare technology, a term primarily used in Nordic countries, encompasses smart home monitoring technologies that allow for surveillance and interaction with individuals involved in care services to support care and potentially transform its provision (Rostad & Stokke, 2021; Star & Ruhleder, 1996). These technologies seek to enhance individuals' safety, functionality, and independence, as well as promote well-being while reducing the need for formal and informal care (Rostad & Stokke, 2021). The technologies can span a variety of technology types, structures, and processes, with telemedicine, telehealth, telecare, e-health, and assistive living technology being some other common terminologies (Glomsås et al., 2020). In Norway, remote patient monitoring is highlighted as one of the measures that can help alleviate future challenges in health care (The Norwegian Directorate of Health, 2021). Furthermore, introducing welfare technology in palliative care may enable patients to enhance illness management, increase quality of life, improve accessibility to palliative care services at home, reduce hospitalization, and decrease hospital expenses (Head et al., 2017;

Kruse et al., 2017). This study explored the experiences of patients with cancer in the palliative phase and HCPs on the use and implementation of a service for remote patient monitoring and remote home care (RHC), an innovative application of welfare technology that includes a non-ambulant service composed of a tablet device for symptom self-reporting, sensor data via medical measuring devices, and patient-HCP communication via chat or phone.

Historically, palliative care has been seen as a “high-touch” specialty, with the common misconception being that welfare technology cannot provide the same level of human compassion (Morgan et al., 2017). As a result, the potential for digital interventions in palliative care has been questioned (Watts et al., 2021). Despite this concern, the empirical evidence for the benefits of digital interventions in palliative care is growing internationally (Finucane et al., 2021; Steindal et al., 2023), indicating that high-technology does not necessarily exclude high touch. The adoption of such technological innovations in health care research suggests that implementation of welfare technologies, which also implies organizational change and innovation, is often met by different levels of resistance on both individual and organizational levels (Nilsen et al., 2016). Furthermore, research supporting the efficacy and acceptability of digital health interventions in palliative care is limited (Finucane et al., 2021)

There is a significant knowledge gap regarding the potential of technology to enhance sustainable patient outcomes in palliative care, as there has been limited prioritization and publication of studies on innovative interventions such as remote patient monitoring (Hancock et al., 2019; Nwosu et al., 2022). Furthermore, without suitable evaluation tools and approaches, there is a risk of implementing welfare technology as an end in itself rather than a means to improve care (Frennert, 2021). Thus, research that integrates intervention effectiveness with successful incorporation into existing organizational contexts is essential.

This study originates from a project established in one city district of a large city in Norway where RHC was implemented with the intention of enabling patients with cancer in the palliative phase to stay safe at home for as long as possible, providing tailored follow-up, and improving the communication between patients and HCPs (Oelschlägel et al., 2023). The overall aim of the study was to elicit the experience with and viability of RHC in palliative home care for patients with cancer. This study illuminates HCPs’ and patients’ experiences with the implementation of RHC in palliative care. The concept of person-centered care, conceptualized by the means of the 6S model for person-centered palliative care, is briefly discussed in Papers I and II. By considering six dimensions- *self-image*, *relief of symptoms*, *social relations*, *synthesis and strategies*, and *self-determination* (Österlind & Henoch, 2021) - the 6S model may enhance HCPs' knowledge of the complex, interrelated issues that patients may experience in palliative home care and was therefore chosen as a guide for discussing the potential of RHC to provide person-centered palliative care in this thesis. The 6S model for person-centered palliative care is thoroughly presented in Chapter 2.1.2. Further, the study takes a service-oriented perspective focusing on the implementation itself using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. The RE-AIM framework (Glasgow et al., 1999) was applied in Paper III for a secondary analysis of the data material collected for Papers I and II. The RE-AIM is an example of a framework under the category of evaluation frameworks, which is compatible with the purpose of assessing the implementation of RHC and further considering its viability for palliative home care for patients with cancer. A thorough explanation of the RE-AIM framework is provided in Chapter 2.4.

# 2 BACKGROUND

In this chapter, the various concepts this study is based on, namely palliative care, person-centered care, and welfare technology, are presented. The chapter identifies knowledge gaps in the field when the study was initiated and argues that there is still a need for more knowledge regarding the use of welfare technology in palliative care. Furthermore, the theoretical perspectives employed to understand, interpret, and discuss the results of the study in this thesis are based on the 6S model for person-centered palliative care (Österlind, 2022; Österlind & Henoch, 2021) and the RE-AIM framework (Glasgow et al., 1999, 2019). These perspectives are presented in Chapter 2.1.2 and 2.4.

## 2.1 Palliative care

Since the late 1960s, there has been significant progress in the development of palliative care as the pioneer Cicely Saunders played a crucial role in bringing attention to and conceptualizing the end-of-life care requirements of patients with cancer. In the 1970s, palliative care began to be recognized as an area of focus, encompassing physical, social, psychological, and spiritual support provided to patients with life-limiting illnesses by an interdisciplinary team (Clark, 2007; Radbruch et al., 2020). Traditionally, cancer care has been criticized for its emphasis on treating the tumor in isolation, often at the expense of addressing the holistic needs of the patient, whereas palliative care has been associated with end-of-life cancer care (Kaasa et al., 2018; Radbruch et al., 2020). The introduction of palliative care emerged partly as a response to the lack of attention to subjective experiences (Astrup, 2017) and patient-centeredness within conventional cancer care. The development of these approaches was intended to redirect the focus toward a more comprehensive and compassionate approach to care that prioritizes the unique needs and preferences of individual patients, regardless of diagnosis (Kaasa et al., 2018).

In 1990, The World Health Organization (WHO) presented a definition of palliative care:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of

> suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.
> (World Health Organization, 1990)

The WHO's definition significantly broadened the view of palliative care, highlighting the importance of incorporating a personal and public health perspective. However, it has also faced opposition. Critics have argued that the definition restricts palliative care only to focus on care needs or issues related to life-threatening illnesses instead of including the challenging experiences of patients suffering from severe, often multiple, chronic conditions. Over the past decades, earlier integration of palliative care has received increased attention. An earlier integration is founded on the understanding that palliative care is not just relevant at the end of life but can and should be initiated early in the disease trajectory, often in parallel with active treatments such as chemotherapy or radiation therapy (Kaasa et al., 2018). Furthermore, an understanding that palliative care should be initiated based on the patient's needs and problems, and not based on prognosis or diagnosis, has been recognized (Radbruch et al., 2020). Such a shift from a disease-centered to a person-centered approach necessitates that HCPs become more attuned to the unique preferences, requirements, and values of each patient, allowing these values to direct their clinical decisions (Kaasa et al., 2018). In 2020, the International Association for Hospice and Palliative Care developed a consensus-based definition of palliative care that broadens the previous scope and focuses on the relief of serious health-related suffering (Radbruch et al., 2020), a concept put forward by the Lancet Commission Global Access to Palliative Care and Pain Relief (Knaul et al., 2018), as follows:

> Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers. (Radbruch et al., 2020:761)

The new definition comprises several bullet points with additional details and recommendations for governments to reduce barriers to palliative care and includes an emphasis on patients' opportunities to live an active life until death by providing relief and improving the quality of life for patients and their relatives who are facing a life-threatening illness. It involves understanding the underlying disease and various treatment approaches, effectively addressing symptoms, fostering collaboration among HCPs, engaging patients actively in their care, and providing support to their family members (Radbruch et al., 2020). The new definition presupposes a systematic collaboration among interdisciplinary team members within and across levels of care to address the needs of patients and their relatives and facilitate a more person-centered focus. This implies an empathic approach by HCPs with willingness and skills to assess and understand the patient's needs (Kaasa et al., 2018; Radbruch et al., 2020).

The WHO and the European Association for Palliative Care (EAPC) both emphasize the need to improve palliative care globally and across Europe, respectively. Key strategies they both endorse include integrating palliative care into all levels of health care, enhancing education and training of HCPs, advocating for palliative care as a priority, and providing guidelines for practice. The WHO focuses on providing tools for the implementation and evaluation of palliative care services, and the EAPC prioritizes research in palliative care to inform effective strategies and interventions and collaboration to share best practices (European Association for Palliative Care, 2023; World Health Organization, 2020; World Health Organization & Worldwide Palliative Care Alliance, 2020).

Although palliative care has progressed from care of dying patients with cancer to also include early integration of palliative care for patients and their families (World Health Organization, 2020), the experiences of patients diagnosed with cancer in the palliative phase were studied in this thesis. Therefore, it is relevant to clarify what is significant regarding palliative care for patients with cancer.

Because of great advancements in cancer treatments during the past decade, many patients live with metastatic disease due to increased treatment options for cancer diagnosis, such as breast, lung, colorectal, and prostate cancer. New immunotherapies, different from traditional chemotherapy, are also being added to standard care. This rise in patients living with advanced cancer impacts palliative care coordination and planning, necessitating a blend of treatments focused on both the tumor and the patient. This evolution has transformed cancer into a long-term health condition, which is recognized by the WHO as one of the four main chronic diseases in 2023 (World Health Organization, 2023).

Patients living with cancer in the palliative phase can be characterized by failing organ functions, burdensome symptoms (such as pain, dyspnea, nausea, anxiety, and depression), rapid changes in health status, and various complications that occur frequently and often simultaneously. The average patient reported experiencing more than three distressing symptoms at the same time (Kaasa & Loge, 2016a). Integrating palliative home care in the early stages of life-threatening illnesses may have several positive outcomes. These include enhancing patient and family satisfaction, improving the quality of life for patients, alleviating burdensome symptoms, reducing aggressive end-of-life treatments, and decreasing both the length and frequency of hospital stays (Davis et al., 2015). When cared for by a team of interdisciplinary HCPs, patients and their relatives may feel better supported (Kaasa et al., 2018; Radbruch et al., 2020). Palliative care can be provided in a variety of settings, including hospitals, nursing homes, and the patient's home (World Health Organization, 2020).

### 2.1.1 Person-centered care

The ongoing changes in the provision of health care challenges the traditional roles and power balances, which affects both HCPs and recipients of care. Two factors of these changes are the improved access to health care information and better-informed patients; consequently, patients are seen as valuable and active members of the health care team (Byrne et al., 2020). The term person-centered care is commonly used to describe the role of the patient within the health care system and the way in which care is provided to the patient, and it is recognized as a critical characteristic of high-quality health care (Byrne et al., 2020; Giusti et al., 2020; Moore et al., 2017). However, there is a lack of consensus regarding a universal definition of person-centered care (Byrne et al., 2020). To identify conceptual core elements related to person-centered care, several researchers have reviewed existing literature in the field (Byrne et al., 2020; Giusti et al., 2020). Byrne et al.'s (2020) integrative literature review identified three core themes essential to person-centered care in nursing:

- *People*, which involves human kindness, holistic view of the individual, family involvement, and shared decision-making.
- *Practice*, which encapsulates the complexity of the professional and personal attributes in daily nursing tasks.
- *Power*, which addresses the balance between the caregiver and the recipient of care.

Although Byrne et al. (2020) took a nursing perspective, these core themes access the essence of what constitutes significance within person-centered care and should be considered in other contexts, such as in an interdisciplinary context, which is the setting for this thesis. Furthermore, person-centered care involves mutual respect, information, support of physical, psychological, social, and existential needs and shared decision-making for both the patient and their family (Giusti et al., 2020).

Overall, there are similarities and differences in the descriptions of person-centered care. The existing literature clarifies that person-centered care is created in a mutual and shared relationship between the person receiving care and the HCPs (Byrne et al., 2020; Giusti et al., 2020; Österlind & Henoch, 2021). This relationship is sometimes called participation, partnership, or co-created care (Österlind & Henoch, 2021). In this study, the understanding of person-centered care presupposes a consideration of the whole life of a patient, meaning that a person is both a patient, which is a role they have or something they are, and at the same time a person, which is who or someone they are (Eklund et al., 2019; Österlind & Henoch, 2021).

### 2.1.2 The 6S model for person-centered palliative care

The 6S model for person-centered palliative care is based on holistic values and the definitions of palliative care in accordance with the overarching goals and policy documents for palliative care in the health and care services (Österlind, 2022) and was chosen as a guide for discussing the potential of RHC to provide person-centered palliative care in this thesis. By considering six concepts- *self-image*, *symptom relief*, *social relations*, *synthesis and strategies*, and *self-determination* -the 6S model for person-centered palliative care may ensure increased knowledge of the complex, interrelated issues that patients may experience in palliative care (Österlind & Henoch, 2021). The concepts of the 6S model are illustrated in Figure 1:

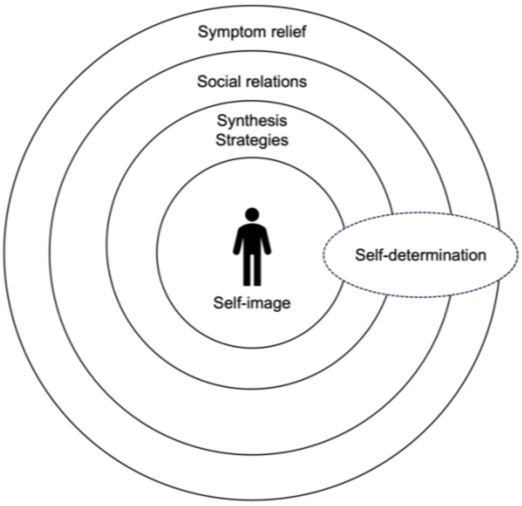

*Figure 1. The six concepts of the 6S model*[1]

The 6S model suggests an approach that combines the principles of person-centered care with the WHO's definition of palliative care and focuses on how one's self-image can be enhanced during severe illness and toward the end of life (Österlind, 2022; Österlind & Henoch, 2021). In the context of palliative care, the literature suggests that person-centered care should focus on both the suffering and the capability of the individual as a person (Öhlén et al., 2017). Person-centered palliative care begins by acknowledging the patient as the focal point, considering their individual needs and desires. This approach entails HCPs engaging in meaningful conversations with patients, allowing them to express what would bring them a sense of meaning, dignity, relief from distress, and affirmation of their values and beliefs. These dialogues serve as the foundation for planning, aiming to provide the best possible quality of life and a dignified death (Österlind, 2022; Österlind & Henoch, 2021). In the context of the 6S model, the goal is to align the care with the person's own values and beliefs, an approach highlighted by a humanistic view of the individual regarding them as a thinking, feeling, social, and meaning-making entity with the potential for ongoing development. This perspective suggests that a person's dignity is deeply connected to their individual identity and existence rather than merely being a function of their performance and actions (Österlind, 2022).

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[1] Illustration reproduced with permission from Österlind, J., & Henoch, I. (2021). The 6S-model for person-centered palliative care: A theoretical framework. *Nursing Philosophy, 22*(2). https://doi.org/10.1111/nup.12334.

*Self-image* is the 6S model's core concept and the starting point of care. *Self-image* concerns the person's own perception of self and includes both cognitive and emotional components. Terms such as self-image and identity are frequently used interchangeably, and similarly significant concepts include the self and personality. The foundation of identity is rooted in the individual and their physical self (Österlind, 2022; Österlind & Henoch, 2021). To preserve this self and facilitate living the best life as possible, *relief of physical symptoms* and suffering is substantial to achieve adequate symptom management, thereby providing the necessary conditions for maintaining self-image. The objective of symptom relief is to enable individuals with severe illness to live as well as possible for the rest of their lives. Symptoms are subjective experiences and are distinguished from signs that are objective manifestations of a disease that can be perceived by someone other than the person themself (Österlind & Henoch, 2021, p. 6). The experience of a symptom includes its occurrence rate, severity, distress, and significance. Symptoms could potentially serve as a window into a person's values, beliefs, and inner self (Österlind, 2022; Österlind & Henoch, 2021).

*Social relationships* reflect the person's social needs, such as the need for fellowship with others (Österlind & Henoch, 2021). Throughout different stages of life, we may primarily provide care to others, or be the ones receiving care. Therefore, many aspects of social relationships are significant, such as support from family, the family's acceptance of the situation, and their readiness for what may come. The interaction among the patient, family members, and HCPs is a central aspect, founded on mutually shared knowledge and comprehension of the situation (Andershed & Ternestedt, 2001; Stajduhar et al., 2008).

The concept of *Synthesis* and choice of *Strategies* concerns existential and spiritual needs. These two concepts are closely linked together; however, synthesis concerns the retrospect summary and finding the meaning of situations and experiences in an individual's life, whereas strategies are prospective and concern the future (Österlind & Henoch, 2021). The concept of self-determination reflects the persons' psychological needs, including the need to be an active participant in own life and to contribute to a life based on one's own needs, values, and beliefs (Henoch & Österlind, 2019; Österlind & Henoch, 2021). Patients' understanding and involvement in their symptom relief and overall care are largely influenced by their capacity for self-determination. For patients to effectively exercise self-determination, they require sufficient information to evaluate the implications of their choices. Both the patient and their family need to collaborate with HCPs, enabling them to collectively plan the future or final stage of life in the best possible way (Carlander et al., 2011; Österlind & Henoch, 2021).

Together, all six concepts reflect the importance of regarding the whole person in all areas of health care, and especially in vulnerable situations in all phases of palliative care. In terms of suffering, the 6S-model acknowledges that a person is given the opportunity to express both good and bad experiences and facilitates for co-creation of care between the person in the palliative phase, who contributes with experiences, knowledge, beliefs, and preferences, as well as professionals (HCPs), who contribute with scientific knowledge and experiences of care (Henoch & Österlind, 2019; Österlind & Henoch, 2021). Based on this, the 6S model may be considered a relevant guideline when implementing new palliative care services. This may be especially relevant for services for remote patient monitoring, such as the RHC under study, where the physical encounter between the patient and HCPs cannot be emphasized as much as in traditional palliative care, and thus, the opportunities to provide and organize person-centered care may be challenged.

## 2.2 Welfare technology - definitions and political perspectives

Although many terms can be used to reference technological innovations, in this study, they are referred to as welfare technology. The term welfare technology was chosen because it is frequently used in Norwegian governance documents and white papers (Arbeiderpartiet & Senterpartiet, 2021; NOU 2011:11; NOU 2023:4). Furthermore, welfare technology is sorted under other health care services, which entails that the recipient of the welfare technology service receives follow up with qualified HCPs (Thygesen, 2019), which concurs with the intervention under study. Welfare technology is an umbrella term, mainly used in Nordic countries, that covers technologies that have the potential to maintain or improve patients' safety, security, wellness, mobility, social and cultural contact, participation, treatment, and care (Rostad & Stokke, 2021). It covers a wide range of technology types, structures, and processes (Salem et al., 2020), complementing telemedicine, telehealth, telecare, e-health, and assistive living technology (Glomsås et al., 2020). Welfare technology can be broadly categorized into four categories: 1) safety and security technology, 2) compensation and well-being technology, 3) technology for social contact and communication, and 4) technology for treatment and care (NOU 2011:11; Thygesen, 2019). Although these categories refer to different aspects of digital care, they often overlap. The intervention under study in this thesis, RHC, belongs to the category technology for treatment and care.

The WHO's Global Strategy on Digital Health 2020-2025 (World Health Organization, 2021) aims to promote universal health by accelerating the utilization of relevant health technologies. It focuses on advancing global collaboration and national digital health initiatives, emphasizing robust governance and advocacy for digital health benefits. The strategy advocates for standard development and best practices where quality, safety, and effectiveness are crucial and underscores the importance of equity and inclusion, ensuring that all have access to digital health technologies, which can help reduce health disparities. Additionally, it promotes research, innovation, and the development of a skilled workforce for effective digital health implementation (World Health Organization, 2021).

The European Union (EU) promotes digital health and care via three main pillars. First, it prioritizes secure access for citizens to their health data, including across borders, enhancing individual control over personal health information. Second, it aims to establish a shared European data infrastructure to promote research, disease prevention, and personalized medicine. Lastly, the EU advocates the development and use of digital tools enabling active participation and promotion of person-centered care (European Commission, 2018). In Norway, the term "welfare technology" was especially highlighted in the NOU 2011:11 "Innovation in Care." Since then, Norway has been actively pursuing the implementation of welfare technology-supported home care to improve the quality of care for older and chronically ill individuals and to reduce the costs of providing care. The Norwegian government's main goal is to enable people to live independently in their own homes for as long as possible while they still receive the necessary care and support (The Norwegian Directorate of Health, 2015; The Norwegian Ministry of Health and Care Services, 2018). The National Welfare Technology Program for the 2022 to 2024 period states that welfare technology should contribute to increased quality across health and care services, generate socioeconomic benefits, and result in greater satisfaction among users of health care services (The Norwegian Directorate of Health, 2022b).

Welfare technology is highlighted as one tool to improve Norwegian cancer care (NOU 2018:16; NOU 2023:4; The Norwegian Ministry of Health and Care Services, 2018). A recent Norwegian government report (NOU 2023:4) suggests that digital tools can enhance precise, individualized cancer treatment and advocates for equal technology access and competent HCPs for all patients with cancer, irrespective of location. The report calls for improved collaboration across sectors and increased investment in technological research for cancer care, with technology serving as a supplement to human care. It also emphasizes the need for patient privacy and autonomy and the development of user-friendly, secure, and reliable technological solutions that protect patient data (NOU 2023:4).

### 2.2.1 Strategies for the provision of palliative care in Norway

Recommendations for the organization of palliative care in Norway follow the structure of the Norwegian health care system, which is divided into four regional health authorities responsible for organizing and providing specialized health services such as hospitals, mental health services, and rehabilitation centers. Primary care services such as general practitioners, district nurses, and home health care services are organized at the municipal level (NOU 2023:4). In Norway, patients in need of basic palliative care are followed by a general practitioner and/or home nursing care within primary care services, whereas patients with more complex palliative needs receive follow-up care from specialist health services, either through palliative teams organized at the hospital or specialized palliative care units (NOU 2017:16).

Being home with their relatives can promote hope and improve quality of life for the patients, which clarifies the need for a broad approach with individually targeted care (Haugen & Aass, 2016). Patients with cancer in the palliative phase have traditionally often been treated in outpatient clinics, enabling them to spend as much time as possible at home (Sandsdalen et al., 2015). However, a fundamental principle is that nurses at all levels of the health care service should possess a basic understanding of palliative care and that patients have access to specialized palliative care services when the generalist level is insufficient. To meet this requirement, all HCPs, regardless of their occupation or field, who come into contact with patients in need of palliative care, should be able to provide basic palliative care, such as symptom assessment, communication, and support for family members. This demands that

HCPs have the necessary competence and that procedures are established for referring patients to specialized expertise when needed (Kaasa & Loge, 2016a; The Norwegian Directorate of Health, 2019).

### 2.2.2 Remote patient monitoring

Remote patient monitoring refers to the use of welfare technology in health care that allows a patient to be monitored from a distance. Remote patient monitoring is anchored in the primary care services and involves the use of technology and digital tools to monitor and treat patients at home (The Norwegian Directorate of Health, 2022b). In Norway, remote patient monitoring is commonly used for patients with chronic diseases such as diabetes or chronic obstructive pulmonary disease (COPD), or those requiring regular follow-up to ensure patients' health and quality of life, as well as to prevent and reduce the need for hospitalizations and patient transportation (NOU 2023:4).

Delivery of remote patient monitoring can be in an asynchronous (passive) manner, a type of interaction or communication that does not necessitate an immediate response from the recipient (HCP), or in a synchronous (interactive) manner, a form of interaction entailing real-time exchange of messages or information between patients and HCPs (Busey & Michael, 2008). In Norway, remote patient monitoring is a non-ambulant service where patients use technology to perform various measurements, such as blood pressure, weight, and oxygen saturation, as well as to answer health-related questions using a tablet or similar device stationed in their home (The Norwegian Directorate of Health, 2022b). The results of these measurements are automatically transmitted from the sensors to the patient's device, allowing them to easily track their progress over time. Additionally, the results are digitally transferred to a follow-up service that monitors the patient's health status. If there are signs of deterioration or aberrant measurements that fall outside the normal range set for the individual patient, HCPs will contact the patient to provide further medical support and guidance based on their individual needs and/or action plans for self-treatment (The Norwegian Directorate of Health, 2022b). Norway has made significant investments in remote patient monitoring. In 2018, a national testing program was launched with the objective of acquiring more knowledge regarding the effects and benefits of digital home follow-up for users. The program aimed to improve user experience and enhance physical and mental health outcomes while simultaneously reducing resource utilization by the health care system. The primary purpose of the program was to establish national recommendations for designing service pathways for the implementation and organization of digital home follow-up (The Norwegian Directorate of Health, 2021).

Few studies have investigated the benefits and challenges with services for remote patient monitoring in palliative care. However, some studies have investigated similar services, and the results from these may be transferrable to the Norwegian context. Systematic reviews have reported a large variety in the technology provided in palliative care and state that it is difficult to draw conclusions on the benefits of palliative care (Head et al., 2017; Rogante et al., 2016; Zheng et al., 2016). However, studies highlight that welfare technology may improve access to care by enabling patients to receive care in their own homes, eliminating the difficulties and burdens related to prolonged waiting times when visiting hospitals, including exacerbation of symptoms, fatigue, worry of infections following chemotherapy, organizational challenges, and travel costs (Pinto et al., 2017; Rahman et al., 2020; van Gurp et al., 2016). Moreover, the possibilities to receive palliative care at home may enhance patients' sense of vitality, tranquility, comfort, and control over their lives (Funderskov et al., 2019; Paul et al., 2019; Rahman et al., 2020; Tasneem et al., 2019; van Gurp et al., 2015). Patients seem to develop an increased sense of security, as they feel reassured by having technology that provides access to immediate responses from HCPs in case they need help (Capurro et al., 2014; Head et al., 2017; Steindal et al., 2020). Furthermore, patients highlighted benefits such as saving time (allowing more home time with their loved ones), increased comfort, and the possibility of taking an active role (Funderskov et al., 2019; Paul et al., 2019; Tasneem et al., 2019). However, they also pointed out the possibility of HCPs missing out on the engagement, physical examination, and potential to prescribe restricted medications that would be possible at an in-person visit (Tasneem et al., 2019).

Patients perceive close monitoring of patient symptoms and concerns through technology as a benefit, allowing HCPs to quickly identify and address their health declines and potential problems (Hochstenbach et al., 2016; Lind & Karlsson, 2013). Research suggests that by reporting their own symptoms, patients are able to communicate their current health issues and worries (Bonsignore et al., 2018; Hennemann-Krause et al., 2015; Hochstenbach et al., 2016; Morgan et al., 2017; Tieman et al., 2016), creating a sense of comfort and not feeling isolated (Lind & Karlsson, 2013). Research suggests that patients perceive telecommunication as empathetic and that having access to HCPs through technology fosters a sense of security and peace of mind (Funderskov et al., 2019; Paul et al., 2019; Tasneem et al., 2019; van Gurp et al., 2015). Furthermore, patients felt more at ease discussing difficult topics when HCPs were not physically present (van Gurp et al., 2015). In addition, it is reported that the use of welfare technology in the home of patients with cancer may seem unifying for the various groups of HCPs involved and strengthens the cooperation between palliative teams in hospitals and general practitioners (van Gurp et al., 2016).

A recent scoping review has suggested that HCPs perceive welfare technology as a valuable tool for improving patient outcomes in palliative care by providing patients and their families with more personalized and readily accessible care. Welfare technology could enable HCPs to closely monitor patients and promptly respond to changes in symptoms or health status (Lundereng et al., 2023). Palliative care nurses may perceive welfare technology as a valuable complement to the traditional services patients receive (Collier et al., 2016). By enabling patients to self-report symptoms as they occur and monitor patient symptoms in real time, welfare technology may provide HCPs with access to clinical data allowing them to adjust treatments promptly (Busey & Michael, 2008; Steindal et al., 2023). Thus, it has the potential to enhance efficiency by streamlining processes such as patient assessments and symptom management facilitating the delivery of palliative care (Lundereng et al., 2023). Despite the anticipated benefits, legal considerations around remote clinical assessments raise concerns among palliative care nurses (Collier et al., 2016). Notably, the implementation of welfare technology in home settings has demonstrated potential in fostering collaboration among various HCPs, strengthening the collaboration between palliative teams in hospitals and general practitioners (van Gurp et al., 2016).

This study explored RHC as a service for remote patient monitoring, which was implemented for patients with cancer in the palliative phase with the intention of enabling patients to stay safe at home for as long as possible, providing individually tailored follow-up, and improving the communication between patients and HCPs (Oelschlägel et al., 2023). Details of the RHC components and follow-up are presented in the Methods Chapter 4.2.

## 2.3 Implementation of welfare technology in palliative home care

Although there is a growing body of evidence supporting welfare technologies in palliative home care (Finucane et al., 2021; Steindal et al., 2023), such evidence cannot change care unless policymakers, health care services, and HCPs adopt and implement the results into their practice (Eccles & Mittman, 2006). The introduction of technology triggers a process of change and has the capacity to transform work practices, organizational structures, and power dynamics within an organization. However, many change initiatives lacks success due to inadequate leadership, lack of clear direction, and a deficiency in systematic project management. Additionally, some initiatives experience delays in their implementation (Nilsen et al., 2016). A frequently cited estimate stated that it takes an average of 17 years to implement clinical innovations into practice (Morris et al., 2011). Moreover, only one in five evidence-based interventions makes it into general usage (Kilbourne et al., 2020), which means that society's return for each medical research investment is diminished even further (Bauer & Kirchner, 2020). These issues highlight an urgent need for more knowledge and have contributed to the development of the new scientific field of *implementation science*, which aims to promote the systematic uptake of research results and other evidence-based practices into routine practice (Eccles & Mittman, 2006; Nilsen, 2015). The term implementation can be defined as the process of understanding factors associated with successful integration of evidence-based interventions within a specific setting. Implementation science aims to identify and apply strategies that overcome the barriers and enhance the facilitators important for the uptake of evidence-based clinical innovations across multiple levels of context (Bauer & Kirchner, 2020; Rabin et al., 2008).

The existing research on the implementation of welfare technology for patients with cancer in the palliative phase is very limited. There are, however, some systematic reviews that have investigated implementation technologies in health, but in other contexts. In their systematic review of evidence for home-based telehealth in pediatric palliative care, Bradford et al. (2016) found that implementation and sustainability were influenced by factors such as a shared vision, ownership, adaptability, economics, efficiency, and equipment. Another systematic review with the purpose of evaluating barriers to adopting telemedicine worldwide identified limited technology and computer literacy as significant hindrances to adoption

(Kruse et al., 2018). Furthermore, a systematic review evaluating implementation barriers and facilitators of telemedicine in post-treatment cancer survivorship care identified various barriers, including a lack of evidence to guide telehealth design; challenges in adapting to different cancer types, ages, languages, and settings; limited cancer-specific applications, costs associated with staffing for intervention delivery; and the difficulties of providing patient-centered care remotely (Chan et al., 2021).The results of these reviews may be transferrable to the context of remote patient monitoring and palliative care.

## 2.4 The RE-AIM framework

Developing efficacious interventions for health care is of great interest. Although methods for determining if an intervention was or was not efficacious exist, questions are being raised concerning the necessity of evaluating other factors, such as robustness, translatability, and public health impact associated with these interventions (RE-AIM.org). The field of implementation science has developed significantly over the last 20 years, which has contributed to a better understanding of the complex factors that influence implementation and to the development of more effective strategies to promote the adoption and implementation of evidence-based practices in clinical and community settings (Moullin et al., 2015; Nilsen, 2015; Peters et al., 2013). However, implementation science is still a relatively new field and has not had sufficient time to establish widely accepted, highly specified models of change or broad generalized theories due to the lack of decades of research. As a result, implementation scientists currently heavily rely on theoretical frameworks, which offer flexibility in application and a systematic way to understand and organize the complex factors that influence implementation efforts, guide the development of implementation strategies, facilitate the evaluation of implementation efforts, and promote the translation of research into practice (Damschroder, 2020).

According to Nilsen (2015) the RE-AIM is an example of a framework under the category of evaluation frameworks, which is compatible with the aim of assessing the implementation and exploring areas of particular importance determining the sustainability of RHC for palliative care set forth by this study. The RE-AIM framework has been widely used in research and evaluation studies and has been validated in various settings, including health care and community settings (RE-AIM.org).

Glasgow et al. (1999) designed the RE-AIM framework to evaluate the population-based impact and expand assessment of interventions beyond efficacy by exploring a set of five dimensions. The RE-AIM framework was applied in this study to assess the implementation of RHC in palliative home care to patients with cancer in the palliative phase. An application of the RE-AIM framework may provide a deeper insight into both intended and unintended outcomes of the implementation of RHC and thus provide a foundation for discussing the results of this thesis. The RE-AIM dimensions and its definitions are presented in Table 1:

*Table 1. The definitions of the five RE-AIM dimensions*

| **RE-AIM dimension and level** | **Definition** |
|---|---|
| **Reach**<br>Individual level | Representativeness, rate, and characteristics of individuals who are willing to participate in a given intervention, including potential barriers for participation |
| **Effectiveness**<br>Individual level | Impact of an intervention on individual outcomes, such as positive and negative effects, quality of life, and economic outcomes |
| **Adoption**<br>Institutional level | Representativeness and proportion of settings that implement the intervention |
| **Implementation**<br>Institutional level | Institutional fidelity to the intervention's protocol and includes consistency in intervention delivery, timing and cost of the intervention |
| **Maintenance**<br>Individual + institutional level | The extent to which the intervention has become institutionalized or part of the routine organizational practices and policies. Maintenance also includes an individual level addressing the long-term effects of intervention outcomes following completion of the intervention |

(Glasgow et al., 1999, 2019)

The purpose of the RE-AIM framework is to assist in the planning, management, evaluation, and reporting of studies with the goal of translating research into practice. It is considered a valuable tool for evaluating the impact of interventions such as the RHC, and its use can help ensure that interventions are efficacious, equitable, and sustainable in real-world settings (Glasgow et al., 1999, 2019; Holtrop et al., 2018). Furthermore, the RE-AIM framework considers the reach and effectiveness of interventions across different populations, which helps to identify disparities and ensure equitable outcomes. This focus on equity aligns with the growing recognition of the importance of addressing health disparities and promoting health across populations (Glasgow et al., 1999, 2019). Although methods for determining if an intervention was or was not efficacious exist, questions are being raised concerning the necessity of evaluating other factors, such as robustness, translatability, and public health impact, associated with these interventions (RE-AIM.org). The RE-AIM framework aims to balance the traditional focus on internal over external validity to improve the sustainable adoption and implementation of efficacious, generalizable, evidence-based interventions (Glasgow et al., 1999, 2019). The five RE-AIM dimensions focus on both the individuals the intervention is intended to benefit, as well as the staff and setting levels of the institution implementing the intervention.

Although the RE-AIM framework has been widely used for evaluating a high number of interventions the past two decades (Glasgow et al., 2019), the literature reveals a shortage of qualitative methods using RE-AIM (Gaglio et al., 2013; Harden et al., 2015; Holtrop et al., 2018). Furthermore, literature searches did not identify studies applying RE-AIM in studies utilizingtechnologies similar to RHC in palliative home care to patients with cancer. Holtrop et al. (2018) argued that qualitative approaches to RE-AIM may help understand more complex situations and results and provide answers as to why and how implementation processes became the way they did. Thus, an application of qualitative methods using the RE-AIM framework can provide a deeper insight into both intended and unintended outcomes of the implementation of RHC in palliative home care to patients with cancer and may contribute to translating the relevant intervention into practice (Holtrop et al., 2018).

### 2.4.1 Application of qualitative methods to the RE-AIM dimensions

The *Reach* dimension assesses the characteristics of the study participants on an individual level (Glasgow et al., 1999) by describing the number and percent of both participants and non-participants to address the representativeness of the study. However, from the qualitative method perspective, key issues will be to understand why people accept or decline participation and to describe details of the participants that are not available from quantitative data (Holtrop et al., 2018). Furthermore, participants in health intervention studies tend to be those who need them least, meaning that the understanding of intervention effectivity to those in the most need may be lost (Glasgow et al., 1999). For example, the reach may be limited by individual factors such as health and social determinations, lack of commitment to study participation, or lack of support from family members. In traditional interventions, these participants would simply not be included, which may lead to false assumptions and/or biased results. These examples of nonoptimal reach may be difficult to properly understand without a qualitative method (Holtrop et al., 2018) and should be considered an important factor for providing viable health care interventions.

Traditional research on clinical effectiveness has mainly focused on physiological outcomes. The *Effectiveness* dimension of the RE-AIM framework has expended this focus to include the effects of an intervention on individuals' quality of life and also includes the unintended consequences the intervention might entail (Glasgow et al., 1999, 2019) on an individual level, usually the patient (Bakken & Ruland, 2009). However, such effectiveness has mainly been summarized quantitatively. A qualitative assessment of the effectiveness of an intervention can provide an understanding of whether participants find the intervention effective and how and why this effectivity was regarded as meaningful or not. Furthermore, a qualitative assessment may provide more information regarding unanticipated negative results, which may have an impact on the intervention's transferability to clinical practice (Holtrop et al., 2018).

The *Adoption* dimension refers to the proportion or number of settings and implementing staff who agree to participate in an intervention (Glasgow et al., 1999; Holtrop et al., 2018). Qualitative key issues of Adoption are similar to those of Reach; however, Adoption applies to the levels of setting and the staff/implementers and their willingness to initiate the intervention (Bakken & Ruland, 2009; Holtrop et al., 2018). It is important to understand why organizations and their staff choose to participate or not and to understand the contextual matters influencing these decisions. Holtrop et al. (2018) argued that qualitative methods are particularly suitable to understand the underlying reasons for Adoption or lack of Adoption, as they provide understanding of superficial and in-depth rationale influencing the uptake of an intervention.

The *Implementation* dimension refers to the extent to which a program is delivered as intended, meaning fidelity to the intervention protocol, adaptions made to the original intervention strategies, cost, and the percent of intervention key strategies delivered as planned (Glasgow et al., 1999; Holtrop et al., 2018). The typical approach to understanding implementation is through the lens of fidelity, which involves assessing how closely the intervention was delivered as intended (Polit & Beck, 2020). This is crucial for understanding the intervention's impact on outcomes. Poor implementation can weaken the effectiveness of an intervention. Fidelity is commonly assessed through checklists completed by staff or observers. Qualitative methods may be helpful to fully understand the implementation process, including the conditions under which consistency and inconsistency are occurring across staff, setting, time, and different components of intervention delivery (Holtrop et al., 2018).

The dimension of *Maintenance* addresses the extent to which an intervention becomes institutionalized. It refers to understanding the intervention's sustainability and the reasons individual benefits continue or fade, and to why the intervention is continued into routine practice or not. By applying qualitative methods combined with stakeholder engagement throughout a study, sustainability issues can be detected early, which enable the implementers to plan for these issues and apply changes to the intervention if necessary. This is important for future intervention designs and scale-up (Glasgow et al., 2019; Holtrop et al., 2018).

Investigating the RE-AIM dimensions using qualitative methods can be beneficial, particularly for studying or evaluating complex interventions such as RHC. By emphasizing depth and meaning to facilitate understanding, qualitative methods can enable a deeper insight into why an intervention succeeded or failed while also identifying the appropriate adaptations to be made.

## 2.5 Knowledge gaps in previous and recent research

When this study was initiated in late 2019, the existing research on remote patient monitoring in the context of palliative cancer care was mostly conducted in a specialized context where the HCPs involved possessed specialized competence in cancer or palliative care (Funderskov et al., 2019; Paul et al., 2019; Tasneem et al., 2019; van Gurp et al., 2015). Furthermore, few previous studies had investigated the experiences of patients regarding remote monitoring of symptoms and symptom management (Bonsignore et al., 2018; Neergaard et al., 2014; Tieman et al., 2016). Literature searches did not identify studies that had explored patients with cancer or municipality HCPs' experiences of using remote patient monitoring in follow-up of patients with cancer in the palliative phase living at home. Thus, the findings from studies where patients with cancer in the palliative phase received follow-up from HCPs with specialized competence in palliative care from hospitals may not be relevant to or have transfer value to primary health services. Empirical knowledge is significant for the planning of remote patient monitoring interventions where patients with poor prognosis are involved and relevant to public health by reaching the overall political goal of using technology as an integrated part of the health care services. Consequently, it was considered important to study patients' and HCPs' experiences to understand mechanisms that are activated in the process of implementing remote patient monitoring in the follow-up of home-based patients with cancer in the palliative phase.

Since 2019, there have been four review articles published that summarize the existing knowledge in the field (Finucane et al., 2021; Lundereng et al., 2023; Steindal et al., 2020; Steindal et al., 2023). The reviews encompass the terms telehealth and digital health and do not refer to the term welfare technology. However, they are considered relevant and are referred to in this study because they present an overview of the published studies on diverse technology provided in palliative care the past two decades and include a broader scope of welfare technology innovations, particularly given the acceleration in their use post-COVID-19 (Finucane et al., 2021; Humphreys et al., 2020). The literature also highlights the need to expand research into telehealth experiences by considering their impact on symptoms and quality of life (Steindal et al., 2020). There is also a dearth of studies focusing on self-reported existential or spiritual concerns, emotions, and well-being (Steindal et al., 2023). Despite HCPs playing a crucial role in telehealth implementation, their lack of acceptance and motivation is identified as a significant barrier to adoption of new technologies (Lundereng et al., 2023). However, gaps in knowledge regarding the use of welfare technologies in palliative home care to patients with cancer persist. More research into the implementation of welfare technology within the specific context of palliative home care in the primary health service setting is needed. Crucial to this exploration are studies focusing on patient-reported outcomes, which offer direct insight into the patient experience. Equally important is a deeper understanding of the factors that influence how HCPs perceive and adopt these technologies. Furthermore, although remote patient monitoring has been introduced in numerous municipalities in Norway to support patients with chronic illnesses, its potential role in providing palliative home care and support within the Norwegian context remains largely unexplored.

# 3 AIMS AND RESEARCH QUESTIONS

The overall aim of the study was to elicit the experiences with and viability of RHC in palliative home care to patients with cancer. Specific aims were applied in three individual research papers as presented in Table 2:

*Table 2. Outline of the study as presented in the three individual papers*

| | **Paper I** | **Paper II** | **Paper III** |
|---|---|---|---|
| **Title** | Implementing welfare technology in palliative home care for patients with cancer: A qualitative study of health care professionals' experiences | Patients' experiences with a welfare technology application for remote home care: A longitudinal study | Implementation of remote home care—assessment guided by the RE-AIM framework |
| **Aim** | Explore municipal HCPs' experiences regarding the significant challenges, facilitators, and assessments associated with implementing RHC in palliative home care for patients with cancer. | Explore the longitudinal experiences using RHC for remote palliative care among patients with cancer living at home. | Report on the use of the RE-AIM framework to assess the implementation of RHC, a technology-mediated service for home-living patients in the palliative phase of cancer. |
| **Research questions** | Which assessments do municipal HCPs consider relevant when using RHC in palliative home care for patients with cancer?<br>What are the challenges and facilitators experienced by municipal HCPs who use RHC in palliative home care for patients with cancer? | Whether and how does the use of RHC in palliative care influence patients' ability to manage their life-limiting illness at home?<br>What are the facilitators and challenges of using RHC to manage life-limiting illness at home? | Explore areas of particular importance determining the sustainability of technologies for remote palliative home-based care. |
| **Design** | Descriptive, exploratory design. | Longitudinal, exploratory design. | An exploratory design utilizing a secondary analysis of data from Papers I and II. |
| **Methods** | Focus-group interviews and individual semi-structured interviews with interdisciplinary HCPs experienced with using RHC for home living patients with cancer in the palliative phase and living at home.<br>Data were analyzed using qualitative content analysis. | Repeated individual interviews with patients experienced with using RHC at baseline, 4 weeks, 12 weeks, and 16 weeks of use.<br>Data were analyzed using qualitative content analysis. | A deductive reflexive thematic analysis using the RE-AIM framework was applied to the datasets of Papers I and II. |

The alignment of the overall aim of the study, the individual papers, and the two theoretical perspectives presented in Chapter 2 (the 6S model for person-centered palliative care and the RE-AIM framework) in this thesis, is illustrated in Figure 2:

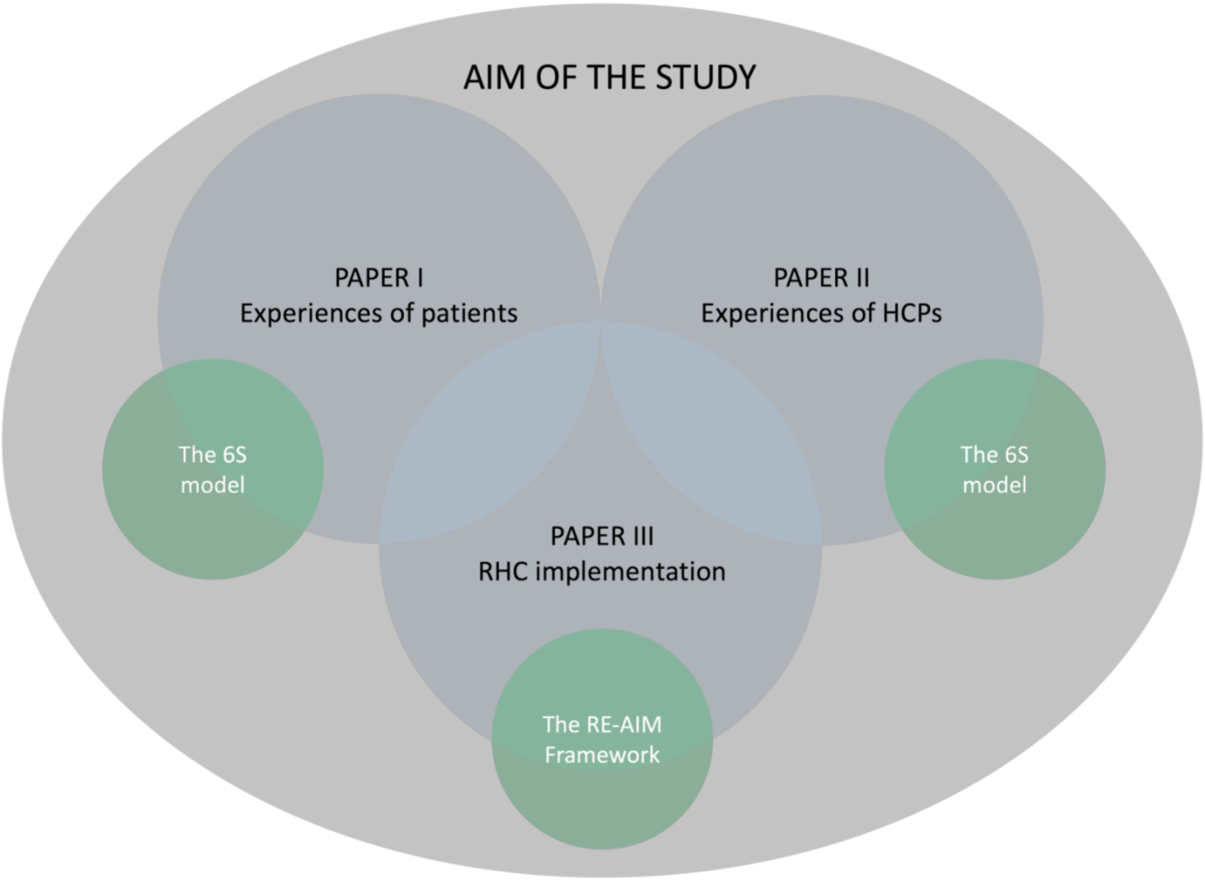

*Figure 2. Alignment between the overall aim, the individual papers, and the theoretical perspectives in this thesis.*

# 4 METHODS

This chapter presents the intervention under study, RHC. Furthermore, it elaborates on the methodological approaches of the three papers, including the setting, recruitment, participants, data collection, and analysis. Finally, ethical considerations in relation to the study are presented.

## 4.1 Research design

A descriptive-explorative, qualitative design was used to explore the experiences held by patients with cancer in the palliative phase and HCPs on the use of RHC. Furthermore, an explorative approach was applied to investigate and assess the implementation of RHC with these patients. Such an approach could allow for a rich understanding of the phenomenon and enables identification of important relationships that may be worth exploring in greater depth (Polit & Beck, 2020). A descriptive-explorative design is suitable because of the limited knowledge regarding the use of RHC in patients with cancer in the palliative phase and the interest in describing the experiences of patients and HCPs in relation to the use and implementation of the RHC. Qualitative methods are associated with the interpretivist paradigm, which focuses on comprehending the world as it truly exists through the subjective perspectives of individuals. Interpretivists acknowledge the existence of an objective reality but argue that truth is relative and dependent on how individuals construct and interpret the world within various contexts (Creswell, 2014). This study aligns with the interpretivist perspective by considering lifeworld experiences as legitimate forms of knowledge. By utilizing a qualitative approach, the research uncovered insights into both patients' and HCPs' experiences that might have otherwise remained unseen or overlooked.

### 4.1.1 Preconceptions

I (the PhD candidate) am a registered nurse with a master's degree in nursing science. I worked for several years in neonatal intensive care before spending the last 10 years employed as an associate professor in bachelor's degree nursing education. When the opportunity arose for a doctoral position associated with this project, I had no clinical experience with palliative care or cancer care and no experiences with the use of RHC in patient follow-up. As a nurse, you still have basic knowledge and understanding of palliative care, and based on this, I was skeptical about whether the technology could be used to offer patients professional palliative care and nursing. However, I am a technology optimist and recognize that technology has an important role in the future health care system. I was therefore curious and excited to start the PhD project.

## 4.2 Intervention - remote home care

The RHC was implemented in the home of patients with cancer in the palliative phase with the intention of enabling patients to stay at home for as long as possible, providing tailored follow-up, and improving the communication between patients and HCPs (Oelschlägel et al., 2023). The intervention period lasted for 16 weeks. An illustration of the RHC implementation is presented in Paper II.

The HCPs included in the study, the RHC service team, were already familiar with RHC and using it to care for patients with chronic illnesses such as COPD and diabetes. The RHC service team consisted of interdisciplinary HCPs, including nurses (including one cancer care coordinator), social workers, physical therapists, physicians, and occupational therapists. The cancer care coordinator had formal education and training in cancer care and palliative care. When included in the project, patients received RHC as a supplement to, *not a replacement for*, standard health care services.

### 4.2.1 RHC components

The RHC to patients with cancer in the palliative phase was based on three components:

1) A tablet device containing an application featuring individualized questions for self-reporting of symptoms.
2) Sensor data via medical measuring devices to measure clinical signs.
3) Patient-HCP communication via chat or telephone.

The first component, a tablet device containing individualized questions for self-reporting of symptoms, was based on the Edmonton Symptom Assessment System (ESAS) questionnaire (Bruera et al., 1991). The ESAS questionnaire is a tool used in palliative care settings to assess patients' symptoms, and it includes nine symptoms common in patients with cancer: pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. Each symptom is rated on an 11-point scale, from 0 (indicating absence of a symptom) to 10 (indicating the worst possible severity of a symptom) (Bruera et al., 1991). The ESAS questions were tailored to each patient's situation, meaning that symptoms that were perceived as irrelevant were removed from the tablet. If patients experienced altered symptoms during the intervention period, the RHC service team adjusted the questions accordingly. The tablet did not include branched questions, meaning questions that direct respondents to different subsequent questions based on their answers.

The second component was the provision of sensor data from medical measuring devices, such as weight, scale, and pulse oximetry. These were carefully selected to match patients' clinical signs, such as weight loss or pulmonary dysfunction. The tablet transmitted self-reported symptoms and measurements from the medical measuring devices to the RHC service team. Patients could monitor and follow the development of symptoms and clinical signs via statistics provided and displayed in a tablet application. This feature is illustrated in Figure 3:

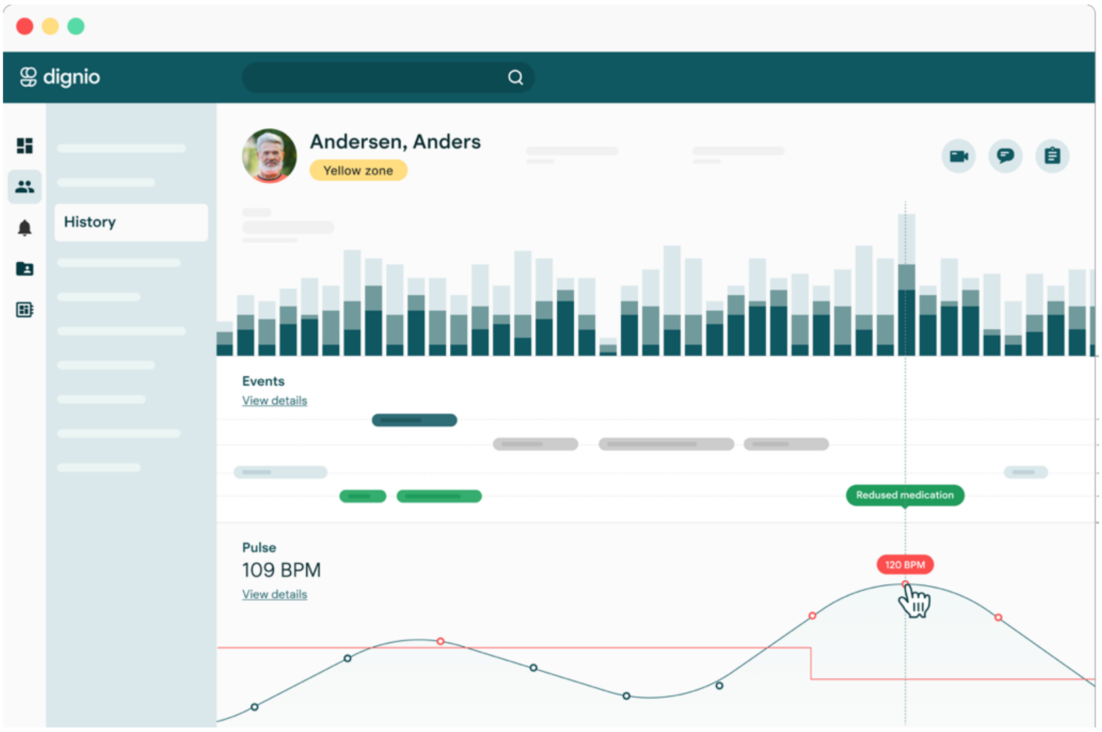

*Figure 3. Statistics provided to patients in a tablet application.*[2]

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[2] The illustration is reproduced with permission from Dignio Norway.

The third component of the RHC enabled patient-HCP communication via a chat functionality in the tablet. Patients could request to talk to a nurse on the telephone by ticking a check box in the tablet. The RHC devices were provided according to each patient perceived needs and therefore varied. Although two patients did not self-report symptoms, all received the tablet because both self-reported symptoms and sensor data were transmitted through the application on the device. An illustration of the variety of RHC devices and components provided is displayed in Table 3:

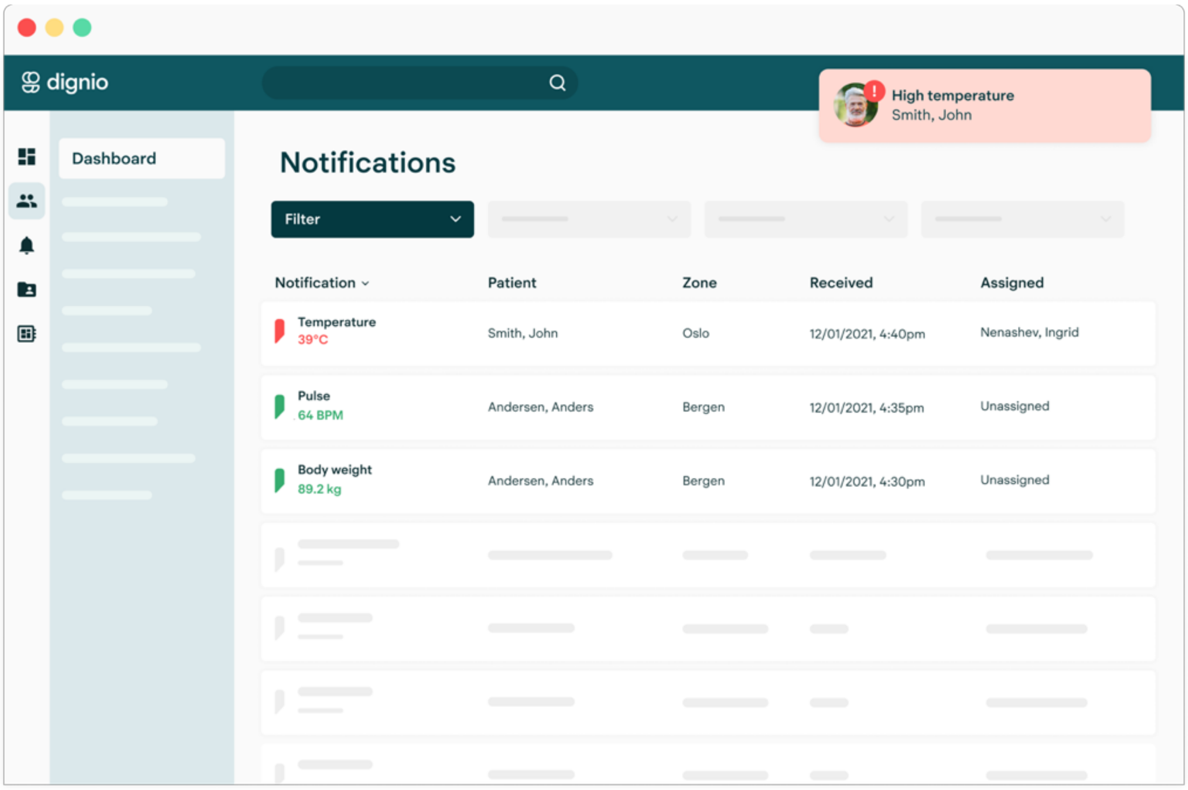
*Table 3. Variety of RHC devices provided to patients (N=11)*

| **RHC devices provided** | **n =** |
|---|---|
| Tablet | 2 |
| Tablet with self-reporting of symptoms | 9 |
| Tablet with chat functionality | 11 |
| Weight scale | 6 |
| Electronic drug dispenser | 2 |
| Blood glucose meter | 1 |
| Pulse oximetry | 1 |
| Blood pressure monitor | 1 |

### 4.2.2 RHC follow-up

The RHC service team operated independently and was not connected to traditional home care services or other health care services. After identifying potential patients, an interdisciplinary team from the RHC service team contacted the patient for an assessment visit to establish a relationship with the patient and determine the appropriate form of follow-up. In the assessment visit, RHC follow-up procedures were established in terms of assessing provision of the appropriate RHC devices and agreeing upon the interval of transmission of data (self-reporting of symptoms and/or measurements of clinical signs) and telephone contact between the patient and RHC service team.

During a trial period for 1 to 2 weeks, patients familiarized themselves with the technology, and adjustments were made as needed. Following the trial period, the RHC service team made a second visit to make final adjustments before starting the regular follow-up. During the intervention period of 16 weeks, patients provided self-reports of symptoms and measurements of clinical signs as needed and according to individual agreements with the RHC service team. The reporting interval varied from daily to weekly. Once the symptom scores and measurements of clinical signs were transmitted, patients received confirmation from the RHC service team that the data had been received. Patients who requested to talk to a nurse received a telephone from a nurse in the RHC service team shortly after. If aberrant measurements were reported, patients received a phone call within minutes, where they were given an opportunity to discuss their answers and collaborate with the HCPs on further assessments. An illustration of an aberrant measurement as received by the RHC service team is provided in Figure 4:



High temperature
Smith, John

## Notifications

| Notification | Patient | Zone | Received | Assigned |
|---|---|---|---|---|
| Temperature<br>39°C | Smith, John | Oslo | 12/01/2021, 4:40pm | Nenashev, Ingrid |
| Pulse<br>64 BPM | Andersen, Anders | Bergen | 12/01/2021, 4:35pm | Unassigned |
| Body weight<br>89.2 kg | Andersen, Anders | Bergen | 12/01/2021, 4:30pm | Unassigned |

*Figure 4. Aberrant measures as received by the RHC service team.*[3]

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[3] The illustration is reproduced with permission from Dignio Norway.

## 4.3 Material

The material for this study included focus groups and individual interviews with HCPs (Paper I) and repeated individual interviews with patients at four different time points over the intervention period of 16 weeks. The first interview was initiated shortly after the RHC home follow-up was installed (T1). The second interview (T2) was conducted after 4 weeks of use, and the third and fourth interviews were conducted after 12 (T3) and 16 weeks (T4) of use (Paper II). The transcribed data material from HCPs and patients was combined for a secondary analysis (Paper III). Figure 5 provides an overview of the material and data used for the three individual papers included in this thesis:

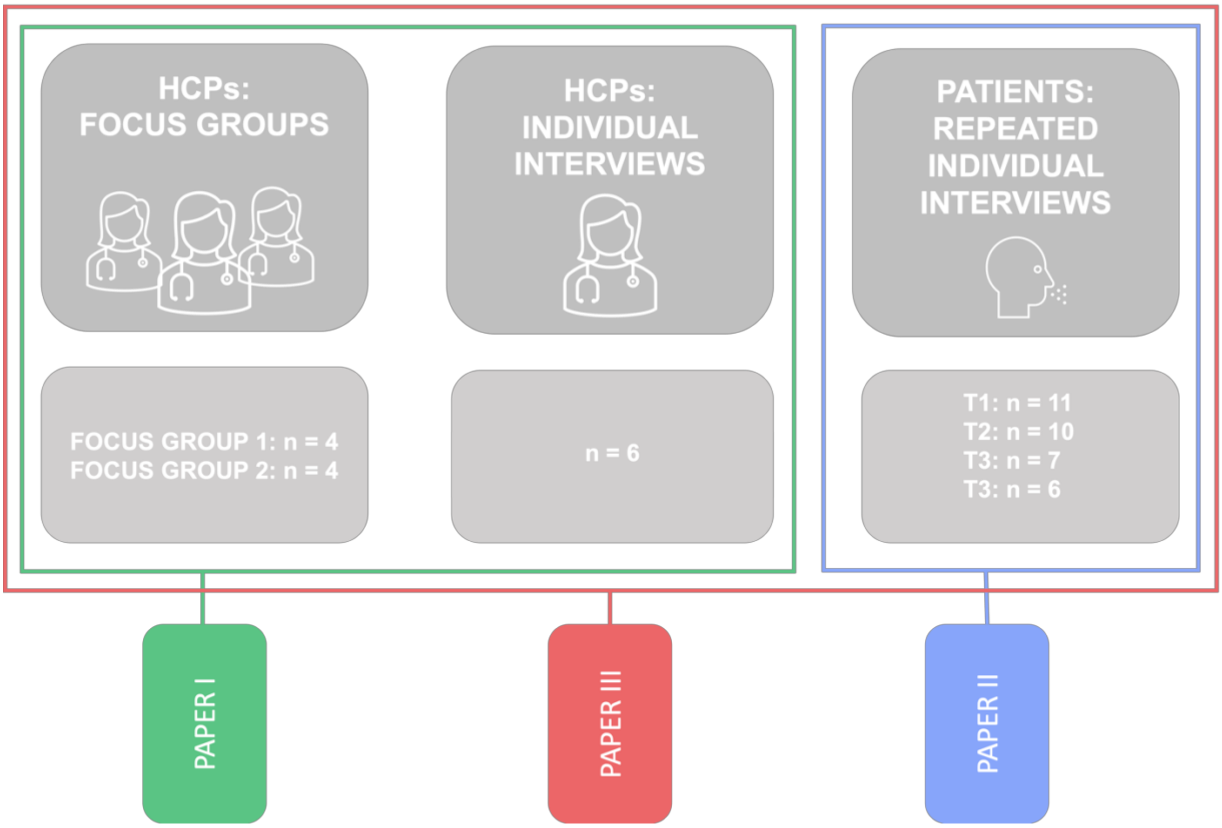

*Figure 5. Overview of the material and data of the three individual papers*

### 4.3.1 Setting

The study was situated in one home care district in a municipality in the eastern part of Norway where RHC was established to provide palliative care for patients with cancer in the palliative phase living at home. A home care district is part of the publicly funded community care services and serves the population living in a defined geographical area (Farsjø et al., 2019). The home care district is densely populated, and all participants lived close to the hospitals and other health care services involved in their care.

### 4.3.2 Recruitment procedures

The HCPs were recruited by a care manager through purposeful sampling (Polit & Beck, 2020) using the following inclusion criteria: interdisciplinary HCPs that had experiences with using RHC in home-based follow-up of patients with cancer in the palliative phase. The population of HCPs with experiences of providing palliative care through RHC was very limited at the time of the data collection. Consequently, purposeful sampling by selecting study cases that were most likely to generate relevant information for the study was deemed appropriate for generation of relevant data (Polit & Beck, 2020). All invited participants agreed to participate in the focus groups (N = 8), and six of the eight included participants agreed to participate in the following individual interviews. All participating HCPs received an information letter containing information regarding the study, the inclusion criteria, and what study participation entailed (Appendix I).

A care manager affiliated with the RHC service team identified and enrolled patients referred to community care services utilizing a purposeful sampling methodology (Polit & Beck, 2020). The inclusion criteria were patients aged 18 years and older, living at home, and diagnosed with incurable cancer in the palliative phase. To achieve diverse experiences with RHC, variations in age, gender, living arrangements, and whether the participants received additional home care nursing were pursued. The care manager contacted potential participants and provided verbal and written information regarding the study, the inclusion criteria, and what study participation entailed (Appendix II). Forty-four patients were invited to participate in the study, and 18 agreed to participate. Due to health-related issues, seven patients were unable to participate, resulting in a total sample of 11 patients. When patients agreed to participate, an initial meeting was scheduled to confirm participation in the study and establish the appropriate follow-up procedures.

### 4.3.3 Participants

#### Interdisciplinary HCPs

The sample of HCPs consisted of two specialized nurses, two nurses, two occupational therapists, one physical therapist, and one social worker. One of the specialized nurses functioned as a cancer care coordinator in the district. The majority of HCPs were experienced providers of RHC, as it was already integrated into the homes of patients suffering from chronic illnesses such as COPD and diabetes. However, most had limited experiences with cancer care and palliative care. Only a few of the HCPs were experienced in cancer care and palliative care; however, they had limited experiences with RHC. The HCPs (N = 8) were both females (n = 6) and males (n = 2) with a mean age of 37 years and a mean of health care work experience of 13 years. The mean years with experience in their current work position was 6 years. All HCPs worked full time, and their years of experience providing primary health services varied from 4 to 27 years.

#### Patients with cancer in palliative phase

All patients suffered from cancer in the palliative phase. The mean age of the patients was 66 (range 30–94) years, and the distribution of females (n = 5) and males (n = 6) was approximately the same. Four patients were cohabiting, and seven lived alone. Three patients received traditional home care nursing in addition to RHC. Some of the patients received palliative chemotherapy (n = 4) or palliative immunotherapy (n = 2).

To provide richer descriptions of experienced presence and severity of symptoms, all patients were asked to rate their symptoms by filling out the ESAS questionnaire (Bruera et al., 1991) for self-reported symptoms prior to each interview. The reports from the patients were variable, indicating that their overall symptom burden frequently changed. Hence, the patients were perceived as heterogeneous in terms of disease load. The presence and severity of pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety, and general well-being reported by patients is presented in Paper II.

## 4.3.4 Data collection

### Focus group interviews with interdisciplinary HCPs

The data collection with interdisciplinary HCPs was initiated with two focus groups in November 2019, approximately 2 years since the first patients with cancer in the palliative phase were included in the study. The composition of the focus groups was made with regard to professional occupation and is displayed in Table 4:

*Table 4. Composition of the two focus groups (N = 8)*

| **Focus group 1 (n = 4)** | **Focus group 2 (n = 4)** |
|---|---|
| Specialized nurse * | Specialized nurse |
| Nurse | Nurse |
| Physical therapist | Physical therapist |
| Social worker | Occupational therapist ** |

* Cancer care coordinator

** Manager and contact person for the study

Focus groups could allow for a broader exploration of a topic or issue, as participants are encouraged to share their thoughts, opinions, and experiences in a group setting. The social interactions between the participants generate the data (Krueger & Casey, 2015), which was considered beneficial for answering the aim of Paper I. The interdisciplinary nature of the HCPs was valued for its potential to offer diverse professional perspectives and experiences, which were seen as valuable for illuminating and discussing the research topic within the group (Krueger & Casey, 2015).

A semi-structured interview guide related to the research questions and based on existing literature in the field (Collier et al., 2016; Dudley et al., 2018; Nilsen et al., 2016; Pols, 2010; van Gurp et al., 2016; van Houwelingen et al., 2016) was developed to facilitate and direct group discussions (Patton, 2015) (Appendix III). Due to the limited population of HCPs possessing the relevant experiences at the time of the data collection, the interview guide was not piloted. However, the interview questions underwent several revisions after author discussions, focusing on content, clarity, and importance. The interview guide addressed four main themes addressing the implementation of RHC for patients with cancer in the palliative phase: expectations, training, use, and cooperation. Question prompts were employed to elicit additional information from the participants (Krueger & Casey, 2015). The participants were encouraged to express their thoughts freely and discuss the topics introduced by the researchers. Both focus groups were conducted in a meeting room at the participants workplace, which was considered both appropriate and comfortable for the participants. The PhD candidate acted as moderator, and the main supervisor functioned as assistant moderator. Both focus group interviews lasted approximately 80 minutes and were audio recorded.

### Individual interviews with interdisciplinary HCPs

Combining focus group interviews with individual interviews is considered beneficial for the provision of a comprehensive and nuanced understanding of the research topic. Involvement in a focus group can stimulate significant reflections among participants after the discussion, insights that could be valuable to capture. Moreover, some participants may hesitate to express their personal views or share certain topics within a group context. They may find these topics easier to address within a one-on-one conversation (Patton, 2015). Important topics that arose during the focus group interviews were identified and further explored through individual interviews with six of the original eight informants.

A semi-structured interview guide based on the themes from the interview guide applied in the focus group interviews and the identified topics was used to facilitate dialogue during the interviews. The following themes were addressed: expectations, use, assessments, remote palliative care, and cooperation (Appendix IV). The PhD candidate conducted the interviews and encouraged the participants to speak freely and elaborate on themes that occurred. Emphasis was placed on making arrangements for the situation to be experienced as a conversation rather than an interview, and attempts were made to provide a space where participants could respond comfortably, accurately, and honestly (Patton, 2015). The individual interviews were conducted at the participants' workplaces between January and February 2020. The interviews lasted between 50 and 70 minutes and were audio recorded.

### Individual interviews with patients

To investigate patients' longitudinal experiences of using RHC over a 16-week period, data were collected by the main supervisor with repeated individual interviews at four different time points over 16 weeks between September 2017 and March 2019. Individual semi-structured interviews were used to capture each patient's unique and personal experience. Furthermore, investigating the same phenomenon in the same group at different points in time could allow for greater understanding of each patient's individual experiences and a longitudinal perspective on whether and how the patients experiences changed over time (Polit & Beck, 2020; Thurmond, 2001).

A semi-structured interview guide was developed (Appendix V). The interview guide consisted of open-ended and probing questions that covered aspects related to the patients' experiences, such as everyday life and health, the use of RHC, impacts of the RHC on daily life and illness management, and expectations of the RHC and follow-ups. The content, clarity, and importance of the interview guide were discussed among authors and revised. The interview guide was not piloted because of the limited study population.

Initially, the plan was to interview the participants about their pre-expectations regarding the use of RHC in advance of receiving the tablet and medical measuring devices. However, after conducting interviews with three patients, it was determined that this approach did not yield sufficient information about the participants' pre-expectations of RHC. As a result, most of the participants were first interviewed (T1) shortly after the RHC home follow-up was implemented in their homes. The second interview (T2) was conducted after 4 weeks of use, and the third and fourth interviews were conducted at 12 (T3) and 16 weeks (T4) of use. The 4- to 8-week interval between interviews was selected to minimize participant burden while allowing for adequate reflection on the use of the RHC application without forgetting important experiences. The interviews took place at a location chosen by the participants, with most being conducted in their homes, except for one in a coffee shop. For two participants, follow-up interviews were conducted over the telephone to avoid potential infection in cases of neutropenia. The interviews were audio recorded, with durations ranging from 9 to 83 minutes. No field notes were taken during or after the interviews. Due to health-related issues, some participants were unable to participate in all four interview sessions. A presentation of the number of patients participating in each interview is displayed in Paper III and Figure 5.

### 4.3.5 Analysis

The data from Paper I and II ware analyzed by qualitative content analysis by the means of Graneheim and Lundman (2004). For Paper III, the datasets from Papers I and II were combined for a secondary analysis, where a deductive reflexive thematic analysis inspired by Braun and Clarke (2022) was applied.

#### Analysis of focus group and individual interview data from patient and HCPs

An inductive qualitative content analysis was utilized to analyze the transcribed data from the focus group interviews and individual interviews with HCPs and patients (Graneheim & Lundman, 2004; Graneheim et al., 2017; Lindgren et al., 2020). A qualitative content analysis involves reducing and making sense of a large volume of qualitative data, with the aim of identifying central consistencies and meanings (Patton, 2015), and allows for an examination of both the manifest (descriptive) and latent (interpretative) content of the participants' statements (Graneheim & Lundman, 2004; Graneheim et al., 2017; Lindgren et al., 2020). The audio recordings were transcribed verbatim, and NVivo 12 was used to facilitate the storage, organization, and analysis of data. This inductive approach began with open observation of the data material, progressed by identifying patterns to synthesis broader and final themes. This process allows results to emerge naturally from the raw data and be sorted into prevalent themes (Patton, 2015). An illustration of the analytical process of developing the main themes for Papers I and II is provided in Figure 6:

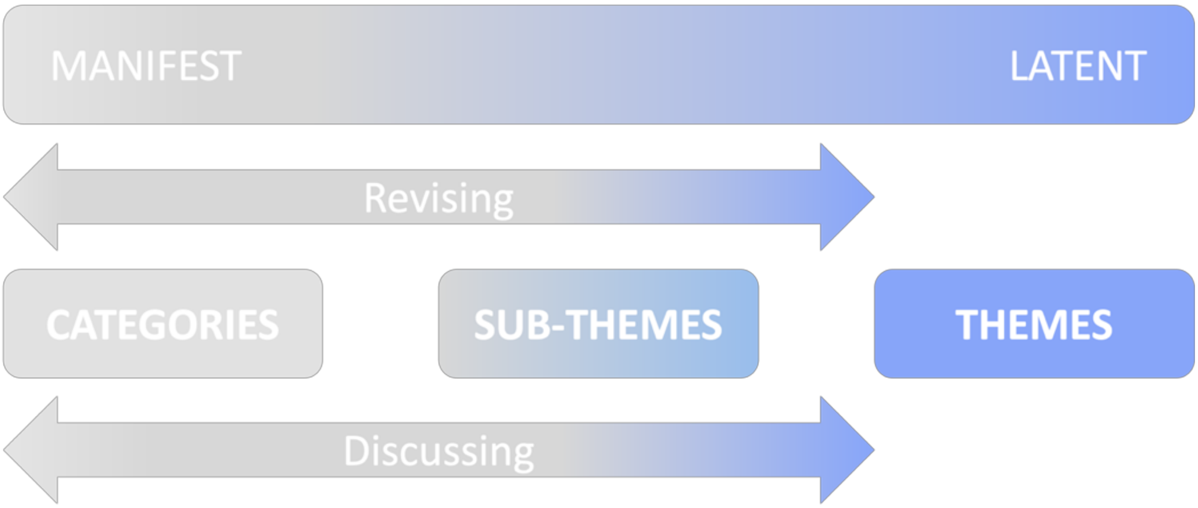

*Figure 6. The analytical process of developing the three main themes.*

For Paper I, transcribed text from the focus group interviews and individual interviews was carefully read multiple times line by line to identify meaning units. Emphasis was placed on avoiding excessively short meaning units to prevent potential loss of context and meaning. The meaning units were condensed, which involved shortening the meaning units by eliminating repetitions and words that were deemed irrelevant while retaining the meaning unit's core content. The condensed meaning units were labelled with a descriptive code at a low level of abstraction and interpretation close to the original text (Lindgren et al., 2020). Based on the spesific aim presented for Paper I, the codes were compared and organized into nine tentative subthemes, each containing several categories that represented the manifest content. This process involved interpreting which groups of codes were interrelated and differed from other groups of codes. Guided by the research questions, these tentative subthemes and categories were discussed back and forth and revised numerous times. To place codes that apparently did not fit into any subtheme, the original aim and data material were revisited. This involved examining the arrangement of meaning units for appropriateness, evaluating the relevance of the codes, checking the level of abstraction and interpretation, and determining whether the subthemes were labeled correctly. Emphasis was placed on capturing the emotions and underlying meanings of the manifest content (Lindgren et al., 2020). Finally, the latent content was categorized into three main themes. The subthemes and themes for Paper I are displayed in Table 5:

*Table 5. Subthemes and themes for Paper I.*

| **Subthemes** | **Themes** |
|---|---|
| Assessment of potential patient burden<br>Assessment of potential patient benefit<br>Implementing a tailored service based on patient's illness experiences<br>Assessments when the patient's condition changes | 1. Shifting from objective measures to assessing priorities for patients |
| Knowledge and competence<br>Work environment interactions | 2. Lack of experience and personal distress of cancer inhibited professional care |
| Inadequate integration of documentation systems<br>Interdisciplinary collaboration at the district level<br>Technological challenges | 3. Prominent organizational challenges question the premises of RHC |

For Paper II, the longitudinal data from patients were analyzed. Transcribed text was organized into cases for each time interval (baseline, 4 weeks, 12 weeks, and 16 weeks) before being condensed into meaning units, which allowed for taking the longitudinal approach into account for a comprehensive understanding of the longitudinal trajectory of each patient (Lindgren et al., 2020; Patton, 2015). Furthermore, the aim was to apply codes that captured the temporal aspect of the data, such as codes that reflected change over time or codes that linked data points across different periods (Patton, 2015). The codes were subjected to a cross-case analysis approach, where patterns that seemed consistent or unique were identified by comparing and contrasting the data across cases to recognize commonalities and differences (Patton, 2015). As Patton (2015) suggested, close attention was paid to the possible contextual explanations of changes in the data, for example, if the patients explained that they had had an episode of acute deterioration followed by a sudden change in satisfaction with the RHC follow-up. Taking the spesific aim for Paper II into account, the codes were compared and grouped into six tentative subthemes, each including multiple categories that represented the manifest content. When codes seemingly did not align with any subtheme, the original aim and data material were revisited. This process entailed reassessing the suitability of how the meaning units were arranged, verifying the relevance of the coding, confirming the degree of abstraction and interpretation, and reviewing the accuracy of the subthemes' labels. The subthemes and categories were repeatedly reviewed and modified until the latent content was classified into three themes (Graneheim & Lundman, 2004; Lindgren et al., 2020). The subthemes and themes for Paper II are displayed in Table 6:

*Table 6. Subthemes and themes for Paper II.*

| **Subthemes** | **Themes** |
|---|---|
| RHC influence on daily life<br>Monitoring of symptoms provides a sense of being in control | 1. Potential to facilitate self-governance in daily life |
| Initiative to communicate and interact with HCPs<br>Ambiguity in the use of RHC | 2. Need for interpersonal relationships and connections |
| Managing the communicational gap between the different levels of health care<br>RHC failure to detect the current situation | 3. Experiences of increased responsibility and unclear utility |

### Secondary analysis of data from patients and HCPs

For Paper III, the transcribed data material from HCPs (Paper I) and patients (Paper II) was combined for a secondary analysis. NVivo 12 facilitated data storage and organization. A deductive reflexive thematic analysis inspired by Braun and Clarke (2022) was applied, as it is considered a beneficial approach for research exploring complex phenomena in depth and for a deeper understanding of the experiences of the participants. Reflexive thematic analysis focuses on identifying patterns or themes within the data and exploring their meaning in relation to the research question (Braun & Clarke, 2022). In a deductive reflexive thematic analysis, the themes are predetermined based on prior theory or research, and the analysis process involves identifying and organizing data that relate to these predetermined themes. This is in contrast to the inductive approach previously described (Papers I and II), where themes emerge from the data through an iterative and bottom-up process (Braun & Clarke, 2022). The predetermined themes were the RE-AIM dimensions of Reach, Effectiveness, Adoption, Implementation, and Maintenance (described in Chapter 2.4.1). Qualitative RE-AIM questions suggested by Holtrop et al. (2018) were used to guide the analysis and assess the perspectives on the implementation of RHC to patients with cancer in the palliative phase and are presented in Table 7:

*Table 7. Qualitative RE-AIM questions (Holtrop et al., 2018)*

| RE-AIM dimensions | Questions guiding the analysis |
|---|---|
| Reach | What factors contribute to the participation/non-participation of the participants?<br>What might have been done to get more of the target audience to participate? |
| Effectiveness | Did the intervention work to affect the outcomes noted?<br>What other factors contributed to the results?<br>Are the results meaningful? |
| Adoption | What factors contributed to the organization and its individuals taking up the intervention?<br>What barriers interacted with the intervention to prevent adoption?<br>Was there partial or complete adoption? |
| Implementation | How was the intervention implemented?<br>By whom and when?<br>What influenced implementation or lack of implementation?<br>How and why was the program or policy adapted or modified over time? |
| Maintenance | Is the intervention being implemented (and adapted) after the intervention core period?<br>What is sustained, what discontinued, what modified, and why? |

The first phase of the deductive reflexive thematic analysis included familiarization with the dataset. The RE-AIM dimensions were applied to the data to provide an initial structure according to each dimension. The datasets were read, re-read, and rearranged multiple times to determine dimensional belonging and to recognize meanings and patterns across the datasets.

The second phase is the generation of codes. To capture the substantial meanings in the dataset, the initially structured data extracted from the patients and HCPs were coded using semantic codes. Semantic coding involves coding the data at a descriptive level, identifying and labeling features of the data that are readily visible, and can help to identify patterns and themes that are based on the explicit content of the data. The semantic codes were revised and processed looking for deeper, hidden meanings and labelled with latent codes, capturing these implicit meanings (Braun & Clarke, 2022). Taking the deductive orientation into account, the latent codes were revised and rearranged according to the RE-AIM dimensions.

The third and fourth phase includes constructing and reviewing potential themes. Using some of the qualitative RE-AIM data questions suggested by Holtrop et al. (2018) (described in Chapter 2.4.1. and Table 7), the latent codes were created and modified multiple times before assembled into potential themes and later themes.

To help identify patterns and connections between different codes or themes, visual mapping was applied. Visual mapping was considered a supportive tool assessing the large and complex data material, as it helped to simplify and condense the information in a way that was easier to understand and work with (Braun & Clarke, 2022). An example of the visual mapping is provided in Paper III.

Phase five included defining and naming themes. This final phase and interpretation of the data were discussed in their entirety by the first (PhD candidate), second (co-supervisor), and final (main supervisor) authors of Paper III. The five themes that emerged from the data were reviewed and adjusted based on the RE-AIM dimensions to ensure that they accurately reflected significant patterns across the dataset:

1. Reach: Protective actions in recruitment—gatekeeping
2. Effectiveness: Potential to offer person-centered care
3. Adoption: Balancing high touch with high tech

4. Implementation: Moving toward a common understanding
5. Maintenance: Adjusting to what really matters

In phase six, the PhD candidate wrote a text presenting the preliminary results, which was carefully read, discussed, and subsequently revised in collaboration with all the coauthors for Paper III.

### 4.3.6 Ethical considerations

This study was approved by the Norwegian Centre for Research Data (reference number: 429408) and the municipality involved. This study was not categorized as medical or health research (defined as research on humans, human biological material, and personal health information aimed at generating new knowledge about diseases and health) and was thereby exempted from review by the Norwegian Regional Committee for Medical and Health Research Ethics.

Patients with a limited life expectancy, such as the patients included in this study, are generally considered to be vulnerable research subjects, and it has been discussed whether research on people in vulnerable situations triggers special ethical considerations. Participants with limited life expectancy seldom expect to benefit personally from the research, so the risk/benefit ratio needs to be assessed (Polit & Beck, 2020). Participation in research may imply an additional burden for these patients. To minimize the burdens associated with study participation, respect participants' autonomy and privacy, and reduce potential stress associated with the interview topics, all patients were interviewed in their preferred settings (Polit & Beck, 2020). A thorough consideration of the time investment required from the patients to participate in interviews, which may be valuable to them due to their health condition, was made. These interviews were carried out by the main supervisor, who has extensive experience as a nurse for patients with cancer in the palliative phase with competence to meet emotional responses that could arise during the interviews. Consent for participation was obtained anew prior to each individual interview, and the interviewer was attentive to the patients' cues to avoid pressuring them if they were uncertain about continuing participation due to poor health or other reasons.

The focus groups and individual interviews with HCPs were conducted in a meeting room at their workplace at a time that was approved by the individual. Including the project manager for the implementation of RHC in the city district in the study sample represents a potential risk of imbalanced power hierarchies within the focus groups. Ideally, such power differentials should be avoided to ensure open, unbiased dialogue (Krueger & Casey, 2015). To mitigate the potential of imbalanced power balances within the data and secure open-minded free speech, all participants from the focus groups were invited to participate in individual interviews where they could freely share their experiences without concern for what the project leader might think about the experiences they shared.

Patients and HCPs received oral and written information and were asked to give written informed consent prior to participation (Appendices I and II). The information clarified that it was voluntary to participate and that the participants could withdraw from the study at any time without any consequences. The data material was dealt with in accordance with the guidelines set forth by the Norwegian Centre for Research Data and the rules of research ethics at the Lovisenberg Diaconal University College. Data were treated confidentially to preserve the participants' requirements for anonymity. Results from the studies were published in such a way that it was impossible to recognize individuals, maintaining their confidentiality.

# 5 RESULTS

The principal results of the study are reported in three individual papers and will be presented in individual chapters, followed by a final chapter presenting convergent and divergent results across the individual papers.

## 5.1 Results of Paper I

The aim of Paper I was to explore municipal HCPs' experiences regarding the significant challenges, facilitators, and assessments associated with implementing RHC in palliative home care for patients with cancer.

HCPs perceived RHC as beneficial for enhancing patients' feelings of safety at home. RHC provided HCPs with access to patients who were previously hard to reach, such as patients who felt ashamed about their living situation and had previously refused contact with home care services. Shortly after implementation of RHC, the HCPs found that tailored clinical questions based on the ESAS questionnaire were more beneficial for making clinical assessments than data derived from the installed medical measuring devices. Furthermore, HCPs experienced that RHC facilitated HCP-patient relationships, and many experienced knowing their patients well. However, the HCPs expressed that in conversations, patients often shifted to mundane topics such as the weather and seemed to avoid focusing on matters related to their illness. This led to feelings of being unable to help, which in turn affected their confidence in their job. Furthermore, HCPs expressed frustration in assessing the causes of changes in patients' reported symptom scores due to the limitations of RHC software, such as the lack of branched questions that directs respondents to different subsequent questions based on their answers. This was especially highlighted as a missing feature when assessing the patients reported pain.

Thus, the HCPs highlighted the need for more flexibility, solution orientation, and a more tailored approach to provide optimal care to patients with cancer in the palliative phase. Furthermore, the results revealed that the tablet-based questionnaires did not include any questions concerning spiritual and existential needs, which were left unattended unless either the HCPs or the patients specifically brought up these aspects in their encounters on the telephone.

None of the HCPs received training in palliative care or cancer care before the RHC was implemented. This was perceived as unfavorable, and the HCPs expressed worries about their ability to capture important changes in patients and highlighted a need for more knowledge and competence to base their assessments on. Furthermore, HCPs expressed feelings of fear and insecurity toward cancer and death, which was linked to the perception that cancer is equal to death and their personal experiences and attitudes toward death. This fear challenged several aspects of their work, particularly in addressing the severity of the cancer prognosis in conversations with patients. However, external guidance from a nurse specialized in palliative care and cancer care helped establish a safe area where problems and challenges could be discussed, making issues with cancer and death less intimidating.

The main challenge with introducing the RHC to patients with cancer in the palliative phase was the lack of integration in documentation systems and cooperation between and across the diversity of health care services involved in care for the patients. This led to added work, a time-consuming process of obtaining necessary patient information, and interrupted information flow between different HCPs. The unfamiliarity of RHC among HCPs outside of the RHC service team also caused difficulties in communication and patient care. This led to a shift of responsibility onto patients with additional work because they had to physically bring their tablets and update different HCPs on their treatment. HCPs emphasized the need for changes and improvements in technological infrastructure to ensure optimal functioning of the RHC.

## 5.2 Results of Paper II

The aim of Paper II was to explore the longitudinal experiences using RHC for palliative care among patients with cancer living at home.

Some patients experienced their everyday lives as predominantly shaped by their illness and displayed emotional responses and teared up when discussing their overall well-being in interviews. Some provided detailed accounts of the consequences of living with an incurable illness, whereas others avoided addressing this aspect and redirected the conversation to different topics whenever the interviewer touched on their diagnosis. RHC provided enhanced routines and control and strengthened patients' capability to manage their illness at home. Assessing symptoms and reporting measurements such as weight, saturation, or blood pressure on a regular basis was considered by patients to be a support for engaging in a more active and governing role related to their illness. Although some patients relied more on their bodily sensations and changes, most patients appreciated the ability to visualize the progression of symptoms in the RHC tablet device. Some patients stated that the provision of statistics and "hard facts" was seen as a source of motivation, for example, by encouraging them to make an effort to eat even when their appetite was poor. Most patients stated that the availability of HCPs through RHC assured them that someone paid attention to their needs and enhanced their feelings of safety at home.

Patients stated that they experienced barriers to contacting HCPs by telephone or chat in situations where they needed support for psychosocial issues such as anxiety or depressive thoughts. Personal relationships and close connections with HCPs were, however, considered by patients as prerequisites for illness management. Patients regarded personal interaction as a crucial element in managing their illness and daily life. Family members were viewed as a major asset in this context, and many patients saw them as their principal source of support in day-to-day life. Furthermore, patients regarded the RHC as a service where they could channel everything related to their illness and ailments to one place. This helped take their minds off the illness and facilitated a re-establishment of meaningful relationships with friends and family. Most patients appreciated the ability to chat and telephone with the RHC service team. However, a few patients, particularly those living alone, expressed feelings of isolation and loneliness, as well as missed opportunities for social contact during the day. In addition, patients highlighted a need for physical assessments of their actual needs. Some patients requested a more personal relationship with the HCPs employed at the RHC service team and expressed a desire to get to know the person "sitting on the other side of the tablet."

Over time, patients experienced a lack of flexibility and deficient tailoring of the RHC content, and the results indicate that using RHC did not alleviate the patients' perception of fragmented health care follow-up. Patients felt responsible for informing the HCPs about details regarding changes in symptoms and treatment regimens, such as medication. Many patients expressed that they spent a considerable amount of valuable time managing doctor's appointments and other related commitments associated with their illness. Furthermore, patients who received treatment and care from multiple HCPs anchored in both specialized and primary health care services felt confused regarding who was responsible for what regarding their health.

## 5.3 Results of Paper III

Paper III aimed to report on the implementation of RHC for home-living patients in the palliative phase of cancer using the RE-AIM framework. Areas of particular importance determining the sustainability of technologies for remote palliative home-based care were explored.

The results suggest that once referred to RHC, patients held positive expectations regarding RHC and found it meaningful to contribute to the development of a new service that could potentially benefit others. However, HCPs felt responsible for not imposing unnecessary stress onto patients they perceived to be frail and vulnerable. Furthermore, HCPs involved in the recruitment of patients eligible for receiving RHC, found the term "incurable ill" to be unpleasant to address when reaching out to patients, which led to reluctance and insecurity in the recruitment process. This resulted in gatekeeping behavior influencing the introduction of RHC to patients with cancer in the palliative phase. This gatekeeping behavior may have prevented access to RHC for eligible patients, hindering RHC *Reach*.

RHC was experienced by HCPs as beneficial for providing care to patients with other chronic conditions, such as COPD and diabetes. Considering patients with cancer in the palliative phase, RHC demonstrated *Effectiveness* by providing patients and HCPs with an overview of symptom development. However, some patients experienced RHC as a static service unable to facilitate their changing condition. Furthermore, opportunities for more face-to-face communication were highlighted as a missing feature of the RHC.

Patients experienced poor integration and increased service complexity, which affected their *Adoption* of RHC. Although most of the HCPs were experienced RHC users and held favorable views toward technology, they were less experienced with patients with cancer in the palliative phase. When patients in the palliative phase of cancer were included in RHC, it brought about additional care requirements and caused shifts in HCPs’ attitudes. HCPs expressed doubt about introducing RHC to such patients, particularly due to the absence of physical proximity. Furthermore, no competence-raising measures were implemented prior to the introduction of RHC to patients with cancer in the palliative phase. These factors represent a hindrance to HCPs’ *Adoption* of RHC and further impacted RHC *Implementation*. Another factor significant to RHC *Implementation* was HCPs’ challenges with access to important patient information. Consequently, the HCPs had to depend on the patients themselves to provide the necessary information.

The HCPs reported positive internal collaboration within the RHC service team, emphasizing transparency in addressing challenges, skepticism, and gaps in expertise. Recognizing the need for additional support was perceived as crucial and played a significant role in facilitating the *Adoption*, *Implementation*, and *Maintenance* of RHC as a satisfactory follow-up for patients with cancer in the palliative phase.

The RHC was *Maintained* as a service for patients in the palliative phase of cancer. The experiences of HCPs led to a shift toward a more person-centered approach, where the objective measurements from the medical measurement devices were given less attention, and an increased focus on tailoring the questions for symptom mapping was applied.

## 5.4 Results across papers

The results from Paper I revealed that the HCPs involved in the recruitment of patients went beyond the predefined criteria for receiving RHC and made decisions regarding participation on behalf of the patients. These decisions were based on the HCPs’ personal perception of RHC as potentially burdensome for patients with cancer in the palliative phase, leading them to make subjective judgments about patients’ ability and readiness to use RHC and engage in the follow-up. For Paper III, the dimensions of the RE-AIM framework were used in a secondary analysis of the datasets of Papers I and II. This allowed for an extended understanding of the mechanisms involved in this “gatekeeping,” which became a prominent factor for the participation reach of RHC. The gatekeeping behavior by HCPs may have led to the loss of eligible patients who could have benefited greatly from receiving RHC.

The results from Paper II showed that the patients initially held positive views regarding the innovative form of follow-up provided by RHC. However, their confidence waned over time as their symptoms evolved without corresponding adjustments or adaptations from the RHC service. The lack of flexibility and responsiveness in the RHC software to changing patient situations generated uncertainty and diminished faith in the effectiveness of RHC. In contrast, Paper I highlighted that HCPs emphasized a shifted focus from objective measurements of clinical signs to prioritizing patients' self-reporting of symptoms in the follow-up. Combining these results from Papers I and II clarifies that the communication about what RHC should contain and how the follow-up should be between the HCPs and patients did not function satisfactorily.

The results from Paper II indicate that the introduction of RHC did not alleviate the patients' perception of fragmented health care services, an observation mirroring the HCPs' experiences presented in Paper I. Patients perceived a sense of responsibility to apprise HCP of any modifications in their treatment regimen (Paper II). This perception aligns with the HCPs' experience, as they found themselves reliant on patients to supply necessary information to facilitate appropriate RHC provision (Paper I). Furthermore, HCPs found the data patients transmitted via RHC insufficient for comprehensive assessments (Paper I). Despite these challenges, which primarily surfaced after an initial RHC usage period, patients recognized that RHC enhanced their sense of safety and security at home. That someone was monitoring their condition and had access to data regarding symptom progression or changes provided reassurance (Paper II). Conversely, HCPs expressed uncertainty and a perceived competence deficiency in providing optimal follow-up due to patients' cancer diagnosis. This feeling was tied to their personal fears and past experiences with the unpredictable and severe nature of cancer (Papers I and III). Notably, the results from Papers I and III highlight that HCPs received no training before implementing RHC for patients with cancer in the palliative phase. This lack of specialized knowledge heightened HCPs' discomfort when discussing diagnoses with patients and contributed to feelings of inadequacy.

# 6 DISCUSSION

The overall aim of the study was to elicit the experiences with and viability of RHC in palliative home care for patients with cancer. This chapter presents a comprehensive discussion on the main study results, highlighting the potential of RHC to deliver person-centered palliative care. It draws upon the concepts outlined in the 6S model (Chapter 6.1) and focuses on findings related to implementing RHC in palliative home care. Emphasis is placed on patient vulnerability and the intervention's complexity, guided by the RE-AIM Framework (Chapter 6.2).

## 6.1 RHC's potential to offer person-centered palliative care

The 6S model suggests an approach that combines the principles of person-centered care with the WHO's definition of palliative care and focuses on how one's self-image can be enhanced during severe illness and toward the end of life (Österlind, 2022; Österlind & Henoch, 2021). By considering six concepts - *self-image*, *symptom relief*, *social relations*, *synthesis and strategies*, and *self-determination* - the 6S model for person-centered palliative care may ensure increased knowledge of the complex, interrelated issues that patients may experience in palliative care (Österlind & Henoch, 2021). Guided by the concepts of the 6S model, the upcoming chapters will discuss the potential of RHC to provide person-centered palliative care.

### 6.1.1 Preservation of self-image and relief of symptoms

The concept of *self-image*, as highlighted in the 6S model, is the most central aspect in person-centered palliative care. The definition of self-image includes identity, self-awareness, and understanding of oneself in relation to others, which emphasizes that the self-image depends on how a person is met when they become seriously ill or weakened by age. A person's self-image and identity change throughout life and develop in relation to others (Johansson, 2002; Österlind, 2022).

As documented in Paper II, the patients in this study exhibited a wide range of symptoms in both frequency and intensity, with their overall symptom burden showing frequent changes. In addition, Papers I and III highlight that HCPs experienced that patients reported unexpected and fluctuating symptoms and measurements and described feelings of anxiety. To live with bothersome symptoms can lead to an individual who previously managed on their own becoming dependent on others. When individuals become dependent on others for their daily life, they may also feel like a burden. All of this can influence how one perceives oneself and cause a shift in their identity. In turn, this can lead to feelings of sadness and depression, which is a natural reaction to the circumstances. Illness can lead to the loss of both physical and cognitive functions, which may hinder engaging in typical activities such as work and leisure. When patients cannot participate as before, they may lose their roles and consequently lose opportunities for affirmation of their identity (Österlind, 2022), which can be utterly challenged in services such as the RHC under study, where physical encounters between HCPs and patients is limited.

Furthermore, several of the patients in this study were affected when their diagnosis was addressed. Some became emotional, whereas others quickly steered the conversation toward other more trivial topics (Paper II). Patients’ emotions in relation to their illness may be closely connected to their personality, which may play a significant role in how patients handle the burden of their illness, manage symptoms, and interact with HCPs. In times of threat to one’s life or identity, certain personality traits may become more prominent, and it is important for HCPs to be aware of each individual’s degree of vulnerability and need for control. Patients with a high degree of vulnerability, such as patients suffering from cancer in the palliative phase, could react with feelings of fear, sadness, or guilt. They may appear helpless, and HCPs might unintentionally downplay their concerns, potentially leading to a perception of rejection and hindering the patient-provider relationship. However, patients who exhibit a strong need for control often request detailed information, display minimal emotional expression, and may experience feelings of shame (Loge et al., 2006). Patients need to discuss their emotions regarding changes from illness to preserve their self-image, (Österlind, 2022). Such opportunities for discussion were available to the patients in this study through the chat feature in RHC or via phone calls. The initial assessment visit where the appropriate form of follow-up was determined was also an option. However, Papers I and III highlight that the HCPs experienced fears and uncertainties regarding the patients’ fluctuating symptoms and diagnoses. This led to HCPs being hesitant to talk about the patients' emotions in relation to their diagnosis, which may have utterly challenged patients' need to discuss their emotions.

According to the national guidelines for palliative cancer care, patients' opportunities to live an active life until death should be emphasized when planning and coordinating care (The Norwegian Directorate of Health, 2019). In addition, one of the objectives of services such as RHC is to enable patients to stay in their own homes longer (The Norwegian Directorate of Health, 2022b), thereby enhancing their perception of normalcy in daily life amidst illness. Consequently, planning for sustained normality is essential. Dadich et al. (2023) found that brilliant community-based palliative care is achieved by focusing on preserving a sense of normalcy for both patients and their caregivers, although living with an incurable illness can compromise an individual's sense of physical safety and mental well-being. In Paper II, RHC was considered beneficial for providing patients with an increased sense of safety in their own homes. However, this sense was not connected directly to such a feeling of increased normalcy as Dadich et al. (2023) suggested but more to the reassurance of knowing that someone paid close attention to their needs. This finding is supported by previous research indicating that the potential of welfare technology for expressing emotions and concerns, coupled with the assurance that someone will provide a response, can have positive effects for patients' experience of safety at home (Capurro et al., 2014). Furthermore, the availability of HCPs through technology promotes patients' peace of mind and relief (van Gurp et al., 2015). Such a sense of safety is highlighted as crucial for successful specialized palliative home care, enabling patients and their families to receive care at home. This sense of security is nurtured by HCPs' availability, proactive actions taken, and attentiveness to the needs and wishes of patients, thereby providing treatment that facilitates for preservation of patients' self-image (Seipp et al., 2021).

Relief of symptoms contributes to relief of suffering and is a part of the definition of palliative care (WHO, 2020). The term relief of suffering is based on the concept of *total pain*, as suffering encompasses all of a person's physical, psychological, social, spiritual, and practical struggles (Richmond, 2005). For example, physical pain is affected by the patient's psychological and social well-being and vice versa (Österlind, 2022). Although there is conflicting evidence concerning the efficacy of welfare technology in enhancing symptom management for patients in the palliative phase (Steindal et al., 2023), studies suggest that technology-driven monitoring and symptom management can be both advantageous and feasible for patients (Bonsignore et al., 2018; Hennemann-Krause et al., 2015).This concurs with the results of Paper III, where RHC demonstrated effectiveness for managing illness at home by facilitating strategies for symptom management and was considered beneficial by patients for improved routines and support at home. This helped them to maintain their daily activities (Paper II) and may have facilitated preserving their-image and identity. This effectiveness of RHC was made possible by setting specific times in the RHC for assessing symptoms, medical measurements, and medication.

The results from Papers I, II, and III show conflicting results from patients and HCPs regarding the tailoring of RHC as patients' illness and symptoms progressed, which clarifies that patients and HCPs had different experiences with regard to the adaption of RHC. Whereas patients experienced the RHC as a static an inflexible service unable to keep up with their changing symptoms and altered needs (Paper II), the HCPs explained that they continuously tailored the content of the RHC based on patients' reported symptoms (Paper I). Patients' experiences of an unsystematic reevaluation and reassessment of their symptoms may represent a lack of systematic symptom control, which is identified as a barrier in palliative care (Kaasa et al., 2018), and contrast with the initial feelings of safety reported by patients in Paper II. When researching literature for this thesis, it became apparent that varying perceptions of time might have contributed to shaping these diverse experiences of the patients and HCPs of this study. There is research suggesting that perceptions of time can vary significantly among individuals, including those living with serious or incurable diseases (Lövgren et al., 2010; van Laarhoven et al., 2011). The perception of time can vary depending on many factors, including the person's age, culture, health status, and psychological state. For instance, individuals living with serious diseases may perceive time differently than those who are healthy (van Laarhoven et al., 2011). Furthermore, research suggests that those with advanced cancer is found perceive time as passing slowly (van Laarhoven et al., 2011), which may be congruent with the experiences of patients in this study. When facing a limited lifespan, such as the patients in this study, each day, hour, or even minute may feel more valuable and urgent.

Based on the previous research on perceptions of time (Lövgren et al., 2010; van Laarhoven et al., 2011), the necessity to reevaluate and modify the RHC based on the changing needs of patients during the 16-week intervention period in this study may have been perceived differently by HCPs and patients. For HCPs, who are accustomed to a fast-paced work environment, these 16 weeks may have passed quickly, However, for patients with cancer in the palliative phase, the same period may have felt much longer. These perspectives may be important to consider in comprehending why, in Paper I, patients experienced that their RHC was not adjusted as their condition changed, whereas on the other hand, Paper II demonstrated that the HCPs perceived that they continuously assessed the patient's condition and correspondingly adjusted the RHC. The experience of time as a "problem," as mentioned by Lövgren et al. (2010), highlights that a critical aspect of health care delivery is the patient's experience during waiting period, which indicates that if RHC is not responsive enough to adapt quickly to a patient's evolving condition, as suggested by the results of this study, it may mirror the experience of a lengthy waiting period without adequate information or support. Such waiting may result in a psychological and emotional toll on the patient, as the wait for necessary symptom relief (Lövgren et al., 2010). From this viewpoint, it is posited that if alterations in RHC were perceived as prolonged by patients, this could potentially heighten their feelings of uncertainty and vulnerability. Thus, incorporating RHC into person-centered palliative care involves HCPs commitment to real-time, responsive care adjustments. RHC should be designed with sensitivity to the fact that delays in updating care to suit changing patient symptoms and needs can have a profound negative psychological impact. From the perspectives of the 6S model for person-centered palliative care (Österlind, 2022), it should be acknowledged that waiting for RHC adjustments leads to unfulfilled symptom relief and may be a source of significant stress, which can impact patients' identity and limit their sense of autonomy and dignity.

Coyle (2004) argued that a diagnosis of a life-threatening illness acts as a catalyst, forcing people to confront their own mortality, an awareness that is typically kept comfortably in the background throughout most of people's lives. Such a confrontation is suggested in this study, where patients found the physical presence of RHC devices in their home and the visualization of developing symptoms as presented in the tablet to be reminders of illness and pending death (Paper II). The act of opening the door to one's own mortality often leads many individuals to experience a personal crisis and a profound encounter with overwhelming and total pain (Coyle, 2004), which highlights the need for relief of symptoms and support for a preservation of their self-image. The results from this study indicates that the RHC service team emphasized personal relationships and good knowledge of the patient as a prerequisite for being able to offer a good service (Paper I), whereas patients sought more physical assessment of their actual needs (Paper II), which indicates that the preservation of a patient’s self-image could become challenging with RHC, where physical interactions between the patient and HCPs are limited to occasional visits from the cancer care coordinator and primarily rely on communication via chat or phone (Papers I, II, and III). To ensure a person-centered approach in RHC that preserves the patient’s self-image and relief of symptoms, it might be beneficial to prioritize building relationships and fostering familiarity to a greater extent, with more frequent intervals physical encounters throughout the follow-up period. Österlind (2022) suggested asking the questions: *What do we need to know about you to tailor the care according to your needs as much as possible? What troubles you the most?* Based on each individual’s self-descriptions, HCPs can gain an understanding of who the person is, what is central in their life and lifestyle, and what are their most troublesome symptoms. By incorporating the questions proposed by Österlind (2022) and recognizing that the perception of time is subjective and can shift depending on the situation, it is possible that the patients’ perception of RHC as inflexible and not keeping up with their evolving symptoms and needs could have been avoided. Additionally, such an approach would contribute to facilitation of a person-centered RHC.

### 6.1.2 Social relations

Social relations are of great importance to patients’ daily lives and quality of life (Österlind, 2022). However, when the patient requires significantly more assistance than they can reciprocate from their close family members, they may perceive themselves as a burden. This sensation of burdening others can lead to diminished feelings of dignity and a sense of guilt, which can influence their self-perception and autonomy. In palliative care, HCPs can have a significant role in helping patients maintain their social relations by being observant, listening, and validating (Österlind & Henoch, 2021). The RHC in this study was based on remote reporting of symptoms and transmissions of medical measurements through a tablet device and had no possibilities for video consultations. However, it had certain human components embedded, such as scheduled telephone conversations. These human components were highly appreciated and considered by patients and HCPs as pivotal for building patient–HCP relationships and the experiences of a satisfactory follow-up (Papers I and II). Similarly, van Gurp et al. (2015) found that teleconsultations have the potential to foster empathetic connections between patients and palliative care specialists, allowing for care that both is professionally responsive to the patients’ individual circumstances and further facilitates patient involvement.

Despite the highly appreciated telephone conversations, patients in this study expressed a need to get to know the person sitting on “the other side of the tablet,” missed more opportunities to interact with the RHC service team face to face and pointed out the necessity for physical assessment of their actual needs. Furthermore, some patients expressed feelings of isolation and loneliness and missed opportunities for social contact during the day, especially those living alone (Paper II). Stajduhar et al. (2010) found that patients suffering from incurable cancer appreciated undivided attention from HCPs, even in the context of limited consultation time. Nonetheless, when implementing technologies for remote patient monitoring, such as the RHC, there is a potential risk of HCPs having reduced time for personal interaction and understanding of their patients. The formation of trust-based relationships between patients and HCPs, along with the opportunity to deliver and accept a compassionate touch, could be put to the test when care is administered remotely (Dorsey & Topol, 2016; Steindal et al., 2020). This could be detrimental in a palliative care setting, where cultivating strong relationships is crucial (Payne et al., 2020).

Patients in this study emphasized family members as their most important source of support in day-to-day life (Paper II). Such an importance of social relationships, particularly in the context of palliative care, is well documented, and the role of family and friends is considered a crucial source of comfort, support, and practical help (Österlind, 2022). Furthermore, the patients in this study highlighted RHC as a service where they could channel all illness-related matters in one place, which in turn made them think of themselves as less of a burden and facilitated greater relationships with friends and family. Palliative care also includes care for the patient’s family and caregivers (Radbruch et al., 2020; WHO, 2020). Person-centered care is crucial not only for the well-being of the individuals who are ill but also for their relatives to provide effective support. It is also essential for the relatives themselves to maintain their own well-being and cope with the challenges (Österlind, 2022). However, in the case of services such as the RHC in this study, which are primarily designed as tools for exchanging information between patients and HCPs, maintaining a natural connection with the patient’s relatives can be challenging.

In this study, the majority of patients had contact with the cancer care coordinator in the district on a regular basis. In Norway, cancer care coordinators are integral to cancer care, offering coordination of services, information, and support to patients and their families across all stages of the illness. This accessible, low-threshold service is incorporated into the standardized cancer care pathways in most municipalities, ensuring follow-up and care. By collaborating with various stakeholders, cancer care coordinators aim to establish effective routines and support networks to enhance the quality of cancer care (Oslo Economics, 2017). In a study examining the experiences and critical reflections of prostate cancer survivors regarding the information received throughout their cancer trajectory, patients perceived the cancer care coordinator as caring and service-minded, which fostered a sense of support and facilitated open discussion of their issues (Aunan et al., 2021). Similarly, both patients and HCPs in this study highlighted the cancer care coordinator as highly significant. Patients appreciated the face-to-face contact (Paper II), and the HCPs relied on the cancer care coordinator's expertise in cancer care and palliative care in situations where they were unsure of how to act (Paper I). Furthermore, the cancer care coordinator functioned as a link between patients, their relatives, and the RHC service. These results collectively clarify that the role of the cancer care coordinator is significant when care is provided remotely in terms of being a liaison between the patient and the health care services, thereby creating meaningful social relationships that are crucial for person-centered palliative care.

As mentioned, RHC is primarily a service for exchanging information regarding symptoms and clinical signs. The patient is the one who sends the information, and the patient's social relationships are given little emphasis. However, the results of this study indicate that RHC can serve as a supportive tool for patients that could enable them to continue residing in their homes and thereby uphold their social relationships. Thus, it can be argued that RHC indirectly facilitates the maintenance and enhancement of patients' social relationships in line with the 6S model for person-centered palliative care. However, in future health care services where care will be offered remotely through technology to a greater extent, the importance of social relationships must be significantly emphasized. To ensure person-centered palliative RHC where social relationships are maintained, the patient and their relatives rely both on each other and the HCPs involved in care. Therefore, it is crucial that all parties cooperate on the care based on the patient's expressed needs (Österlind, 2022). In terms of offering person-centered care as suggested by the 6S model, the initial RHC assessment visit should also emphasize questions concerning the patients' social relationships by asking questions such as

*Who do you consider to be closest to you? Who do you consider as your next of kin?* (Österlind, 2022). HCPs may presume that patients identify their immediate relatives as their closest kin. However, social relationships and the social network look different for different individuals and often vary over time. Some people have a large social circle, whereas others have few or no close connections. Relationships can also vary from being very close at one point in life to becoming more peripheral later on. Thus, it is paramount that the identification of such individuals comes directly from the patient. Such information becomes crucial in circumstances where it is necessary to contact family members, or when the patient develops cognitive deficits and can no longer accurately identify the appropriate individual (Österlind, 2022; Österlind & Henoch, 2021).

### 6.1.3 Synthesis and strategies

The concepts of synthesis and strategies in the 6S model revolve around the existential concerns that often become more pronounced as one approaches the end of life. These two concepts are interconnected. Synthesis involves the retrospective process of summarizing one's life and reflecting on past situations and experiences, whereas strategies are forward-looking and pertain to the remaining life ahead (Österlind, 2022; Österlind & Henoch, 2021).

The existential dimension deals with questions that are crucial to human existence and are brought to the forefront when this existence is threatened (Österlind, 2022), such as when diagnosed with cancer in the palliative phase. The results from Paper III highlighted that patients recruited for participating in this study considered it meaningful to contribute to the development of a service that might be to the benefit of others later. This is supported by previous research stating that patients with cancer nearing the end of their lives may have selfless life goals, such as desiring a meaningful existence, feeling connected to something greater, and contributing to society (Bloomer et al., 2017; Brohard, 2020). However, several factors, such as the advancement of the cancer, preexisting medical conditions, and symptoms such as pain, difficulty breathing, anxiety, depression, and delirium, can hinder seriously ill individuals from maintaining meaningful activities (Stark et al., 2012). The patients in this study suffered from cancer in the palliative phase, which may entail anxiety and depressive symptoms, stemming from factors such as uncertainty, anticipation of suffering and losses, and fear of mortality (Stark et al., 2002; Traeger et al., 2012).

In Paper II, patients stated that they experienced barriers to contacting HCPs by telephone or chat in situations where they needed support for psychosocial issues such as anxiety or depressive thoughts. In addition, in Paper I, the HCPs expressed that in conversations, patients quickly shifted to everyday topics, such as the weather, and seemed to avoid focusing on matters related to their illness. Although HCPs may consider everyday topics mundane, they can hold significant importance for patients. Providing person-centered palliative care requires HCPs to actively seek opportunities to engage with patients regarding their personal narratives, including stories from their past, present, and future aspirations. It is also crucial that HCPs receive and respond to the patient's account in a way that positively impacts the patient's self-perception and sense of identity (Österlind, 2022). However, instead of acknowledging the importance of these conversation topics, the HCPs in this study were left with a feeling of being unable to help, which in turn affected their confidence in their job (Paper I). These suggested failures in RHC to facilitate patients' psychosocial needs (Paper II) were utterly amplified by several of the HCPs perceiving the words cancer and incurable as unpleasant (Paper I). This displeasure could also represent the HCPs personal fear of cancer, which concurs with the general cultural perception of the word cancer as something associated with death and pain (Loge et al., 2006). The HCPs in this study shared a similar fear of cancer and death, which was amplified by their limited prior experience and insufficient expertise in providing care for patients with cancer (Papers I and III). This fear led to a hesitation in the HCPs regarding discussing with the patients about topics related to their diagnosis.

Besides experiencing barriers of contacting HCPs through RHC for needed support for psychosocial issues (Paper II), no patients in this study made statements indicating an unfulfilled attention to their existential or spiritual needs. However, questions dealing with existential matters were not addressed in the questions for symptom mapping in the RHC and were left unattended unless either the HCPs or the patients specifically brought up these aspects in their encounters on the telephone. The difficulty in measuring and quantifying these concerns may have contributed to this phenomenon (Payne et al., 2020) and is contradictory to previous research stating that addressing the needs of individuals requiring palliative care necessitates acknowledging and engaging with patients' spiritual dimension (Quinn & Connolly, 2023). Incorporation of spiritual care within palliative care is significant to patients' experiences of attention of to their spiritual needs (Best et al., 2020; Puchalski et al., 2014). Previous research indicates that HCPs frequently express challenges in understanding the concepts of spirituality and spiritual care, which often leads to a failure to address the spiritual needs of patients adequately (Appleby et al., 2018; Hvidt et al., 2016). This is a matter of significant concern because the spiritual dimension is an inherent and essential aspect of human existence, and individuals commonly experience spiritual needs when facing potentially life-limiting illnesses such as cancer in the palliative phase. However, the misconception that spirituality is solely associated with religious traditions can result in some patients rejecting conversations addressing existential or spiritual questions, merely because they do not identify as 'religious'. Consequently, patient concerns related to seeking and creating meaning outside of religious frameworks may be disregarded (Best et al., 2020). By actively engaging in a person's life narrative, including their spirituality or religiousness, HCPs can assist in enhancing the individual's comprehension and aid them in discovering significance in their life and health condition (Österlind & Henoch, 2021). However, it is of great importance that HCPs possesses significant knowledge and competence in cancer, palliative care, and communication to facilitate such engagements. In the palliative care of the future, where technology such as RHC is most likely to play an extensive role, it is of great importance that features addressing existential or spiritual concerns are incorporated in the technology to ensure a person-centered approach. Such an incorporation entails careful involvement of patients and their families in the planning of care (Steindal et al., 2023).

Considering the dimensions synthesis and strategies, conversations in which the technology allows for face-to-face contact may help patients find meaning or acceptance in their situation, emphasizing the significance of not underestimating the importance of small talk in palliative care (Österlind, 2022). However, as previously mentioned, the RHC in this study did not include possibilities for video conversations. Thus, it was not possible for patients to interpret nonverbal signs regarding how their information was received by the HCP. Such a lack of visual confirmation to their reported needs may have impacted the patients' self-image and sense of identity (Österlind, 2022). Furthermore, as suggested in Paper II, patients experienced that topics related to their psychosocial needs were difficult to address, and they sought more physical assessments of their actual needs. Visual features such as video may enable patients to build interpersonal relationships with HCPs over time (Steindal et al., 2023). Videoconferencing presents an advantageous medium for delivering emotional support and empathy, enabling HCPs to evaluate patients' individual circumstances and respond to their emotions with deliberate care choices (Hutchinson et al., 2022; van Gurp et al., 2015). Thus, by including options for video conversations in RHC in the future and thereby enabling HCPs to connect to the person’s narrative more attentively and empathetically, there are opportunities for HCPs to deliver person-centered palliative care by promoting a sense of coherence, synthesis, self-image, and identity as patients navigate through the experiences of living with incurable illness (Österlind & Henoch, 2021).

### 6.1.4 Self-determination

Person-centered care with preservation of a patient’s self-image, relief of troublesome symptoms, social relations, and existential and spiritual needs is closely connected to promoting the person’s self-determination. Self-determination encompasses the psychological needs of patients, including the desire to actively participate in their own life and shape the end of life based on their personal beliefs and values. Self-determination is similar to the concept of autonomy, and these two concepts are frequently used interchangeably or considered to encompass each other (Österlind, 2022). The results from Paper II suggest that RHC enhanced self-determination and patient autonomy in relation to living at home with cancer in the palliative phase by assisting patients in managing their illness at home. The tablet device provided patients with the means to monitor symptom progression, and many felt it offered enhanced control and fostered improved routines. Research suggests that the use of welfare technology among older adults can bolster patient autonomy by augmenting their sense of responsibility, motivation them to self-manage, and promoting independence (Kruse et al., 2020), which may be transferrable to the context of this study. Within the concepts of the 6S model for person-centered palliative care, autonomy and self-determination focus on the patient’s inclination to actively engage in their care and navigate their lives in tune with their values, beliefs, and preferences (Österlind, 2022; Österlind & Henoch, 2021). RHC might offer patients such possibilities to receive care in their desired setting, potentially playing a crucial role in their quality of life. However, it remains essential that the services offering palliative care resonate with these preferences, guaranteeing uninterrupted care, aid, or support as necessary (McCaffrey et al., 2016; Sandsdalen et al., 2015).

As previously mentioned, the patients in this study experienced that during the intervention period, the content of the RHC was not adjusted to their deterioration or changing needs (Paper II). When patients’ condition declines, their focus may shift from broader care decisions, such as the care setting, to priorities concerning immediate pain relief and comfort. During this stage, a patient’s autonomy can be at risk (Wilson et al., 2014). There can be significant consequences related to a loss or decrease in autonomy. Patients with late-stage cancer experience that frustrations may arise if uncertainty regarding functional abilities makes it difficult to plan both daily activities and long-term projects (Sand et al., 2008). However, loss of autonomy can be bolstered by prioritizing personal aspects of care, which can significantly help an individual retain a sense of control (Wilson et al., 2014). Although such individualization was highlighted as a priority among the HCPs in this study (Paper I), it was not recognized by most patients (Paper II).

A core component of effective cooperation among different HCPs is seamless exchange of information among organizational structures (Melby et al., 2015). However, Papers II and III demonstrate that patients felt burdened by having to take on an administrative role to handle appointments, treatment, and care. Instead of functioning as a coordinating service where patients could receive care and guidance based on their reported needs, RHC was perceived by some patients as yet another service they had to relate to and coordinate. In addition, the HCPs reported delayed access to essential patient data and disrupted communication among HCPs, which further led to a situation where the HCPs had to rely on patients to stay updated on crucial information regarding treatment and care (Papers II and III). These results point to organizational glitches and insufficient structure in the RHC follow-up, such as lack of adjustments and unsystematic symptom mapping. Such a disrupted information flow is recognized as a persistent challenge within the Norwegian health care systems due to the segregation of primary and specialized health care services (NOU, 2023:4), complicating the process of information exchange for all stakeholders involved in patient care. Internationally, the significance of similar obstacles has been recently corroborated, noting that the importance of investing in the necessary infrastructure for establishing viable digital health systems, as well as the need for strategic integration, planning, and training of relevant professionals who could help establish and maintain the required systems, is of the utmost importance (Payne et al., 2023). Moreover, such a shift of responsibility onto the patients represents a threat to patient safety, as research suggests that patients forget 40% to 80% of the medical information they receive and that nearly half of the information they actually do remember is wrong (Kessels, 2003; Lundereng et al., 2020). Despite the progressive adoption of welfare technology intended to facilitate coordinated health care and enhance the continuity of care in Norway over the last decade (NOU, 2011:11), this study demonstrates that complexity and frustration regarding information sharing in health care is still present. Such a disruption of information flow poses a threat to the delivery of person-centered palliative care, as the HCPs depend on accurate and complete patient information to properly assess and administer care. It is unreasonable to expect patients to handle an extra burden by providing this critical information, as demonstrated in this study, and HCPs should not be put in a situation where they are obligated to rely on information from patients. Even though RHC had the potential to facilitate a service where HCPs had the correct information and where patients' autonomy and self-determination could have been upheld, organizational challenges ensured that this was not the case.

As suggested in Paper III, some HCPs felt responsible for not posing unnecessary stress or burdens for the patients, whom they perceived to be very fragile. These HCPs were concerned about the idea of abandoning palliative care as a specialty requiring personal interaction and attention. These results can be referred to as "gatekeeping" behavior (Kars et al., 2015; Snowden & Young, 2017) in terms of preventing eligible patients' access to RHC. On reviewing relevant literature, it appears that although gatekeeping is occasionally discussed, it is predominantly associated with implications for research recruitment. However, the gatekeeping behavior documented in this study did not only potentially influence study participation, but more significantly, it may have deprived patients—who could have experienced benefits from RHC—of the opportunity to receive it. As suggested in Paper III, there are multifaceted explanations for the gatekeeping that occurred in this study. First, the HCPs were unexperienced in using RHC for provision of cancer care and palliative care. They felt troubled with the idea of abandoning palliative care as a high-touch, not high-tech, specialty and were worried about placing additional burdens onto patients they perceived as vulnerable and already loaded with strain (Paper I). Similar results were found in a study involving older women with incurable cancer, where cancer care coordinators involved in the recruitment of patients might have excluded those experiencing daily struggles and whom they perceived as vulnerable (Staats et al., 2020).

Second, studies suggest that HCPs might exhibit reluctance and apprehension toward the integration of welfare technology in palliative care, fearing that it may diminish patient interaction and amplify the emphasis on the physical aspects of the patient's condition (Lundereng et al., 2023; Neergaard et al., 2014), potentially neglecting their psychological, spiritual, and existential requirements. Similar results were demonstrated in Paper III, where

HCPs were troubled with the idea that introducing RHC may lead to abandoning palliative care as a high-touch, not high-tech, specialty. Patients requiring palliative care are often characterized as vulnerable. The term vulnerability can be perceived as contrasting with autonomy, as autonomy typically implies independence and self-sufficiency in decision-making, detached from external influences. This binary perspective can lead to situations where experiences of vulnerability appear incompatible with the fundamental ethical principle of autonomy; however, recognizing such vulnerability can be viewed as a means to shape palliative care practice, ensuring the inclusion of patients' existential needs and their autonomy (Jämterud, 2022). Additionally, there exists a common belief within the clinical field that care is dichotomized into either high-tech or high-touch, with the assumption that these approaches are mutually exclusive (Morgan et al., 2017). Nonetheless, literature points out the advantages for both patients and HCPs when incorporating technology in palliative care (Finucane et al., 2021; Steindal et al., 2023), indicating that high-tech does not necessarily exclude high-touch. Although technology alone cannot substitute for face-to-face interactions, a combination of RHC and in-person care may be preferable for patients in the palliative phase (Steindal et al., 2023).

Third, some of the HCPs in this study found the term of being "incurably ill" as uncomfortable to address when reaching out to patients in telephone conversations and in the recruitment for RHC. Such discomfort is another reason for the gatekeeping behavior addressed in the literature (Kars et al., 2015). Although it is a fundamental right of any person to refuse to participate in any research or implementation of new interventions, it is also a fundamental right to be asked in the first place (Kars et al., 2015; Snowden & Young, 2017). Furthermore, facilitating patients to actively engage in the provision of their own care enhances their autonomy, supporting their desire to actively participate in their own life and shape their remaining life based on their personal beliefs and values. It is reasonable to assume that the HCPs in this study were uncertain about whether the patients were aware of having received an incurable diagnosis, and the HCPs perceived uncertainty may be an expression of their desire not to be the ones to make the patient aware of it. Loge et al. (2015) claimed that there is no empirical evidence regarding whether most patients in Norway who have a limited life expectancy are informed about the incurable nature of their disease. Consequently, it cannot be taken for granted that patients have been provided with information about their incurable diagnosis or life expectancy. Research suggests that patients may be discouraged from participating in interventions or research studies if they are in denial of their incurable disease or if they do not acknowledge their mortality. In addition, patients may be overwhelmed by the severe prognosis (Brohard, 2020). Although information regarding diagnosis and prognosis may be communicated, it remains uncertain whether patients truly comprehend or accept this information. The lack of clarity regarding patients' knowledge about their illness, treatment options, and life expectancy poses a significant challenge when creating informational materials and providing oral information about studies (Loge et al., 2015).

A patient's comprehension of and engagement in symptom management and their care depends on their capacity for autonomy or self-determination. However, for an individual to fully exercise self-determination, they require sufficient information to evaluate alternatives and the outcomes of their choices. Both the patient and their family require close dialogue with the HCP to collaboratively shape the best possible palliative care (Österlind & Henoch, 2021). Such collaboration demands an open and trustworthy dialogue between the patient, their family or close ones, and the HCPs about the patient's preferences throughout their illness trajectory (Henoch & Österlind, 2019), which may be challenged by services such as RHC, where care is delivered remotely, and the physical proximity is limited. Our results highlight the continued requirement to raise awareness about the benefits of integrating technology in palliative home care and further demonstrate a demand for an ongoing effort to alter negative attitudes toward combing palliative care and technology. Furthermore, patients in the palliative phase may be interested in and willing to engage in new interventions, despite the initial concerns of HCPs. At the same time, the discussion in this thesis highlights the significant role of the cancer care coordinator as a link between the patient, RHC, and other health care services involved in treatment and care. This role could become increasingly important for the preservation of patient autonomy and self-determination as more patients are set to receive support from services such as RHC.

## 6.2 RHC implementation

Recent recommendations for the implementation of welfare technology interventions in cancer and palliative care suggest an increased focus on country-specific policies, compatibility of health apps, ensuring access for all, including vulnerable groups, and fostering digital literacy (Payne et al., 2023). Furthermore, palliative care is a complex practice that requires a wide range of competencies from those practicing it (Hökkä et al., 2020), which was suggested as limited within the HCPs under study (Paper I). HCPs' remote assessments of patient-reported symptoms depend on their knowledge and experience with the individual patient (Lundereng et al., 2023). At the institutional level, emphasis should be placed on understanding the needs of patients and HCPs, establishing best practice guidelines, educating clinicians on digital health, reducing barriers and bureaucracy, and ensuring robust technical support (Payne et al., 2023). By considering the dimensions of the RE-AIM framework- *Reach*, *Effectiveness*, *Adoption*, *Implementation*, and *Maintenance* (Glasgow et al., 1999) -the results from Paper III indicate that although RHC demonstrated *Effectiveness* by facilitating for enhanced routines in patients' daily lives (Papers II and III), it was perceived as inflexible, especially as the illness advanced (Paper II). Furthermore, the HCPs were skeptical about RHCs' ability to provide palliative care and struggled to balance high-touch with high-tech, whereas patients experienced poor integration and increased service complexity, both hindering *Adoption*. A major issue concerning the *Implementation* of RHC was a lack of competence in palliative care in the HCPs. Combined, these results are in contrast to a person-centered palliative care approach which considers the individual's needs and preferences as the foundation of care (Österlind & Henoch, 2021). In addition, these results suggest that welfare technology innovations, such as the RHC, are often underestimated in terms of their complexity. Therefore, it is deemed appropriate to further discuss the complexity of implementing new welfare technological solutions, such as the RHC, in person-centered palliative care.

### 6.2.1 RHC intervention complexity

Very few interventions can be categorized as truly simple, and their complexity can vary significantly in terms of the number of components involved and the range of outcomes they produce (Craig et al., 2008; Skivington et al., 2021). Complexity within interventions can occur along several dimensions, such as the number of components within the intervention, the number and difficulties of behaviors required by those delivering or receiving the intervention, the number of groups or levels targeted by the intervention, and to what degree the intervention can be tailored to individual patients (Craig et al., 2008; Polit & Beck, 2020; Skivington et al., 2021). Figure 7 illustrates RHC as a complex intervention for patients with cancer in the palliative phase:

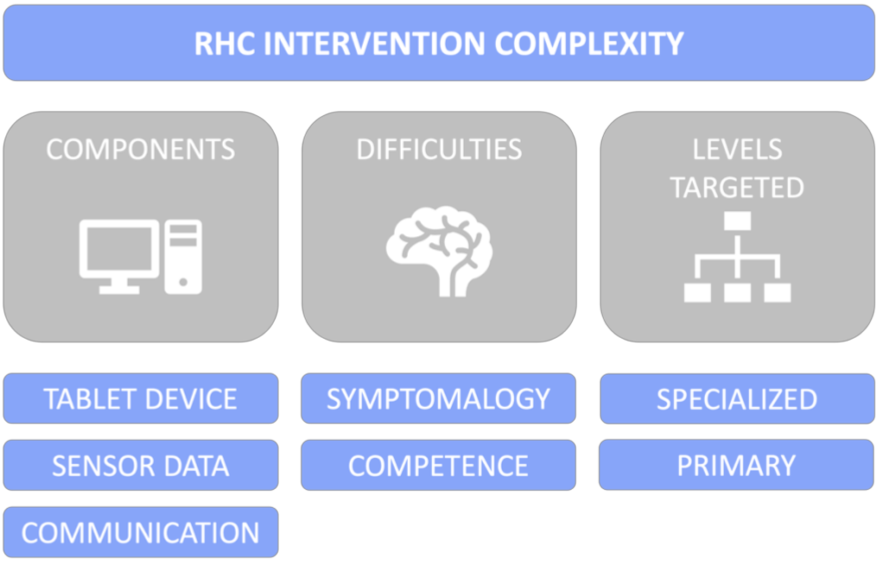

*Figure 7. RHC as a complex intervention to patients with cancer in the palliative phase.*

First, the RHC technology is based on three components: a tablet device containing individualized questions for self-reporting of symptoms, sensor data via medical measuring devices (such as weight scales, pulse oximeters, blood glucose meters, blood pressure monitors, and electronic drug dispensers), and patient-HCP communication via chat or telephone. Furthermore, the RHC was designed with a high level of flexibility to deliver individualized and tailored care to the patients. However, it is reasonable to assume that this flexibility was not fully leveraged, given that patients reported a lack of adjustments in the RHC in response to their changing needs (Papers II and III).

Second, the inclusion of patients with cancer in the palliative phase to the RHC increases the difficulty for the HCPs providing care. Patients with cancer in the palliative phase are characterized by failing organ functions and rapid changes in health status, combined with troublesome symptoms, such as pain, dyspnea, nausea, anxiety, and depression. In addition, they often have various complications that occur frequently and often simultaneously, and the average patient experiences more than three distressing symptoms at the same time (Kaasa & Loge, 2016b). This concurs with the results of Paper I, where the HCPs considered patients with cancer in the palliative phase to be sicker and with more unpredictive and unforeseen compared with patients they were previous familiar with, such as patients with COPD and diabetes. Additionally, the results emphasized lack of competence regarding cancer and palliative in the HCPs (Papers I and III).

Third, the complexity represented by patients with cancer in the palliative phase adds to the number of groups or levels targeted by the intervention, because all patients in the palliative phase require interdisciplinary care across health care service levels (primary and specialized) (The Norwegian Electronic Health Library, 2020). Given the remote delivery of care, RHC inherently extends beyond a single organizational entity, which utterly challenges implementation. These entities frequently have divergent organizational cultures, practices, care models, and governing processes. Additionally, RHC extends to involve a multitude of stakeholders, including patients, interdisciplinary HCPs, information and communication technologists, economists, managers, policymakers, and so on. The implementation of RHC amplifies the challenges due to the interdisciplinary nature of decision-making, problem-solving, and change management, which often align with specific disciplines (van Dyk, 2014). In terms of disciplines, the RHC was originally designed to accommodate patients with chronic diseases such as COPD and diabetes. These patients are often provided with a tailored self-management plan designed to foster patient empowerment, aid in symptom recognition, and allow patients to discern when their condition exacerbates and to undertake suitable action as advised by their general practitioner or other HCPs (The Norwegian Directorate of Health, 2022a). However, the patients with cancer in the palliative phase recruited for this study were not equipped with a self-management plan, which may have utterly challenged the provision of care and support.

The application of the RE-AIM framework in Paper III highlights that several barriers to the successful implementation of RHC for patients with cancer in the palliative phase could have been mitigated through the application of comprehensive framework, such as the RE-AIM, in the planning and execution stages of the implementation process. Furthermore, it becomes evident that the significance of the complexity inherent in RHC should have been accorded greater attention during the implementation process. This is supported by Glasgow et al. (2019), who promoted increased utilization of the RE-AIM framework throughout the implementation phase, emphasizing iterative applications and not confining its use solely to initial planning and summative evaluation. The results from this study indicate that although the RHC was well established as a service for patients COPD and diabetes, the HCP felt overwhelmed and unprepared for using it to care for patients with cancer in the palliative phase. Furthermore, patients experienced the RHC as unfulfilling to their changing needs and questioned its utility as time went by (Papers I, II, and III). These results suggest that the decision-makers involved in extending RHC from patients with COPD and diabetes to patients with cancer in the palliative phase may not have conducted thorough assessments of the palliative care needs and the imperative to ensure a person-centered approach. This suggestion is supported by research stating that on the introduction of technologies, the involved actors (such as patients, their relatives, and HCPs) may have varying perceptions of the “problem” the technology is supposed to solve, how the technology should be used, and to what extent the use of the technology is experienced by the other actors involved (Obstfelder et al., 2007; Stokke et al., 2019).

Introducing new technology always presupposes active mobilization of the technology users (patients and HCPs), where the definition and negotiation of needs and creative adaptations are clarified (Andreassen et al., 2019; Thygesen, 2019). Such co-creation of care between the person in the palliative phase who contributes with experiences, knowledge, beliefs and preferences and HCPs who contribute with scientific knowledge and experiences of care is further highlighted in the 6S model as a prerequisite for person-centered palliative care (Henoch & Österlind, 2019; Österlind & Henoch, 2021). It is reasonable to believe that because the RHC was already familiar to the HCPs, the decision-makers placed no emphasis on such an active mobilization of the actors involved, which may have led to insecurity and unfulfilled person-centered palliative care.

# 7 METHODOLOGICAL CONSIDERATIONS

Guided by the qualitative concept of trustworthiness, the methodological considerations of the study are discussed in this chapter. The final part of the chapter presents the strengths and limitations of the study.

## 7.1 Trustworthiness

In qualitative research, the term trustworthiness is frequently used to describe the degree of confidence qualitative researchers have regarding their data and analyses and is often assessed by four criteria: *credibility*, *transferability*, *dependability*, and *conformability* (Graneheim et al., 2017; Polit & Beck, 2020). These criteria will be used to discuss the methodological considerations applied to enhance the trustworthiness of this study.

### 7.1.1 Credibility

Credibility concerns the degree of trust placed in the interpretation and analysis of a research study (Lincoln & Guba, 1985). Polit and Beck (2020) underscore that in qualitative studies, this trust is fostered by affirming the accuracy of the results specific to the research participants and their context. To enhance credibility, the sample of interdisciplinary HCPs had experience of employing RHC for follow-up of patients with cancer in the palliative phase living at home. To ensure contextual accuracy and diverse experiences pertinent to the research questions, the HCPs were both male and female at different ages and with diverse professional backgrounds and experience in health care and their current position.

Data from patients were collected by time triangulation at four different time points (Polit & Beck, 2020). Investigating the same phenomenon in the same group at different points in time allowed for greater understanding of the phenomenon under study (Polit & Beck, 2020; Thurmond, 2001) and further facilitated patients' reflections between the interviews, which was considered to enhance credibility. Furthermore, the longitudinal approach facilitated building trustful relationships with the patients and could have made patients more willing to share rich descriptions of their experiences (Patton, 2015). In addition, a longitudinal approach allowed for an in-depth understanding of the phenomenon under study and may have conveyed more details of the context and patients under study, which was considered to facilitate credibility (Creswell et al., 2023). The sample of patients consisted of a diverse group of both males and females at various ages with different cancer diagnoses with varying symptoms and conditions that received individualized RHC. Including patients with various experiences enhanced the investigation of the research question from a variety of aspects, which strengthened the credibility of the study (Graneheim & Lundman, 2004). Together, these diverse experiences allowed for a broad range of topics to be discussed in the patient interviews and facilitated the collection of comprehensive responses relevant for addressing the research questions for Paper II. During individual and focus group interviews (Papers I and II), all patients and HCPs were encouraged to share both positive and negative experiences regarding their use of RHC, which may have enhanced credibility by adding depth and richness to the data (Polit & Beck, 2020).

For Paper III, the application of the RE-AIM framework was considered to add both depth and breadth to the results of Papers I and II, which may be considered to enhance the credibility of both of these papers. In addition, the RE-AIM framework provided a more comprehensive and realistic understanding of the RHC intervention, which was considered to enhance the credibility of the study in its whole. By applying a deductive reflexive thematic analysis (Braun & Clarke, 2022) driven by the five dimensions of the RE-AIM framework, a clear identification and explanation of the theoretical assumptions guiding the analysis was emphasized in the reporting of the results for Paper III. Credibility was enhanced by explicitly stating these assumptions and the logic behind the interpretations and making the analysis process transparent. To reduce to preunderstanding of the results from Papers I and II, promote alternative interpretations and agreement, and improve the reliability and credibility of the results in the analysis of Paper III, the analytical process was conducted collaboratively by a group of researchers with varied research backgrounds in welfare technology and palliative care.

### 7.1.2 Dependability

Dependability refers to the consistency of the research. It focuses on the logical, traceable, and documented process of the research inquiry. To enhance dependability, researchers should provide a clear and detailed description of their methods so their study can be replicated (Patton, 2015; Polit & Beck, 2020). Consistency was emphasized by the same researcher collecting all data for Papers I and II. Furthermore, thoroughness was emphasized at every stage of the research process. This is manifested in the methodology chapter of this thesis and in all the papers. Particular attention was given to providing a comprehensive account of the methods. Each of the individual papers detailed the different stages of the analyses, and in Papers I and II, illustrations were published demonstrating the analytical process of qualitative content analysis (Graneheim & Lundman, 2004) where one moves from the raw data to main themes. For Paper III, a deductive reflexive thematic analysis (Braun & Clarke, 2022) guided by the RE-AIM dimensions (Glasgow et al., 2019; Holtrop et al., 2018) was chosen as the analytic method for a secondary analysis of the data material from Papers I and II. For this paper, visual mapping was employed, as it allows for the researcher to comprehend the complexities of the data by making them more visually accessible and to help understand how themes relate to each other (Braun & Clarke, 2022). An example of the visual mapping for the secondary analysis is demonstrated in Paper III. All papers were reported according to the consolidated criteria for reporting qualitative research checklist (Tong et al., 2007).

### 7.1.3 Confirmability

Confirmability refers to the degree to which the results are influenced by the focus of the inquiry rather than the researcher's personal biases. Strategies to enhance confirmability include reflexivity, where the researchers reflect on their role and potential biases (Lincoln & Guba, 1985; Patton, 2015; Polit & Beck, 2020). Because the researcher is the instrument in qualitative inquiry, the role of the researcher is central to the trustworthiness of the study (Patton, 2015). Furthermore, the researchers' background and their connections to the participants may represent a risk of biases, as personal preferences and preconceptions may affect the data collection and interpretations (Creswell et al., 2023; Polit & Beck, 2020).

Due to limited knowledge and experience in the field of cancer, palliative care, and welfare technology, I may have had preexisting beliefs that potentially could have led me to search for or favor data confirming these beliefs and potentially disregarded data that contradicted these beliefs. To avoid such confirmation bias, reflexivity in terms of critical self-reflection about my potential biases, preconceptions, and preferences were applied in the research process (Polit & Beck, 2020). Furthermore, I made a thorough effort to acquire knowledge and understand the prevalent theories, methodologies, and debates and experienced a significant learning curve within these fields. The main supervisor was an invaluable source of knowledge. He helped construct literature searches and consistently provided tips about key pieces of literature and new research that would be appropriate to read. I had no prior relationship with the participants before the interviews (Paper I). Conducting the focus group interviews and individual interviews with HCPs for Paper I as an outsider lacking expertise of the field represented both challenges and opportunities. As an outsider, I might have lacked a deep understanding of the context, which may have led to misinterpretations or misunderstanding of the responses the participants provided. The participants might also have perceived me as an outsider and felt uncomfortable disclosing all relevant information (Patton, 2015). Measures to address this matter were applied by opening each focus group and individual interviews with the HCPs by explaining my background and highlighting the overall interest in gaining as much valuable information as possible. However, such restraints were not perceived as an issue, as all participants spoke freely and seemed eager to explain. Certain technical terms and jargon may also have posed a barrier. To avoid such errors, measures of asking the participants for explanations or richer descriptions were taken. Thorough preparation and understanding of the subject, active listening, upholding an empathetic approach, and clear and open-ended questioning was emphasized in all focus group and individual interviews with HCPs. Furthermore, participants were asked to confirm or refute any perceptions I might have brought into the interview situation to control for contextual biases. To avoid biased questioning, the transcripts from the individual interviews with patients were not available to me before after the data collection from the HCPs was completed. Moreover, the main supervisor, who is highly experienced in the field of cancer and palliative care, was present in the focus group interviews. It was considered a strength to have two people present during the focus group interviews in the initial phases of the analysis. However, being an interviewer with an outside perspective may lead to novel insights and unbiased questioning, which could potentially unearth aspects of the topic that insiders may overlook due to their proximity to the subject matter (Patton, 2015). This may have led to new insights and questions that have not been previously asked, thereby allowing for a contribution to an expanded understanding within the field (Malterud, 2017).

To further enhance confirmability, the identification of subthemes and themes that preserved the underlying meaning of the text was sought in the analysis of all individual papers.

Furthermore, by referring to disagreements among the participants and using direct quotations in the presentation of the results in Papers I, II, and III, nuances in the results were highlighted underscore that the interpretations reflect the participants opinion and are not merely a result of the researcher's imagination (Graneheim & Lundman, 2004; Patton, 2015).

### 7.1.4 Transferability

Transferability refers to the degree to which the results can be applied to other contexts or groups (Patton, 2015; Polit & Beck, 2020). Because all participants in this study were recruited from the same home care district, it is important to acknowledge that the experiences of patients and HCPs residing in more rural areas of Norway may have diverged from those who participated. As a result, the transferability of the results to other contexts might be restricted. However, as thoroughly discussed in this chapter, meticulousness was emphasized in all stages of the research process, which is also documented in the three individual papers. This diligence, combined with rich descriptions of the participants' experiences, context, and results, are measures that can promote transferability. However, the interpretation of the results and their relevance for other settings must be evaluated by those who read the papers (Polit & Beck, 2020).

## 7.2 Strengths and limitations

### 7.2.1 Study design

To ensure the highest level of effectiveness, Craig et al. (2008) recommended systematically developing interventions by utilizing the best evidence and relevant theories. This process involves testing the interventions through a well-structured approach, beginning with pilot studies that target key uncertainties in the design. However, when funding for this PhD study was granted, RHC was already implemented and used for patients with chronic conditions such as COPD and diabetes, and the process of expanding RHC to patients with cancer in the palliative phase was on the brink. It was not possible for the PhD candidate to participate in the development of the intervention or influence the content of the follow-up, which may be considered a limitation.

### 7.2.2 Recruitment procedures

The sample size for both Paper I (HCPs) and Paper II (patients) was determined using the theoretical framework of information power (Malterud et al., 2016). According to this model, the data material provided sufficient information power due to the focused aims of the individual papers, which allowed for a comprehensive exploration of the research questions in the specific context of utilizing RHC in palliative care. Furthermore, both HCPs and patients possessed extensive knowledge and personal experiences with the phenomenon under investigation, and the dialogue between the interviewee and participants was considered to be of high quality. Adhering to these principles was considered to enhance credibility and information power, which allowed for a smaller sample size to be sufficient for Paper I (N = 8) (Malterud et al., 2016).

As previously discussed, gatekeeping behaviors occurred among HCPs involved in the recruitment of patients. Gatekeeping behavior during recruitment may occur in palliative care interventions where those involved in recruitment are concerned that participation may exacerbate psychological distress and physical discomfort in patients (Kars et al., 2015). Gatekeeping poses a frequent challenge in medical research, especially in studies involving vulnerable research subjects (Sharkey et al., 2010), such as patients with cancer in the palliative phase. The literature suggests that the practice of gatekeeping may impact the sample size in studies investigating vulnerable populations, an outcome that was also observed in this study. Similar to the results of this study (Papers I and III), fear of burdening patients in vulnerable life situations makes HCPs often prioritize patient comfort over study participation, demonstrating a protective attitude toward those with advanced illnesses (Kars et al., 2015). Due to the gatekeeping behavior among the HCPs involved in recruitment, several patients may have been prevented from participating in the study. Consequently, patients with a multifaceted life situation or significant illness burden might have been excluded, potentially impacting the study's credibility, which should be considered a study limitation. However, when the gatekeeping behavior was discovered, strengthening actions were employed, and the inclusion of patients proceeded as planned.

Several of the patients recruited for participation in this study and to receive care with RHC were prevented from completing the entire intervention period due to severe illness or death. This may have led to the loss of patients with severe illness and symptom burden, which may have impacted the data. Furthermore, it represents a possible limitation to the longitudinal perspectives of Paper II.

The sample for Paper I was interdisciplinary HCPs with experiences of using RHC to care for patients with cancer in the palliative phase. Furthermore, the included HCPs were all employed on the same team and were well acquainted with one another's work habits, which led to open discussions and minimal inhibitions among them, which is considered a strength.

### 7.2.3 Data collection

As some of the patients included in the study received regular home care nursing in addition to the RHC, the original plan was to also include home care nurses and general practitioners in the sample for Paper I. Focus group interviews were planned with home care nurses, but unfortunately, the Covid-19 pandemic fully broke out, and the lockdown put a stop to the plans. The plan to include general practitioners in the district was abandoned for the same reason. Data from the home care nurses and general practitioners could have provided a broader insight into how RHC functioned as a unifying service and could simultaneously have offered valuable data regarding collaboration and information transfer. Furthermore, incorporating observations of the HCPs in this study's material could have offered additional insights into their behaviors and characteristics (Polit & Beck, 2020) and strengthened the results, particularly in understanding their utilization of RHC and collaboration within the RHC service team.

Piloting of an interview guide may help determine if the questions asked captures the information or themes the research intends to study (Polit & Beck, 2020). Thus, a potential limitation might be that no pilot testing of the interview guides was performed. For Paper II, this was due in part to the limited study population, and the time pressure to complete data collection, as the patients participating suffered from incurable cancer with uncertain life expectancies. Considering Paper I, the exploratory nature of the study and the constrained population of HCPs with the necessary experiences, the feasibility of piloting the interview guide was considered limited. Nonetheless, the questions in the interview guides for both Papers I and II underwent multiple revisions through extensive discussions among the authors, focusing on aspects such as content, clarity, and significance. Although piloting the interview guides may have led to utter revisions or different questions, this meticulous process of revising the interview guides was considered to enhance the credibility of Paper I and II (Polit & Beck, 2020).

### 7.2.4 Analysis

The main supervisor collected data from the patients. This separation of data collection and analysis by different researchers can be viewed as both a limitation and a strength. First, having analysis performed by another researcher that the one who collected the data may introduce potential biases or misinterpretations, as the data collector may possess valuable insights, contextual understanding, and tacit knowledge that could inform the analysis (Patton, 2015). To avoid such misinterpretations and ensure confirmability (Polit & Beck, 2020), peer briefing where the second and last authors asked critical questions of the preliminary results during each step of the analytic process for Paper II was applied (Patton, 2015). Second, such a lack of continuity in researchers assessing the data collection and analysis may also lead to a disconnection between the research questions, data collection process, and subsequent analysis. However, having an independent researcher perform the analysis can enhance objectivity and rigor by reducing biases and preconceived notions. Such an approach allows for fresh perspectives, alternative analytical techniques, and a more critical examination of the data. Consequently, it may contribute to a more robust and comprehensive analysis that can enhance the credibility of the study results (Patton, 2015; Polit & Beck, 2020).

For Paper III, the RE-AIM framework was used for a secondary analysis of the results of Papers I and II. Although there has been a growing application of the components within the RE-AIM framework in research, there have been few published examples of qualitative approaches and methods using the framework.

A limitation of not having quantitative data when using the RE-AIM framework is that it can be difficult to quantify effectiveness, dissemination, and economic consequences of implementation, leading to challenges in measuring and evaluating concrete outcomes and estimating cost-effectiveness, which may limit the ability to achieve a deeper understanding of implementation success and generalize findings across different contexts. However, taking the overall aim of the study into account, an application of qualitative methods to the RE-AIM framework can enhance the comprehension of RHC viability by providing in-depth and context not available through quantitative studies. Furthermore, qualitative approaches to the RE-AIM Framework can guard against false assumptions that a program or intervention, such as the RHC, is ineffective when in reality, the reasons for implementation setback was not visible in quantifiable data. They can also shed light on the circumstances and kinds of adaptations that are advantageous (Holtrop et al., 2018), as qualitative results often capture the complexity of human experiences and systems in a way that quantitative studies cannot. Holtrop et al. (2018) argued that the paramount contribution of qualitative methodologies to RE-AIM lies in their capacity to elucidate the reasons behind the obtained RE-AIM results and their evolution. Such elucidation was offered in Paper III by performing a deductive reflexive thematic analysis-guided by the RE-AIM dimensions and furthermore present the results and discussing them within each RE-AIM dimension.

However, a potential limitation of Paper III is that the RE-AIM framework was applied after data for Papers I and II were collected, meaning that no specific questions aligned to the RE-AIM framework were addressed in the interview guides. This might have yielded different data compared to if targeted questions were present. Nonetheless, having such specific questions might have limited perspectives during interpretation, possibly causing a miss on concepts critical for implementation, yet not directly addressed by RE-AIM questions. Furthermore, the PhD candidate was already familiar with the data extracts. Although this familiarization could certainly be seen as advantageous, it simultaneously posed a challenge. To reduce the preexisting understanding of the data material and themes assembled for Papers I and II, the analytical approach and established interpretation that had been derived from the analysis of Papers I and II was questioned. Braun and Clarke (2022) highlighted that even with a deductive approach, there is room for flexibility and openness to new themes or variations that emerge from the data and suggest that researchers remain reflexive throughout the process and continually reflect on the interplay between the predetermined themes and the emergent themes. This iterative process facilitated new insights proved essential in offering a new perspective, enabling interpretations from an implementation standpoint.

# 8 CONCLUSIONS AND IMPLICATIONS

The overall aim of the study was to elicit the experiences with and viability of RHC in palliative home care for patients with cancer. The discussion of this thesis assessed the results of the individual papers and suggests that the delivery of person-centered palliative care using RHC has potential to provide patients with symptom control and enhanced routines at home. Considering person-centered palliative care, this may support patient's self-image and facilitate for self-determination and autonomy. In palliative care, the role of HCPs is significant in helping patients maintain their social relations by identifying the individuals who are closest to the patient and providing them with support. Such identification of close ones and the provision of support is challenged in services such as the RHC, where the design and content are limited to encounters between patients and HCPs. However, our results demonstrate that RHC functioned as supportive tool enabling patients to stay at home, which in turn facilitated the maintenance and enhancement of patients' social relationships. A prerequisite for RHC to provide person-centered care to patients with cancer in the palliative phase is a tailored approach where patients changing needs are considered when care is planned and delivered. Furthermore, the results underline the significance of preserving patient self-determination when introducing RHC. HCPs need to respect the patients' capabilities and opportunities to utilize new technologies such as the RHC, and to not impose their personal biases and judgments by acting as gatekeepers when the technology is implemented. In addition, organizational glitches, and lack of viable systems for transfer of significant patient information, poses a risk of shifting responsibility onto patients. This may lead to a lack of patient security and an unintended autonomy where patients bear the primary responsibility for maintaining and conveying information crucial for further care.

The results highlight that the RHC was deficient in addressing the spiritual and existential needs of patients. Although this finding was not unexpected, it contrasts with a person-centered palliative care approach. Furthermore, this study highlights the importance of considering the complexity of the RHC intervention, particularly when implemented for patients with cancer in the palliative phase. An application of the RE-AIM framework during the planning stage of the implementation may ensure that HCPs and policymakers can more effectively understand how new technologies such as the RHC can be adapted from one context to another to facilitate for person-centered care, and furthermore how to sustain viability of RHC in palliative home care to patients with cancer.

## 8.1 Implications for practice

According to the results of this thesis, several potential implications for practice can be identified. RHC was originally designed for patients with chronic illnesses such as COPD and diabetes. The results of this study emphasize the need for careful adjustments to other patient groups, such as those with cancer in the palliative phase. Such adaptation may include adjustments in tailoring the content and adjusting it as the patient's condition changes, as well as providing enhanced training in assessing the reported symptoms and clinical signs for both patients and HCPs. Furthermore, given the complexity of implementing RHC in palliative care, HCPs may require additional training to deal with their uncertainties, enhance their knowledge, and better equip them with skills to handle the organizational and infrastructural issues related to information sharing and application adjustments. Furthermore, the need for available decision support for HCPs delivering RHC to patients with cancer in the palliative phase should be considered.

The importance of maintaining strong interpersonal relationships between patients and HCPs and measures to uphold patient autonomy and self-determination were highlighted in the discussion of this thesis. From a person-centered palliative care approach, RHC should include assessments to help patients maintain their social relations. Such assessments could involve identifying key individuals in the patient's social network and providing them with support and resources. Furthermore, the current RHC model appears to lack focus on the spiritual and existential needs of patients. To facilitate a more comprehensive follow-up, it may be necessary to incorporate questions in the RHC that specifically address these needs, especially for patients with cancer in the palliative phase, where issues of life, death, and meaning may become prominent. This incorporation should involve training HCPs in spiritual care or incorporating spiritual care specialists into the care team. Based on the findings of this study, emphasis should be placed on person-centered care, particularly in a palliative context. This involves viewing patients holistically, addressing not just their physical needs, but also their psychological, social, and spiritual needs. The use of the 6S model may be considered to achieve this. It should be considered whether the follow-up of especially spiritual and existential needs should involve more physical contact with HCPs.

Because future professionals within health care will use welfare technological solutions such as RHC extensively for patient follow-up, the results from this study are highly relevant for health educations at both bachelor’s and master’s levels.

## 8.2 Implications for future research

Due to gatekeeping in the recruitment in this study, eligible patients may have been prevented from receiving RHC and participated in the study. To enhance future care of patients in palliative care, recognizing the importance of evidence-based care is essential. Understanding patient perspectives on research participation may allow for better approaches by researchers and HCPs. It is critical to include those with incurable illnesses in clinical research rather than excluding them due to prognosis, perceived burden, or vulnerability. They should have opportunities to participate in novel interventions, such as RHC, and research where suitable. Although direct benefits to their condition may not be guaranteed, research participation can provide indirect value, such as enhancing care for future patients. Throughout, it is vital to approach this with sensitivity and respect (Bloomer et al., 2017).

Results of this study highlights several possible implications for future research. Future studies should prioritize understanding the areas of uncertainty and gaps in cancer and palliative care knowledge that HCPs face while implementing RHC in the care of patients with cancer in the palliative phase. Identifying these aspects could facilitate the development of training programs tailored to address these uncertainties, thereby supporting the viable integration of technologies for remote patient monitoring in future health care interventions.

Given the importance of the patient-HCP relationship, future studies could examine how to best strengthen these relationships within the context of remote care. This might include investigating communication strategies and techniques for information sharing across and between the primary and specialized health care services.

Furthermore, future studies could delve deeper into the issue of patient autonomy, especially in the context of remote patient monitoring and the use of new technologies. This might involve understanding patients’ experiences and perspectives to better align technology with patient needs and preferences. In addition, focusing on how best to address the spiritual and existential needs of patients when using RHC in palliative home care should be emphasized. Such studies may include exploring the potential role of spiritual care specialists and the effectiveness of various interventions. The effectiveness and applicability of the 6S model in delivering person-centered palliative care in the context of RHC could be explored within such a context. This might involve conducting longitudinal studies to examine patient outcomes and experiences over time.

The findings of Paper III demonstrate that the RE-AIM dimensions provided significant insight into areas of particular importance to ensure the sustainability of RHC in future health care. However, there is a lack of studies investigating the impact of using implementation frameworks such as RE-AIM during the planning and roll-out stages of complex health care services, such as the implementation of RHC in palliative home care, to inform best practices for future implementations.

This study offers preliminary insight into the experiences of patients and HCPs with the use of RHC in homebased palliative care. There is a need for more large-scale comprehensive research to evaluate the underlying technology, ascertain the content of RHC, and determine how the service should be designed to optimize patient care in the face of future health care demands.

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# Original papers

I. Oelschlägel, L., Dihle, A., Christensen, V. L., Heggdal, K., Moen, A., Österlind, J., & Steindal, S. A. (2021). Implementing welfare technology in palliative homecare for patients with cancer: a qualitative study of health-care professionals' experiences. *BMC Palliative Care*, *20*(1), 146. https://doi.org/10.1186/s12904-021-00844-w

II. Oelschlägel, L., Christensen, V. L., Moen, A., Heggdal, K., Osterlind, J., Dihle, A., & Steindal, S. A. (2023). Patients' experiences with a welfare technology application for remote home care: A longitudinal study. *Journal of Clinical Nursing*, *32*(17-18), 6545-6558. https://doi.org/10.1111/jocn.16592

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**RESEARCH** **Open Access**

# Implementing welfare technology in palliative homecare for patients with cancer: a qualitative study of health-care professionals' experiences

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**Abstract**

**Background:** Introducing welfare technology in home-based palliative care has been suggested to be beneficial for improving access to health care at home and enhancing patients' feelings of security and safety. However, little is known about the experiences of municipal health-care professionals using welfare technology in palliative home care. The aim of this study was to explore municipal health-care professionals' experiences regarding the significant challenges, facilitators, and assessments associated with implementing a technological solution named "remote home care" in palliative home care for patients with cancer.

**Methods:** A qualitative, descriptive, exploratory design was used. Data were collected through focus-group interviews and individual semi-structured interviews with interdisciplinary health-care professionals who had experience using remote home care in clinical encounters with cancer patients who were in the palliative phase and living at home. Data were analyzed using qualitative content analysis.

**Results:** Three themes were identified: 1) shifting from objective measures to assessing priorities for patients, 2) lack of experience and personal distress regarding cancer inhibits professional care, and 3) prominent organizational challenges undermine the premise of remote home care.

**Conclusion:** The results showed that shifting from a disease-focused to a person-centered approach enables health-care professionals to assess patients' personal priorities.

However, health-care professionals' uncertainty and lack of knowledge and experience, along with organizational issues concerning information-sharing, represent great challenges that have the potential to inhibit professional care. The availability of networks through which difficult issues can be discussed was highlighted as being a fundamental resource for facilitating the provision of care.

**Keywords:** Health personnel, Telemedicine, Palliative care, Patient care management

## Background

As the number of people with cancer worldwide continues to grow, the need for palliative care (PC) is concurrently increasing [1]. The introduction of welfare technology (WT) in home-based PC can improve patients' access to health-care professionals (HCPs)

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and enhance patients' feelings of security and safety [2]. Patients in need of PC, value coordinated and continuous care with a good relationship and access to HCPs when needed [2–4]. Most patients appreciate to receive care and spend as much time at home for as long as possible, and some wants to die at home [3, 5, 6]. Home-based palliative care has been found to be more cost-effective than in-hospital care [7]; however, this effectiveness is dependent on close cooperation and dialogue among the patient, the patient's family, and the HCPs [8]. Recently, the COVID-19 pandemic has led to a massive disruption of health care services and has generated a rapid need for the development of technology solutions that support remote PC and minimize both patients' and providers' risk of exposure to the virus [9].

The concept of WT is broadly defined under a wide range of terms, including "telecare," "telehealth," "telemedicine," "e-health," and "assistive living technology" [10]. WT models vary in terms of technology types, structures, and processes [11], but a defining feature of such technologies is that they can afford rapid interactive exchange of information between patients at home and HCPs, or passive information exchange, in which the recipient is not required to give an immediate response [12]. According to Glomsås and Knutsen [10], WT may provide opportunities to enhance patients' (and their families') safety, security, wellness, mobility, social and cultural contact, participation, treatment, and care. For HCPs, WT can also provide useful information, overviews, and logistical solutions concerning the homecare service and collaboration with patients and families [10, 13].

The use of video-conferencing in the homes of patients with cancer has been found to strengthen cooperation among HCPs, palliative teams in hospitals, and general practitioners, and has been perceived as a more efficient approach than those included in traditional care models [14]. Teleconferencing with patients, patients' relatives, and HCPs, and the use of electronic self-reporting of symptoms provides access to clinical data that would otherwise be unavailable [15]. However, these previous studies have also underlined the importance of HCPs having extensive experience in PC. At least one face-to-face meeting and an initial patient assessment appear to be essential for such services to function optimally and with maximum patient safety. Competencies such as coaching skills, communication skills, ethical awareness, a supportive attitude, and the ability to combine clinical experience with technology use have also been highlighted as fundamental when caring for patients through the use of WT [15, 16].

HCPs have reported that technology-based monitoring of patients' symptoms improves the interaction between patients and HCPs, as well as the efficiency and quality of care. Furthermore, the ability to instantly identify changes in patients' comfort, symptom burden, and medication needs seems to help HCPs make better interventions to manage pain and symptoms [17]. Some HCPs who specialize in PC and oncology consider allowing patients to use technological applications to screen and score their symptoms to be a positive development [18]. However, in one case study, an HCP questioned whether patients' self-reporting of symptoms could act as a constant reminder of deterioration and pending death to the patients [19]. Additionally, the use of technology-supported monitoring when caring for the most seriously ill patients could amplify the risk of overlooking subtle clues that influence decision-making and care planning [20]. Moreover, the legal considerations of performing clinical assessments remotely has also been questioned [15].

Previous research clarifies divergent experiences and several concerns addressing HCPs competencies in technology and communication skills [15, 16]. However, in most published articles, it is challenging to extract and separate the HCPs explicit experiences from patients' and relatives' experiences. Most of these studies have been conducted within a specialized context, where the HCPs under study have had formal education or extensive experience in providing cancer and/or palliative care [21]. However, the expected increase in patients diagnosed with cancer who need PC at home creates a need to obtain knowledge regarding municipal HCPs' perspectives on the use of technology in the context of home-based care, as well as their perceived importance of such technology. Thus, a thorough examination of the challenges and potential facilitators regarding implementing WT in municipal PC would be of great importance for future care planning.

The aim of this study was to explore municipal healthcare professionals' experiences with implementing an application for remote care in palliative home care for patients with cancer. The application was named "remote home care" (RHC), which is a service that enables HCPs to remotely monitor and manage patients' safety, security, wellness, treatment, and care. In this study, we addressed the following research questions: 1) Which assessments do municipal HCPs consider relevant when using RHC in palliative homecare for patients with cancer? 2) What are the challenges and facilitators experienced by municipal HCPs who use RHC in palliative homecare for patients with cancer?

## Methods

### Study design

A descriptive and exploratory design approach was chosen to collect and analyze HCPs' experiences concerning the use of WT in home-based care. Data were collected through focus-group interviews and semi-structured interviews. Considering the complexity of the research topic, the focus-group interviews were a suitable data-collection approach, as they afforded discussions among multiple informants and allowed us to capitalize on group dynamics to collect rich information [22]. In the subsequent individual interviews, topics that emerged in the focus groups were further explored, with the participating HCPs being given more time to reflect on these topics and discuss them more freely.

### Setting and recruitment

A single municipality in Norway in which RHC was used to provide care for palliative patients was the setting for this study. The municipality had established a RHC service center, where all patient care was provided with WT remotely. The RHC offers interdisciplinary services and function as a separate unit supporting traditional home-based care. A care manager recruited HCPs using purposive sampling by applying the following inclusion criterion: interdisciplinary HCP with experience of using RHC in home-based follow-up of patients with cancer who were in the palliative phase. The final study sample comprised eight informants: specialized nurses ($n=2$), nurses ($n=2$), a social worker ($n=1$), a physical therapist ($n=1$), and occupational therapists ($n=2$). One specialized nurse functioned as a cancer care coordinator in the district. The sample included both female and male informants. All informants worked full-time, and their years of experience providing municipal health care varied from four to 27 (Table 1 presents the characteristics of the sample). The authors had no relationship with the participants prior to their inclusion in this study.

**Table 1** Characteristics of the sample (health-care professionals)

| | |
|---|---|
| **Gender** | |
| Female | 6 |
| Male | 2 |
| **Age** | |
| Years, mean (range) | 37 (27–50) |
| **Profession** | |
| Specialized nurse[a] | 2 |
| Nurse | 2 |
| Social worker | 1 |
| Physical therapist | 1 |
| Occupational therapist[b] | 2 |
| **Experience from healthcare** | |
| Years, mean (range) | 13 (4–27) |
| **Experience from current position** | |
| Years, mean (range) | 6 (1–10) |

[a] One of the specialized nurses functioned as cancer care coordinator in the district

[b] One of the occupational therapists functioned as project manager

### Structure, content, and functionality of the remote home care

To implement the RHC, patients with cancer in the municipality who were in the palliative phase and who were living at home underwent an initial assessment meeting with representatives from the RHC service team. They were given a tablet device that featured questions concerning different symptoms. In addition, appropriate digital medical devices such as pulse oximetry, blood glucose meters, blood pressure monitors, and weight scales were installed in the patients' homes. The RHC service team gave the patients a brief introduction to how the technology should be used and informed them to make contact if problems arose.

The HCPs received the patients' data, had regular telephone contact with the patients, and responded to digital messages from the patients or their families. Aberrant measurements were detected using predefined individual values. In addition, a patient could request to talk to a nurse through the RHC application; to respond, the nurse had the option of sending messages in the application or telephoning the patient. The HCPs were available for contact from 8 am to 3 pm, Monday to Friday. A cancer care coordinator was connected to the RHC service and had regular face-to-face meetings with the patients. No videoconferencing was included in the RHC.

When recruiting HCPs, the RHC service center emphasized experience from the municipal health service and previous experiences of using WT. When employed at the RHC service center, all HCP received basic training in the RHC technology by a more experienced HCP.

During the study, elements of the service that required change were investigated. Tailored questions based on the Edmonton Symptom Assessment System (ESAS) were included in the tablets. The ESAS was initially developed as a clinical tool for documenting the symptom burden in patients with advanced cancer and is an example of a patient-reported outcome measure (PROM) questionnaire frequently used to monitor symptoms in palliative cancer care [23].

### Data collection

Two focus-group interviews, featuring four informants in each group, were conducted in November 2019 at the informants' workplace. The first author (RN, MNSc, PhD candidate) acted as a moderator, and the last author (RN, PhD, Professor) functioned as assistant moderator. The group interviews lasted approximately 80 min. An interview guide based on previous research in the field was developed. Due to the exploratory nature of the study and the limited population of HCPs possessing the relevant experiences, the interview guide was not pilot tested. However, the questions were revised several times after discussions between the authors regarding content, clarity, and importance. The interview guide was used to facilitate and provide the focus for the group discussions. The informants were encouraged to speak freely and discuss the topics introduced by the researchers; question prompts were used to obtain additional information [24] (Table 2 presents details of the focus groups). The focus-group interviews were audio-recorded.

Important topics that arose during the focus-group interviews was identified by listening to the audio-recorded focus-group interviews and further explored by the first author through individual interviews with six of the original eight informants. A semi-structured interview guide based on the identified topics was used to facilitate dialogue. The informants were encouraged to speak freely and elaborate on themes that occurred. The individual interviews were conducted between January and February 2020 at the informants' workplace and lasted between 50 and 70 min each (Table 2 presents details of the individual interviews). The individual interviews were audio-recorded.

## Data analysis

The focus-group and individual interviews were transcribed verbatim by the first author. NVivo 12 was used to facilitate the storage, organization, and analysis of data. The data were analyzed using qualitative content analysis [25, 26]; this analytic process affords the analysis of both manifest and latent content, which adds depth and meaning to informants' statements [25, 26]. The transcribed text was read numerous times to gain a sense of the content. An inductive approach was applied, with meaning units being identified. The meaning units were condensed, preserving the core meaning, and descriptive codes were outlined.

Guided by the aims of the study, the codes' similarities and differences were compared and organized into nine tentative sub-themes, each containing several categories constituting the manifest content. Guided by the research questions, the tentative sub-themes and categories were discussed and revised multiple times before the latent content was categorized into three main themes. Each

**Table 2** Details of the focus groups and individual interviews

| | | |
|---|---|---|
| **Focus group 1** | **Informants:**<br>Specialized nurse<br>Nurse<br>Social worker<br>Occupational therapist | **Themes addressed in the interview guide:**<br>Expectations of RHC prior to/after implementation to patients with cancer in palliative phase<br>- *Relevance*<br>- *Impact on workday*<br>- *Cooperation*<br>- *Competence/experience*<br>Practical utilization of RHC<br>- *Competence*<br>- *Training*<br>- *Patient training*<br>Processing inquiries from patients<br>- *Non-visual contact with patients*<br>- *Certainty in assessments and decision making*<br>- *Consulting options*<br>RHC: PC and seriously ill patients<br>- *Experiences*<br>- *Challenges*<br>- *Benefits* |
| **Focus group 2** | **Informants:**<br>Specialized Nurse<br>Nurse<br>Occupational therapist<br>Physical therapist | |
| **Individual interview** | **Informant:**<br>Occupational therapist (project manager) | **Themes addressed in the interview guide:**<br>Experiences of using RHC to patients with cancer in palliative phase<br>- *Positive*<br>- *Negative*<br>Receiving information via technology<br>Competence<br>- *Tech competence*<br>- *Cancer competence*<br>- *Palliative competence*<br>- *Support/cooperation*<br>RHC: PC and seriously ill patients<br>- *Limited life expectancy*<br>- *Severe diagnosis*<br>Challenges and benefits |
| **Individual interview** | **Informant:**<br>Occupational therapist | |
| **Individual interview** | **Informant:**<br>Social worker | |
| **Individual interview** | **Informant:**<br>Nurse (cancer care coordinator) | |
| **Individual interview** | **Informant:**<br>Nurse | |
| **Individual interview** | **Informant:**<br>Nurse | |

theme was outlined using sub-themes. To ensure intersubjectivity, a group of three researchers participated in the analytic process (Table 3 illustrates the analytical steps).

### Trustworthiness

The informants for this study were HCPs who had first-hand experience of using RHC to follow-up patients with cancer who were living at home. As the informants worked in teams and knew each other's work routines well, they all spoke freely and seemed to have limited barriers around each other. The informants had a wide range of experiences, which meant that a variety of topics were discussed, and this extra information allowed to collect more comprehensive responses that were relevant to answer the research questions [25]. Therefore, it is likely that the data are credible and represent HCP experiences. Both the focus-group and individual interviews provided sufficient and rich descriptive data concerning both culture and context to assure applicability and transferability to other settings or groups [25]. The first author had no extensive knowledge of the research field prior to this study.

An inductive approach to the material was emphasized. The first author analyzed the data, and the second and last authors read the transcripts and discussed the analysis with the first author. To incorporate different perspectives during the data-analysis phase and the interpretation of the results, a group of researchers possessing diverse research expertise in WT, PC, and chronic illness, participated in the final analysis. In order to strengthen the credibility of the results and reduce the risk of biased interpretations, the analysis process was methodical and systematic [22]. Transcripts were not returned to participants for comments or corrections.

### Ethical considerations

This study was approved by the Norwegian Centre for Research Data (reference number: 429408) and leaders in the municipal's health-care services. Informants received oral and written information regarding the study and were guaranteed that their data would remain confidential and anonymous throughout the research process and the publication of the results. All HCP informants signed informed consent forms prior to the data collection.

## Results

Three themes emerged from the data analysis: 1) shifting from objective measures to assessing priorities for patients, 2) lack of experience and personal distress regarding cancer inhibits professional care, and 3) prominent organizational challenges undermine the premise of RHC (The themes, sub-themes, and categories are listed in Table 4).

### Shifting from objective measures to assessing priorities for patients

The HCPs expressed concerns regarding RHC becoming "another thing" that patients would need to relate to and familiarize themselves with. They reported that the initial assessment meeting between the patients and HCPs from the RHC team was important for gaining knowledge of the patients' situations, as the benefits and burdens of installing medical measuring devices needed to be carefully assessed. However, the HCPs worried that, for patients, visualizing the exacerbation of their cancer through viewing deteriorations in their vital measurements could act as a constant reminder of their pending deaths. This potential burden was highlighted as being more significant than the benefit of receiving objective data on the patients' vital signs. Weight monitoring was highlighted as an example of a measurement that is expected to deteriorate but did not provide relevant data for care assessments. Informants perceived that the RHC contributed to improvements in the coordination and continuity of care. Further, they felt that the RHC enhanced patients' feelings of safety, as they knew

**Table 3** Illustration of the analytic process

| | |
|---|---|
| **Meaning unit** | "It's something with the term incurable cancer. It does something to the ones following up. When it says cancer, their shoulders rise immediately."<br>"There's something about cancer and palliative phase. It has some expectations attached. That often makes your shoulders rise a little. When you're talking to the patients, and you move over to topics like life and death and the patient's anxiety and expectations and so on." |
| **Condensed meaning unit** | The term incurable cancer makes the shoulders rise |
| **Coding** | Fear of cancer and death |
| **Category** | Cancer-specific competence |
| **Sub-theme** | Knowledge and competence |
| **Theme** | Lack of experience and personal distress of cancer inhibited professional care |

**Table 4** Categories, sub-themes and themes

| Categories | Sub-themes | Themes |
|---|---|---|
| Reminder of pending death | Assessment of potential patient-burden | Shifting from objective measures to assessing priorities for patients |
| Patients' capacity to handle the technology | | |
| Continuity | Assessment of potential patient-benefit | |
| Coordinated services | | |
| HCPs experiences of "getting closer" | | |
| Increased possibilities to help | | |
| Expectations of patient's feeling increased safety | | |
| Possibilities to reach more patients | | |
| Interaction with patients | Implementing a tailored service based on patient's illness experiences | |
| Medical measuring devices | | |
| Messaging | | |
| Patient training | | |
| Individualized questions | | |
| Addressing the religious and spiritual | | |
| Individualizing is crucial | | |
| Close cooperation facilitates important decisions | Assessments when the patient's condition changes | |
| Need for clear measures | | |
| Cancer-related issues | Knowledge and competence | Lack of experience and personal distress of cancer inhibited professional care |
| The importance of personal suitability and experience | | |
| Training and guiding of HCPs | | |
| Cancer coordinator key-role | Work environment interactions | |
| Communication and teamwork in decision-making | | |
| Shared responsibility | | |
| The service (remote home care?) is little known | Inadequate integration of documentation systems | Prominent organizational challenges questioned the premises of RHC |
| A shift of increased responsibility to the patients | | |
| Multiple service actors challenge the information-flow | | |
| General practitioners | Interdisciplinary collaboration at the district level | |
| Home Care Services | | |
| Hospital | | |
| Limitations in the application | Technological challenges | |
| Possibilities in the application | | |

someone was paying attention to their needs. This aspect was considered beneficial for both patients and their families.

> *One patient ... felt he was a burden to his family... The tablet became a container for him to talk about his illness and became an outlet for whatever needs he had. Until then, his situation had affected his relationship with his wife and children. (Focus group 2, informant 5)*

The HCPs also mentioned patients who felt ashamed of their lives or living situations, and who refused to allow anyone to enter their home, declining help from homecare services. In such cases, RHC was perceived as a good alternative for following-up the patient:

> *Some patients don't want home nursing and ... want to manage everything on their own but really need someone to drop by (....) But welfare technology [RHC] is neutral, something you don't have to deal with in the same way. This can be a compromise for those who refuse to receive direct homecare. By using the RHC, we have a form of contact. (Focus group 2, informant 8)*

Thus, the opportunity to care for patients who had, in the past, proven to be almost inaccessible was described as a great benefit of the RHC. Further, the HCPs also highlighted the importance of being flexible and solution-oriented in cases when the implemented service did not work as expected.

The informants had extensive experience of remotely caring for patients with other diagnoses, such as chronic obstructive pulmonary disease (COPD), by assessing remote measures of vital signs and delivering care based on predefined treatment options. However, the focus-group participants found patients with cancer in the palliative phase to be sicker and to have more diverse symptoms than other patients, and that the medical measuring devices that had predefined limit values and provided objective data provided a poor basis on which to base PC assessments. The HCPs expressed worries regarding missing important patient information. One informant stated:

> *It was more different with palliative patients with cancer than those with COPD and diabetes. We thought the way we'd already done it, with vital measurements, would fit in. Rather than paying attention to the individual. (Informant 2)*

The informants argue that there is a need to change from an approach based on digital measuring devices to a more tailored approach in which the patients' explicit experiences of illness and symptoms founded the basis for the assessments. The HCPs therefore implemented clinical questions based on ESAS in the tablet application, and individually adjusted the questions for each patient. Symptoms such as nausea, pain, lethargy, appetite, constipation, and number of toilet visits were highlighted by one of the informants as relevant when tailoring questions. ESAS questions that were considered irrelevant were removed. One informant highlighted that spiritual and existential needs were not addressed in the ESAS questions, despite the fact that such issues are particularly important for seriously ill and dying patients. The informant argued that HCPs should transcend personal obstacles and seek to address religious and other meaningful aspects, as these are significant to patients' lives and PC:

> *I think there are no questions [in the application] addressing the existential… It mustn't be forgotten … At least in a palliative situation because it affects everything ... In many cultures, the religion is a part of everything in life ... There is something about seeing the whole patient. (Informant 3)*

Informants felt uncertainty and frustration on how to assess the causes of changes in patients' reported symptom scores. This was partly because the RHC has several limitations, including a lack of content suitable for the fundamental assessment of symptoms, such as warnings regarding changes in specific symptoms and the ability to track these changes through customized and branching questions. Reports concerning values of a psychosocial nature could be influenced by issues other than cancer-related problems, such as financial issues or challenges concerning the patients' living situations:

> *I call the patient first to hear where he's in pain … We've thought that high scores on anxiety was about the patient experiencing worsening or received some bad news, but then it was worries about finances. There can be many everyday issues a sick person worries about. I call them to listen and to understand what's at stake. (Informant 6)*

There was some disagreement among the informants whether being unable to assess patients in person amplified problems. One informant underlined the importance of participating in the initial assessment meetings with the patients, as this helped HCPs to form an overall picture of patients' contexts and life situations. Meanwhile, another informant mentioned that the patients were more willing to share information when communicating over the telephone, and that this negated the need for physical meetings. In such cases, before any actions were implemented, the HCPs called and talked to the patients in order to make individualized assessments of the causes of the changes in the patients' scores.

### Lack of experience and personal distress regarding cancer inhibits professional care

Most of the HCPs expressed feelings of fear and insecurity regarding cancer and death. One informant believed that this was closely connected to the general perception of cancer as representing death, and to the HCPs' personal experiences and attitudes toward death. This led to distress among the informants and challenged several aspects of their everyday work. The focus-group participants mentioned having concerns on how to address the patients' cancer prognoses when conversing with the patients and mentioned that they were afraid of inadvertently offending the patients. In the individual interviews, one informant stated:

> *With the first cancer patients we had [included in RHC], many of us felt some discomfort and stress. I think it's because everyone has a relationship to cancer. It is so widespread and serious… It's like a dark and serious jungle. (Informant 5)*

The metaphor of a "dark and serious jungle" implies that the informant must negotiate an unpredictable and unsafe landscape without sufficient equipment to address the situation; it also exemplifies a personal fear of cancer. The HCPs' personal fear of cancer and death was further reinforced by their limited experience and lack of expertise in caring for patients with cancer and was especially prominent in the initial phase of the RHC implementation. Informants described overwhelming feelings of insecurity and a lack of general knowledge about the different types of cancer diagnoses, treatment options, and symptoms. They also expressed concerns regarding their ability to recognize important changes in patients and a fear of having limited options regarding performing assessments.

None of the informants had received specialized training in cancer or PC before implementing RHC for patients with cancer. Some said that they would have benefited from initial formal training in cancer-related topics, while others felt that this would have had no significant impact for them. The latter informants suggested that extensive experience and personal suitability together with competence in empathic communication as more relevant than formal competence in cancer care. The informants agreed that the cancer care coordinator provided great support through his/her expertise, and that they could rely on this expertise when required to make complex assessments in clinical situations. One participant explained:

> *I think I would've felt safer with courses or training before we jumped into it [RHC in palliative care]. We were kind of 'just dragged along' and we just tried. However, I didn't feel so insecure that it was unjustifiable because we had the cancer coordinator to support us. (Informant 6)*

As HCP insecurity became more apparent, it became clear that they had a great need for guidance regarding cancer-related issues and complex patient situations. The team sought external guidance from a nurse who was specialized in PC and oncology. This "guidance resource" provided substantial support for the assessments and decisions the HCPs needed to make.

> *A success criterion was that we've been able to work collaboratively and with each other's support. The humility of each other's experiences. .... To talk about talk about elements we find difficult. And you don't need to have so much knowledge, it's just that you are curious about the person behind the disease. That's the most important thing. ... (Informant 4)*

External guidance had a strong positive impact and represented a resource for discussing problems and challenges, which made issues concerning cancer and death less intimidating.

### Prominent organizational challenges undermine the premise of RHC

According to the informants, the most prominent challenge implementing the RHC was lack of integration across different health-care systems and services in the documentation concerning the patient's treatment and care. The presence of multiple health-service providers disrupted the information flow, and a great deal of time was spent obtaining necessary patient information concerning medication, appointments, and treatment changes.

> *There are many actors involved and we don't receive information because the systems don't communicate. We don't have that contact or agreement with the people enabling us talk to each other either. We cooperate with one hospital, while many of the patients receive follow-up from other hospitals. (Informant 1)*

The lack of integration across documentation systems was further challenged by the fact that RHC was relatively little known, especially among general practitioners (GPs) and hospitals. Although the HCPs cooperated well with most GPs in the same city district, problems occurred when patients had GPs in other districts. These GPs had no knowledge of their patients receiving care through RHC, which led to disruptions in the information flow. Limited knowledge of RHC became especially prominent when patients were discharged from hospital treatment and no one at the hospital was aware that the RHC service should be notified of the discharge and updated on the patients' treatment regimens:

> *The specialist healthcare service doesn't think about sending information to the district [the RHC service]... We're caring for seriously ill people without really having the latest news about them. (Informant 4)*

The lack of integration across health-care services and the unfamiliarity of RHC was explained by informants as representing a shift in responsibility from the health-care system to patients. The focus groups discussed and explained that patients had to physically bring their tablet to everyone involved in their treatment to show important changes in vital measures, symptoms, and medication. In the individual interviews, informants mentioned that the lack of integration led to situations where they had to rely on the patients having the latest information about their treatment and medication in order to provide adequate care:

> *We don't get access to assessments determined by the hospital or the GP. We have to ask the patients*

> *about what was said and done, for instance, changes in medication. (Focus group, informant 3)*

These infrastructural glitches were perceived as challenging by the HCPs, who clarified the need for changes and improvements in the technological infrastructure and highlighted that the RHC would never be able to function optimally if these challenges persist.

## Discussion

The aim of this study was to explore municipal healthcare professionals' experiences regarding the significant challenges, facilitators, and assessments associated with implementing RHC in palliative home care for patients with cancer. Our results suggest that a tailored approach based on questions from the ESAS questionnaire has the potential to identify individual patients' priorities, and that such information is essential for establishing a solid basis for PC assessments. Furthermore, insecurity and a lack of sufficient knowledge and experience with cancer care among HCPs leads to a prominent fear of cancer that may inhibit assessments and professional care. Providing guiding sessions on cancer and PC seems to have an important effect, offering HCPs a safe place to discuss problems encountered. However, prominent organizational barriers represent major issues, making it difficult to obtain and share the information necessary to provide seamless and optimal service to patients.

In our study, the HCPs perceived the RHC as a service that could be used to effectively care for home-dwelling patients with chronic illnesses. However, when introducing RHC to patients with cancer who required PC, the HCPs found it challenging to assess and understand the patients' care needs based only on remote measures of vital signs (for instance, weight loss is an expected symptom in patients with advanced cancer [27]. In previous studies, HCPs reported that the RHC-afforded ability to instantly identify changes in patients' comfort, symptom burden, and medication needs is beneficial for improving palliative interventions [17]. However, Neergaard and Warfvinge [18] found that HCPs in palliative-care teams have concerns that monitoring vital signs might lead to excessive attention to patients' physical problems, and that it may be better to focus on good communication instead.

To support the shift to a more person-centered approach, tailored ESAS questions were implemented in the RHC. The results indicate that this enabled HCPs to make more relevant person-focused, palliative-care assessments. Furthermore, the ESAS questions helped the HCPs to base their care assessments on patients' actual priorities and fostered better conversations when they telephoned patients. This result is supported by previous research, which found that symptoms and overall quality of life can only be assessed through patients' self-reports [7]. Furthermore, there may be limitations to the monitoring of symptoms through telehealth applications, with such systems being unable to adequately capture how patients feel [28]. PROMs such as ESAS supplement clinical observations and objective findings with individual patient information [7] and provide a basis for dialog with the patient regarding his/her situation, which contributes to patients providing more honest self-reporting of symptoms [2].

Our results also showed that questions assessing spiritual and existential needs were not addressed in the tablet-based questionnaires. This finding raises concerns regarding whether HCPs lack insight into patients' existential and spiritual needs, which were not addressed unless the HCPs or the patients explicitly mentioned such aspects in conversations. In PC, a person's narrative is considered significant for providing good care and ensuring a good death and, for many patients, the body and soul are considered inseparable [29]. Moreover, studies have highlighted that dialog between the ill person and the HCPs is fundamental for providing quality PC [30]. Thus, if questions addressing existential and spiritual needs are absent from welfare technology applications, it is reasonable to question whether such applications can comprehensively meet palliative-care needs.

In our study, the HCPs mentioned that they had adequate communication and technology skills, and RHC technology seemed to be accepted and well-adopted. Research highlights that videoconferencing, which was not included in the RHC in our study may enhance communication and care, and may be used for clinical assessments of patients [13, 31]. The HCPs in our study knew their patients well despite not meeting the patients physically or having the possibilities of videoconferencing. The initial assessment meeting provided insight into the patient's life situation and surroundings which was considered important when assessments were done by telephone conversations with the patients. Another interesting finding was that the RHC proved to be an effective service for monitoring patients who had previously refused contact with homecare services, meaning it allowed HCPs to provide care to patients who would otherwise not have been contactable. Coaching and communication skills, the ability to combine clinical experience with technology, ethical awareness, and a supportive attitude have been highlighted in several studies as fundamental and indispensable when using technology in patient care [15, 16]. Furthermore, telehealth apps such as RHC may contribute to improving the patient-HCP relationship if a personal relationship is established in addition to digital communication [2, 32].

Our results showed that a challenge to implementing RHC in palliative homecare is a lack of experience and adequate knowledge about cancer among HCPs. The HCPs we interviewed reported feeling anxious and uncomfortable addressing cancer diagnoses when conversing with patients. This fear became prominent when patients' conditions changed, and the HCPs needed to make abrupt assessments remotely. The quality of PC is dependent on the availability of HCPs who possess the competence and confidence to meet the care needs of patients and their families [33]. Bausewein and Daveson [34] clarified that, when implementing PROMs such as ESAS in palliative-care practice, an educational component that allows HCPs to understand why a measure is needed and how it could benefit their practice can have a positive effect on their care. Our results showed that the HCPs desired support and guidance soon after implementing RHC for their patients, and that such support was considered an important facilitator for implementing RHC in palliative homecare. In situations in which HCPs must manage patients who are dying, mentoring from experienced colleagues can represent supportive relationships for the HCPs [8, 35–37]. Furthermore, increased exposure to patient death has been highlighted as beneficial for changing attitudes toward death and reducing anxiety among HCPs [38]. Although the HCPs in our study cared for patients with incurable cancer (i.e., not dying patients), the above findings accord with our finding that the provision of guidance sessions, led by a specialized nurse, concerning cancer and PC may contribute to HCPs having more knowledge of cancer-related topics and may also represent a reliable resource for discussing feelings regarding severe illness and death.

Continuity of care was found to be a requisite for quality health care. Continuity involves both an individual and an organizational component, with access to valid patient information enhancing both patient safety and the consistency of care across organizations [39, 40]. Our results indicate that the RHC facilitated the provision of a service in which patients could communicate illness-related issues. However, organizational issues in patient information-sharing and the fact that RHC was little known across the health care system made it difficult for HCPs to obtain and share significant patient information, which was considered a major challenge. This disruption of information is acknowledged as a problem across healthcare services in Norway, where the primary health-care services and hospitals are divided into different organizational structures [41], making information-sharing a complex matter for those involved. This challenge has also been highlighted in international studies, which have mentioned that reliable technological infrastructure and the integration of telehealth applications into existing services are critical for technology-supported homecare to be effective [15, 42]. Although the implementation of electronic patient records to ensure coordinated health care and improved continuity of care [43] has gained momentum since the beginning of the millennium, our study demonstrates that complexity and frustration regarding information-sharing is still present.

## Limitations

A limitation to this study may be its small sample size, and the fact that all participants were recruited from one municipality in Norway. At the time of data collection, the population of HCPs with relevant experience of using RHC in municipal palliative cancer care was very limited. All the informants had practiced RHC. Moreover, it is not certain whether a higher number of participants would increase the richness of the data [44]. The participants' willingness to share their interdisciplinary experiences was considered to provide rich descriptions and variations in the data material. The scope and availability of health services are not constant throughout Norway, and it is likely that HCPs working in more rural districts could have experiences that are different to those of the HCPs who contributed to this study. Therefore, the transferability of our findings to other contexts may be limited. Attempts were made to include homecare nurses, and GPs in the study, but organizational challenges as well as the COVID-19 pandemic made this matter difficult. Including only HCPs from the RHC service center might exclude a multidimensional understanding of the municipal PC network.

## Conclusion

Our study of municipal HCPs' experiences with the use of a welfare technology application for providing palliative homecare to patients with cancer in Norway indicates that a shift from a disease-focused approach to a person-centered approach enables HCPs to remotely assess elements that are priorities for patients. Concurrently, lack of sufficient knowledge, experience, fear, and uncertainty among HCPs concerning serious illness and death proved to be a great challenge with the potential to inhibit palliative-care assessments and professional care. Providing networks where difficult issues can be discussed was found to represent an important resource that facilitated the implementation of RHC in palliative homecare for patients with cancer. Finally, our study suggests that welfare technology applications, such as RHC, cannot function satisfactorily until digital infrastructure is fully established throughout society. Until appropriate systems for the transfer of patient information and documentation across the several organizational structures of the health-care systems are in place, it will remain nearly impossible for HCPs to offer a full-fledged service in which patients' interests are fulfilled. This fact should be considered in future research projects in which new technologies are to be implemented and explored.

**Abbreviations**

COPD: Chronic obstructive pulmonary disease; ESAS: Edmonton Symptom Assessment System; HCP: Health-care professional; PC: Palliative care; PROM: Patient-Reported Outcome Measures; RHC: Remote home care; WT: Welfare technology.

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**Authors' contributions**

LO provided funding for this study. LO and SAS developed the study design, with contributions from all authors. LO and SAS conducted the focus-group interviews, and LO conducted the individual interviews. LO, SAS, and AD contributed to the analyses and interpretations. LO drafted the manuscript. All authors (LO, AD, SAS, VLC, KH, AM, and JÖ) provided important intellectual content, constructive comments and revisions in the development of the article manuscript. All authors approved the submitted version.

**Authors' information**

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**Availability of data and materials**

Data are available upon reasonable request to the corresponding author.

## Declarations

**Ethics approval and consent to participate**

The study was reported to the Norwegian Centre for Research Data (reference no. 429408) prior of data collection. The Norwegian Centre for Research Data concluded that the managing of personal data was in accordance with privacy legislation. The study did not require further approval from an ethical committee as it was not categorized as medical and health research (defined as research on humans, human biological material, and personal health information, aimed at generating new knowledge about diseases and health).Informants received oral and written information regarding the study and were guaranteed that their data would remain confidential and anonymous throughout the research process and the publication of the results. All informants signed informed consent forms prior to the data collection. This was approved by the Norwegian Centre for Research Data.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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# Patients' experiences with a welfare technology application for remote home care: A longitudinal study

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## Abstract

**Aims and Objectives:** To explore the longitudinal experiences using an application named remote home care for remote palliative care among patients with cancer living at home.

**Background:** Introducing welfare technology in home-based care for patients with cancer in the palliative phase is internationally suggested as a measure to remotely support palliative care needs. However, little is known about the experiences of patients utilising welfare technology applications to receive home-based care from healthcare professionals in a community care context. Although living with cancer in the palliative phase often presents rapidly changing ailments, emotions and challenges with patients' needs changing accordingly, no studies exploring the longitudinal experiences of patients were found.

**Design:** A qualitative study with a longitudinal, exploratory design.

**Methods:** Data were collected through individual interviews with 11 patients over 16 weeks. The data were analysed using qualitative content analysis. The COREQ checklist guided the reporting of the study.

**Results:** Three themes were identified: (1) potential to facilitate self-governance of life-limiting illness in daily life, (2) need for interpersonal relationships and connections, and (3) experiences of increased responsibility and unclear utility of the Remote Home Care.

**Conclusion:** The results showed that remote home care facilitated patients' daily routines, symptom control and improved illness-management at home. Interpersonal relationships with healthcare professionals were considered pivotal for satisfactory follow-up. Infrastructural glitches regarding data access, information sharing and lack of continuous adjustments of the application represented major challenges, with the potential to impose a burden on patients with cancer in the palliative phase.

**Relevance to Clinical Practice:** By exploring the experiences of patients in palliative care over time as the disease progresses, this study provides constructive insights for the design and development of welfare technology applications and optimal care strategies.

**Patient or Public Contribution:** The remote home care was developed by interdisciplinary healthcare professionals.

KEYWORDS
cancer, eHealth, palliative care, person-centred care, qualitative study, telehealth, telemedicine

## 1 | INTRODUCTION

Internationally, patients in palliative care (PC) desire to live meaningful lives based on their own preferences, with support for symptom control, physical functioning and psychological well-being. With limited time to live, patients consider engagement in meaningful activities important (Sandsdalen et al., 2015). Most patients requiring PC remain in their own homes for as long as possible, with some choosing to die at home (Radbruch & Payne, 2010; Sandsdalen et al., 2015; Skorstengaard et al., 2017). Furthermore, patients express preferences regarding continuity and coordinated care and the importance of good relationships with healthcare professionals (HCPs) (Klarare et al., 2017; Sandsdalen et al., 2015). However, patients receiving PC at home report unmet needs such as the lack of continuous communication with HCPs, uncertainty as to who should be contacted in times of need, and poor continuity in care (Ventura et al., 2014). Introducing welfare technology in home-based PC is suggested to provide patients with improved access to HCPs and to increase feelings of safety and security at home (Steindal et al., 2020).

Several terms are applicable to reference technological innovations; however, in this paper, we refer to the term welfare technology. Welfare technology is an umbrella term, mainly used in Nordic countries, that covers technologies with the potential to offer rapid, interactive exchanges of information between patients at home and HCPs. The goal is to sustain or improve individuals' safety, functioning and independence, thereby promoting well-being and reducing the need for formal and informal care (Rostad & Stokke, 2021). By interacting with the individuals involved in the service, welfare technologies do not only support care, but also has the potential to change how care is provided (Star & Ruhleder, 1996). Welfare technology covers a wide range of technology types, structures and processes. Other common terms are telemedicine, telehealth, telecare, e-health and assistive living technology; however, there is no clear distinction between them (Glomsås et al., 2020).

## 2 | BACKGROUND

Welfare technology in PC may aid in symptom control, support psychosocial issues, improve access to HCPs and increase patients' sense of safety and security at home (Head et al., 2017; Steindal et al., 2020; Widberg et al., 2020). Furthermore, research suggests that welfare technology in PC may improve information sharing, decision-making and communication, as well as reduce costs (Finucane et al., 2021; Widberg et al., 2020).

Previous research utilising qualitative methods has explored experiences of video consultations with HCPs specialised in PC, from the perspective of patients with cancer in the palliative phase (Funderskov et al., 2019; Hennemann-Krause et al., 2015; Read Paul et al., 2019; Tasneem et al., 2019; van Gurp et al., 2015). The results from these studies showed that video consultations can facilitate empathic patient–caregiver relationships, which enables professional care and increased patient involvement (van Gurp et al., 2015). Knowing that HCPs would be available through technology promoted peace of mind and relief for patients. Furthermore, patients highlighted benefits such as saving time, allowing more home time with their loved ones, promoting comfort and the possibility of taking an active role in managing their situation (Funderskov et al., 2019; Read Paul et al., 2019; Tasneem et al., 2019). In addition, welfare technology allows for enhanced access to HCPs, which is highly appreciated among patients living in rural areas (Bonsignore et al., 2018; Stern et al., 2012). However, the physical presence of HCPs in addition to welfare technology has been reported to be highly valued by patients (Read Paul et al., 2019). Therefore,

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

- A longitudinal study of patients' experiences of using an application for remote palliative care at home with follow-up from municipality healthcare professionals.
- The study demonstrates that applications for remote palliative care at home has the potential of providing patients with enhanced routines and control when managing their illness at home.
- When applications for remote palliative care are planned and implemented in patients with severe illness, such as cancer in the palliative phase, this study argue that a person-centred approach is crucial for the experiences of supportive care.

in-person communication combined with video consultations may strengthen the personal relationship between the involved patient, family, and HCPs and allow for the continuous provision of home care (Hennemann-Krause et al., 2015; Hochstenbach et al., 2016).

Some studies have investigated the experiences of patients in palliative care using diverse welfare technology applications for symptom management at home (Bonsignore et al., 2018; Hennemann-Krause et al., 2015; Stern et al., 2012). The results indicate that the remote monitoring of symptoms allows for improved self-management and remote support for cancer pain (Hennemann-Krause et al., 2015). Another study found that the remote monitoring of symptoms led to symptom relief in patients with dyspnoea, depression and poor well-being (Bonsignore et al., 2018).

The majority of previous studies were conducted in a specialised context where the HCPs involved possessed formal education and/or extensive training in cancer care and PC (Bonsignore et al., 2018; Funderskov et al., 2019; Hochstenbach et al., 2016; Read Paul et al., 2019; Stern et al., 2012; Tasneem et al., 2019; van Gurp et al., 2015). None of the identified studies explored patients' experiences of using welfare technology in palliative homecare in a community care context with follow-up from HCPs without specialised training in cancer or PC. Although patients living with cancer in the palliative phase may present with rapidly changing ailments, emotions and challenges with resultant changes in their PC needs (Kaasa et al., 2018), previous studies have mostly collected data at one point in time (Bonsignore et al., 2018; Hochstenbach et al., 2016; Read Paul et al., 2019; Tasneem et al., 2019). Therefore, exploring patients' experiences during the disease trajectory could be of great significance for the development of optimal patient care.

The aim of this study was to explore the longitudinal experiences of using a welfare technology application for remote PC among patients with cancer living at home. The application was named remote home care (RHC), which is a service that enables HCPs to remotely monitor and manage patients' safety, security, wellness, treatment and care (Oelschlägel et al., 2021). The following research questions guided the study: (1) Whether and how does the use of RHC in palliative care influence patients' ability to manage their life-limiting illness at home? (2) What are the facilitators and challenges of using RHC to manage life-limiting illness at home?

## 3 | METHODS

### 3.1 | Design

A qualitative, longitudinal and exploratory approach was chosen to provide knowledge of patients' experiences with RHC (Rahman et al., 2020). Data were collected through individual interviews at baseline, 4, 12 and 16 weeks with patients diagnosed with incurable cancer to describe their experiences of using RHC in palliative home care over a 16-week time period (Polit & Beck, 2020). The longitudinal approach with repeated interviews could allow for exploring continuous experiences and provide patients time to reflect between the interviews which could facilitate the provision of rich data for analysis (Polit & Beck, 2020). Data were analysed with qualitative content analysis (Graneheim & Lundman, 2004; Lindgren et al., 2020). The study was reported according to the consolidated criteria for reporting qualitative research guidelines (COREQ) (Tong et al., 2007) (Supplementary file 1).

### 3.2 | Setting

The study sample was recruited from one home care district in a municipality situated in the eastern part of Norway where RHC was established to provide remote palliative care for patients with incurable cancer living at home. A home care district is part of the publicly funded community care services and serves the population living in a defined geographical area (Farsjø et al., 2019). The home care district is densely populated, and all participants lived close to the hospitals and other healthcare services involved in their care. The RHC service office is an independent community care service offering only remote home care and is not attached to the traditional homecare services.

### 3.3 | Participants

A care manager associated with the RHC service team was responsible for recruiting patients referred to community care services using a purposeful sampling procedure (Polit & Beck, 2020). The inclusion criteria were patients aged 18 years or older, living at home, and diagnosed with cancer in the palliative phase. To recruit a sample with diverse and substantial experience in the use of RHC, variations in age, sex, living status, and whether they received additional homecare nursing were sought. Once relevant participants had been identified, an assessment meeting was arranged to agree on follow-up and participation in the study. Forty-four patients were invited to participate in the study, of which 18 agreed. Seven patients were prevented from participating, leaving a total of 11 patients. The characteristics of the sample are presented in Table 1.

To provide richer descriptions of experienced presence and severity of symptoms, all participants were asked to complete the Edmonton Symptom Assessment System (ESAS) questionnaire for self-reported symptoms (Bruera et al., 1991) prior to each interview. The questionnaire consists of 11-point numeric rating scales ranging from 0 (no symptom) to 10 (worst possible). All reported symptoms varied greatly among the participants. At baseline ($n = 11$) and 4 weeks ($n = 10$), lack of appetite and best well-being were the most reported symptoms. However, at 12 ($n = 7$) and 16 weeks ($n = 6$), a lower severity of these symptoms was reported (Figure 1).

### 3.4 | Intervention—Remote home care

The RHC was implemented in the home of patients with cancer in the palliative phase with the intention of enabling patients to stay at home for as long as possible, providing individually tailored

TABLE 1 Characteristics of the sample ($N = 11$)

| Characteristics | n |
|---|---|
| Age, years | |
| Mean (range) | 66 (30–94) |
| Gender | |
| Female | 5 |
| Male | 6 |
| Living situation | |
| Cohabiting | 4 |
| Living alone | 7 |
| Receiving homecare nursing | |
| Yes | 3 |
| No | 8 |
| Diagnoses | |
| Pulmonary cancer | 2 |
| Ventricular cancer | 1 |
| Myleomatosis | 2 |
| Cholangiocarcinoma | 1 |
| Colon cancer | 2 |
| Ovarian cancer | 1 |
| Cervical cancer | 1 |
| Gallbladder cancer | 1 |
| Cancer treatment | |
| Palliative chemotherapy | 4 |
| Palliative immunotherapy | 2 |
| None | 5 |
| Measuring devices provided | |
| Tablet | 2 |
| Tablet with self-reporting | 9 |
| Weight scale | 6 |
| Electronic drug dispenser | 2 |
| Blood glucose meter | 1 |
| Pulse oximetry | 1 |
| Blood pressure monitor | 1 |

follow-up, and improve the communication between patients and HCPs. The RHC team was experienced with providing care with the use of RHC as RHC already was implemented in the home of patients with chronic diseases such as chronic obstructive pulmonary disease and diabetes. The RHC service team consisted of multidisciplinary HCPs such as nurses (including one cancer coordinator), social workers, physical therapists, physicians and occupational therapists. The cancer coordinator had formal education and training in cancer care and palliative care. When included in the project, patients received RHC as a supplement to standard healthcare services. After inclusion, an assessment visit with representatives from the RHC service team was conducted in the patients' homes. During the visit, all of the patients received a tablet device containing an application featuring questions from the ESAS questionnaire (Bruera et al., 1991). The tablet device also included a function for patients to chat with HCPs at the RHC service team. Carefully selected measuring devices for physiological parameters, such as pulse oximeters, blood glucose meters, blood pressure monitors, electronic drug dispensers and weight scales, were also installed in the patient's homes. The tablet device application and measuring devices were adjusted according to each patient's specific situation. Individually adjusted values or measurements were set up to automatically alert so that aberrant measurements were easily captured.

After the assessment meeting, the patients entered a two-week trial period, focusing on getting to know the measuring devices and tablet application. During these two weeks, necessary adjustments to the measuring devices, individual values and questions related to the self-reporting of symptoms were addressed. After the trial period, the intervention was administered by the RHC service team who received patients' self-reported symptoms and medical measurements automatically. The patients reported symptoms and measurements as needed and according to agreements with the RHC service team. The interval for reporting varied from daily to weekly. After transmitting symptom scores and medical measurements, patients received a confirmation that the data had been received by the RHC service team. If aberrant measurements were reported, patients received a telephone call from a HCP within minutes. The patients were then given the opportunity to elaborate on the answers they had submitted and at the same time discuss further assessments in collaboration with the HCP. The RHC service team provided regular contact with the patients via telephone and responded to chat messages from patients or relatives. Some patients had regular face-to-face contact with cancer coordinators. No videos were included in the RHC.

The RHC service team was available for contact from 8:00 AM to 3:00 PM on Monday to Friday. The patients were followed-up for 16 weeks. However, the RHC continued as a healthcare service for the patients after the data for this study were collected (Figure 2).

## 3.5 | Data collection

A semi-structured interview guide was developed to facilitate reflection and conversation with participants. The interview guide consisted of open-ended and probing questions that covered aspects related to the patients' experiences, such as everyday life and health, the use of RHC, impacts of the RHC on daily life and illness management, and expectations of the RHC and follow-ups. Owing to the limited study population, the interview guide was not piloted. However, the researchers discussed the questions, and revisions were made to facilitate relevant and clear questions in accordance with the aim of the study.

The last author conducted individual semi-structured repeated interviews between September 2017 and March 2019. The initial plan was to interview participants before they received the tablet and medical measuring devices. However, after three interviews it was deemed that approaching the participants before the RHC was implemented did not provide rich data regarding their expectations

FIGURE 1 Presence and severity of pain, tiredness, drowsiness, nausea, appetite, shortness of breath (SOB), depression, anxiety, and general well-being at baseline and at 4, 12 and 16 weeks of follow-up. [Colour figure can be viewed at wileyonlinelibrary.com]

of RHC. Therefore, most of the participants were first interviewed shortly after the RHC home follow-up was established and then interviewed again at 4, 12 and 16 weeks of use. The time interval of 4–8 weeks between the interviews was considered to put minimum strain on the participants, while at the same time provide time to reflect on the use of the RHC application without important

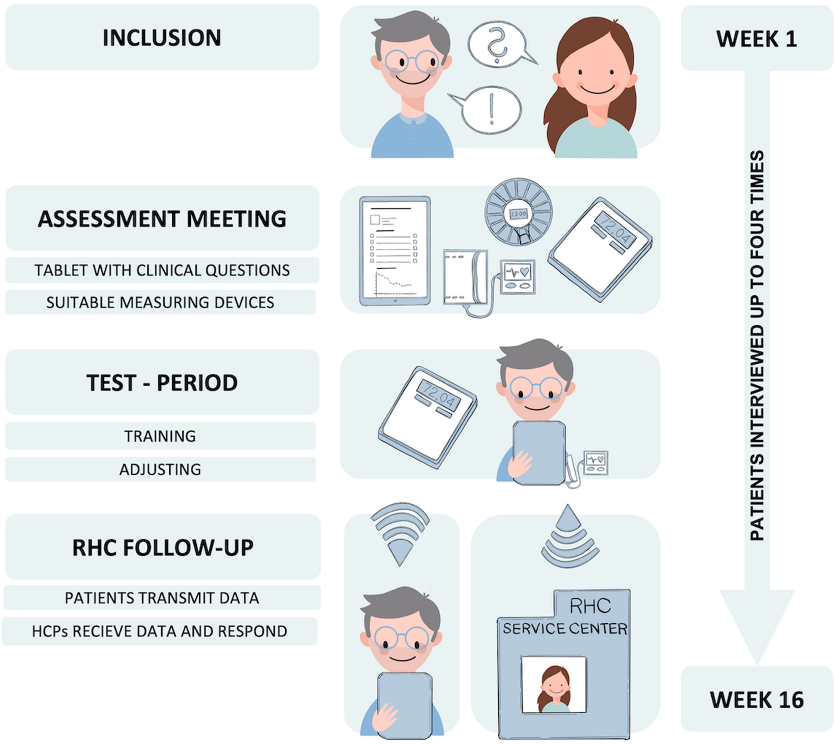

FIGURE 2 Remote home care (RHC) inclusion, assessment, test-period, follow-up and interviews. [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 2 Illustration of the analytic process

| Theme | Potential to facilitate self-governance of life-limiting illness in daily life | | | |
|---|---|---|---|---|
| Sub-theme | RHC influence on daily life | | Monitoring of symptoms provides a sense of being in control | |
| Categories | Improved routines | | Individual control of symptoms | |
| Codes | Improved monitoring routines | Improved medication routines | Individual control of pain | Individual control of weight |
| Condensed meaning | The weight monitor has helped with weighing routines | The technology has helped with medication routines | The tablet statistics provide an individual overview of pain development | The tablet statistics help to maintain weight |
| Meaning unit | The weight monitor has helped me to follow a routine of weighing myself every day with the goal to gain weight. (Patient 1) | The technology helps me stay in control. I messed up a lot before. Sometimes, I forgot the medications for maybe two, three days. But now it is like clockwork. (Patient 9) | I find the tablet useful. Especially for my own part and that I can follow the statistics. I can look at how the pain develops and see whether there is a pattern. Also, to keep up with the weight and make sure it does not drop. (Patient 2) | |

experiences being forgotten. The participants were interviewed at a place of their own choice. Most of the interviews were conducted in the participants' homes, except for one of the interviews conducted in a coffee shop. For two of the participants, follow-up interviews were conducted via telephone to avoid risk of infection in cases of neutropenia. The interviews lasted from 9 to 83 minutes and were audio-recorded. No fieldnotes were made during or after the interviews. Due to health-related issues, some of the included patients were unable to participate in all four iterations; 11 patients were interviewed at baseline, 10 patients at 4-weeks, 7 patients at 12-weeks and 6 patients at 16 weeks, leaving a total of 34 interviews. The authors had no relationship with the patients prior to the study commencement.

## 3.6 | Analysis

The interviews were transcribed by one of the researchers and a professional transcriber. NVivo facilitated the storage and organisation of data. The data were analysed using qualitative content analysis of both manifest and latent content to add depth and meaning to participants' statements (Graneheim & Lundman, 2004; Lindgren

TABLE 3 Themes and sub-themes

| Themes | Sub-themes |
|---|---|
| Potential to facilitate self-governance of life-limiting illness in daily life | RHC influence on daily life<br>Monitoring of symptoms provides a sense of being in control |
| Need for interpersonal relationships and connections | Initiative to communicate and interact with HCPs<br>Ambiguity in the use of RHC |
| Experiences of increased responsibility and unclear utility of the RHC | Managing the communicational gap between the different levels of healthcare<br>RHC failure to detect the current situation |

et al., 2020). The first author analysed the data. To obtain a sense of the full corpus, the data material was read iteratively before being organised into condensed meaning units. Considering the entire context of the material, the condensed meaning units were abstracted and labelled with a code close to the text. The codes were initially compared in terms of differences and similarities before being organised into tentative sub-themes. Each sub-theme contained several categories constituting the manifest content. Guided by the research questions, the tentative categories, and sub-themes were discussed among the researchers and revised multiple times before the latent content was abstracted and interpreted into three themes. To ensure intersubjectivity, the second and last authors asked critical questions of the first author's preliminary findings during each step of the analytic process (Table 2 illustrates the analytical process).

## 3.7 | Trustworthiness

Sample size was considered using the theoretical model of information power (Malterud et al., 2016). According to the model, sufficient information power for the data material was obtained by the narrow study aim, including patients in the palliative phase receiving RHC, conducting repeated interviews allowing for reflections between the interviews, and by the participants willingness to share both negative and positive experiences. By following these principles, a smaller sample size is needed (Malterud et al., 2016).

To investigate patients' longitudinal experiences, data were collected by time triangulation at four different time points. Investigating the same phenomenon in the same group at different points in time allowed for greater understanding and enhanced trustworthiness (Polit & Beck, 2020; Thurmond, 2001). To enhance dependability, the last author conducted all interviews and used the same interview guide each time. To obtain different perspectives, reduce the risk of biased interpretations and strengthen the credibility of the results, the final analysis and interpretation of results was discussed in its entirety with a group of researchers possessing diverse research expertise in welfare technology, PC and chronic illness. The identification of sub-themes and themes that preserved the underlying meaning of the text was sought. Furthermore, emphasis was placed on highlighting nuances in the results, for example, by referring to disagreements among the participants and using direct quotations in the presentation of results (Graneheim & Lundman, 2004). The participants were not asked to provide corrections or feedback regarding the transcripts or results. However, during the interviews, questions such as 'Have I understood correctly that you …?' and 'Do you mean …?' were asked to validate the immediate interpretations of participants' communication (Polit & Beck, 2020).

## 3.8 | Study approval and ethical considerations

The Norwegian Regional Committee for Medical and Health Research Ethics considered the study to not be notifiable. The study was reported and approved by the Norwegian Centre for Research Data (NSD) (reference number: 429408) and leaders in municipal healthcare services. Prior to participation, the participants received oral and written information regarding the study and were assured that all data would remain confidential throughout the research process and publication of the results. All included patients received and signed informed consent forms prior to data collection. The interviewer was experienced with caring for patients with incurable cancer and allowed for ample time at each interview to accommodate participants' need to express feelings and allow time for dialogue on their experiences with RHC. Data were managed and stored securely. Details of the participants were kept separate and locked following the guidelines set forth by the NSD.

# 4 | RESULTS

Three themes emerged from the data analysis: (1) potential to facilitate self-governance of life-limiting illness in daily life, (2) need for interpersonal relationships and connections, and (3) experiences of increased responsibility and unclear utility of the RHC. The themes and sub-themes are presented in Table 3.

## 4.1 | Potential to facilitate self-governance of life-limiting illness in daily life

Some patients experienced very little discomfort, while others carried a heavy symptom burden and described their everyday life as dominated by illness. Patients became emotional and tearful when addressing the question of general well-being at the start of each interview. Some patients spoke in detail about the consequences of living with an incurable diagnosis, while others did not address this fact and appeared to divert the conversation to something else if the interviewer touched on their diagnosis. However, patients explained that assessing their symptoms through questions on the tablet established a meaningful routine with a moment to think through their own symptom experiences and overall situation, which again was considered a support for adopting a more active role governing their illness.

> It is positive for reviewing symptoms and side effects and to look back and assess how I experienced my symptoms the foregoing week.
>
> Patient 7_interview 4

Patients were particularly interested in monitoring their weight, and some explained that the visual representation of weight loss provided by the tablet was a motivation to eat, even if their appetites were poor. Some patients expressed that weight loss was not emphasised by their general practitioner (GP) or treating hospital. They felt reassured that their weight was taken seriously through the RHC. In contrast, other patients stated that weight statistics on the tablet provided no meaningful information. One patient expressed that the visual bodily changes were more significant than the numbers on the tablet screen:

> It's ok to use the weight monitor, but I don't look at it. I know by my waistband how much I weigh.
>
> Patient 3_interview 3

According to the patients, the accumulation and visualisation of data over time on the tablet offered valuable insights regarding how symptoms and clinical signs developed over time, especially related to blood glucose levels, weight and pain. For example, patients explained that it was helpful to monitor their pain patterns and the variations in pain intensity, which in turn provided enhanced insight and feelings of control over the situation and prepared them for what may come. Several patients expressed that this type of control was relevant to governing their illness at home, and that it felt significant to have access to facts rather than diffuse assumptions as the illness progressed:

> The technology helps because it provides control. You know where you're at. How much I weigh and how much sugar I need to eat. Everything. The technology helps to handle the cancer, I think.
>
> Patient 9_interview 2

While only a few patients provided concrete responses on how RHC affected their daily lives, many experienced that self-reporting symptoms on the tablet and transmitting measures of clinical signs as scheduled had a positive impact, helping them govern their daily routines. Two patients received an electronic drug dispenser that alerted them at fixed times and thereby experienced fewer aliments related to improved medication routines. However, both patients experienced the sound from the dispenser's alarm as stressful and expressed that the device attracted unwanted attention when they were outside their homes among other people. One patient experienced this attention as burdensome and eventually stopped using the drug dispenser.

> The drug dispenser causes me to feel sick and stigmatized because the alarm attracts unwanted attention (…) It's too visual when the alarm starts ringing outside among other people.
>
> Patient 4_interview 2

When receiving RHC, patients were able to self-report symptoms, and interaction with HCPs provided the opportunity to channel everything related to their illness and ailments to one place. One patient explained that in this way, he was able to take his mind off illness and everything associated with it, which helped him re-establish meaningful relationships with friends and family. However, some patients experienced the RHC equipment as a disturbing and visible reminder of their illness and death. This experience was not addressed in the first two interviews but was problematised when the patients had used RHC for a longer period. The physical presence of digital equipment in their homes made it difficult for them to ignore the severity of their life situations. One patient had to put away the tablet and weight monitor for longer periods to focus on aspects other than death and illness.

> I'm reminded of the disease when I look at the tablet and the weight scale (…) I can't bear being reminded of it all the time.
>
> Patient 2_interview 3 and 4

## 4.2 | Need for interpersonal relationships and connections

Patients differed in whether they used the opportunity to chat with the HCPs via the tablet. Some patients were unaware of the opportunity to chat with HCPs, whereas others appreciated this as a useful and effective form of communication. These patients often used the chat option to ask questions concerning their illness or to inform HCPs that they were going away for some days and that they would not bring the measuring devices or tablets with them.

Some patients expressed concerns about sharing private information in the chat with HCPs that they had never met in person. These participants preferred contact by telephone as they considered it to be more personal. Patients described the barriers to contacting the HCPs by chat or telephone as being extremely high, especially regarding their need of support with psychosocial issues such as anxiety or depressive thoughts.

> If I'm feeling a lot of anxiety, I think I'd rather make an anonymous call to the mental health helpline than to have a dialogue on that thing [the RHC tablet device]. It feels wrong to bring up psychosocial issues on the tablet.
>
> Patient 7_interview 1

However, a number of patients considered the possibility of communicating with HCPs by chat rather than telephone as an advantage, making the communication of psychosocial matters less intimidating.

The majority of patients perceived the combination of the self-reporting of symptoms and the option of telephone contact with HCPs as a great advantage, as it provided certainty that the HCPs actually paid attention to their situation. Patients felt confident that the HCPs would telephone them back if they failed to submit measurements or self-report symptoms as scheduled. The option to communicate with someone who knew their situation well made them feel that they were being taken seriously and enhanced their sense of security at home.

> The tablet is a form of security. I don't know what kind of people they are – 'those at the other end,' but they do react if they discover something abnormal in my condition.
>
> Patient 5_interview 4

Patients emphasised that it would have been meaningful to meet the HCPs face-to-face to obtain a personal impression of who they were interacting with regularly and to be assured that the HCPs were fully aware of their individual care needs. These patients expressed uncertainty about whether the HCPs were able to obtain an overall picture of their situation via telephone, chat or the RHC application without physical meetings:

> I miss home visits where they can consider my needs; not just looking at the statistics.
>
> Patient 1_interview 2

Furthermore, some patients expressed scepticism about whether the intention to introduce RHC in home care was for their own benefit or as a procedure to reduce costs in the healthcare system. These patients worried that RHC could contribute to a 'colder society' with less human touch.

Personal contact was considered by the patients as important for managing illness and everyday life. Relatives were seen as a significant resource in this regard, and by several patients perceived as their most important supporters in everyday life. Some patients, especially those who lived alone, expressed feelings of loneliness and missed opportunities for social contact during the day. Some patients had regular contact with the cancer coordinator, often just to talk or obtain assistance with daily life issues. Patients who received follow-up from the cancer coordinator agreed that this person played a significant role, both in coordinating the health services and as a provider of personal support and dialogue. One patient walked regularly with a cancer coordinator and expressed that this was beneficial for both her physical and mental health. These findings demonstrate the necessity of including physical meetings when delivering customised and comprehensive PC using RHC.

### 4.3 | Experiences of increased responsibility and unclear utility of the RHC

As they did not receive in-person visits by HCPs, patients felt responsible for transmitting answers via the RHC system which provided a clear image of their situation. Furthermore, patients worried that skipping transmissions or answering incorrectly would have an impact on the care they received, and described the accurate use of the RHC as a significant responsibility:

> The technology is an excuse for not visiting people. The human contact is gone. You sit there alone. And you alone are to blame for the answers you transmit.
>
> Patient 6_interview 2

The patients received various follow-ups by HCPs in both the specialist- and municipal healthcare services and expressed confusion about knowing who was responsible for what regarding their health. Furthermore, the sharing of information between various healthcare services was perceived as unsatisfactory, and patients called for improved systems with the ability to integrate significant data related to their disease and improved interaction between the various HCPs involved in their care. To remedy unsatisfactory documentation systems, patients physically brought their tablet to appointments with the hospital and GP to show trends in their symptom data on the tablet. Furthermore, patients agreed with the district's nutritionist to log their daily food intake. This was not integrated in the tablet's application and needed to be noted manually on paper, making a visual overview of nutritional intake less accessible to the patients. The patients experienced this as cumbersome and non-innovative and requested improved solutions, such as being able to log daily food consumption on the tablet.

> I have to write down what I eat and drink on a piece of paper. It would've been much easier to just register everything on the tablet. Then everyone would know.
>
> Patient 11_interview 2

Due to these organisational glitches, patients felt a significant responsibility to ensure that the various HCPs possessed the correct information regarding their current situation. Patients explained that they frequently used the chat option on the tablet to update or inform the HCPs or the RHC service team when changes in treatment or medication were made, for example. One patient elaborated that she was required to explain aberrant measurements of weight caused by intravenous treatment at the hospital. The RHC service team had no knowledge of this because of the unsatisfactory information sharing of patient data across levels of care:

> The nurses use the chat to make small comments on my measurements. For instance, weight gain. Then I write back that I've had four liters of intravenous to explain the cause.
>
> Patient 2_interview 3

Some patients expressed that they spent much valuable time taking responsibility for managing their care and asserted that the introduction of RHC had no impact on this aspect. Furthermore, patients felt insecure about where they should turn for help with various issues such as the exacerbation of symptoms or fever induced by palliative chemotherapy. Patients appeared unsure whether potential situations could be prevented or caught early by transmitting symptoms or measurements to the RHC service team, allowing for early assessments and intervention. Few patients believed that the RHC service team could help with such events. However, most patients were able to obtain hospital admission without referral and relied on the hospital to help in acute situations.

> The city district [RHC service team] has said that maybe they could help so I wouldn't have to go to the hospital. Then I just wrote back that I must go to the hospital if I get a fever or become very sick.
>
> Patient 8_interview 2

Some patients perceived the questions on the tablet as static and inflexible. Patients were concerned that the tablet questions only requested the occurrence and severity of symptoms and felt responsible for elaborating on the symptoms they reported, especially regarding pain. On their own initiative, these patients frequently used the chat option on the tablet to inform and explain the pain location and its variation in character to the HCPs. Over time, some patients experienced the questions on the tablet as monotonous and boring to answer and requested changed wording to make the routine self-reporting of symptoms more inspiring. Some also experienced large variations in their illness trajectory during the day or week, such as rapidly fluctuating ailments, and felt uncertain whether the RHC was able to detect these changes. This was especially challenging during palliative cancer treatment periods when the burden of troublesome ailments was greater. During the interviews, these patients expressed uncertainty regarding the RCHs' personal utility and requested more flexibility regarding when and how they could report their symptoms and measurements.

> I answer questions once a week (...) It can be difficult to answer because the pain and symptoms vary all the time during the day. I'm not sure if they catch these variations by me answering once a week.
>
> Patient 9_interview 2

During the 16 weeks of follow-up, patients experienced changes in their health conditions. Despite this, patients noted that the content of the RHC was not adjusted accordingly. This was only achieved if the patients explicitly informed the RCH service team that changes needed to be made. In general, the clinical questions on the tablet and digital medical devices remained the same even though their symptoms and needs improved or worsened. Some patients had several ailments that were not captured by the questions on the tablet, whereas others experienced the questions as too specific and missed questions that addressed activities of daily living.

> There's no further development, no change. It's the same questions from week to week. They need to get their finger out and do something more. Other questions concerning life and health (...) There must be a meaning behind the questions. What are the definitions of the questions? Do you have pain? What does that mean?
>
> Patient 6_interview 4

Some patients questioned the purpose of RHC and how it could benefit their situation and requested more information, while others experienced improvements in their health condition and did not have the same need to report symptoms or follow the development of physiological parameters, such as weight, as before. Several patients requested improved communication with the RHC service team regarding plans for future follow-ups with RHC.

## 5 | DISCUSSION

This study aimed to explore the longitudinal experiences of using a welfare technology application named RHC for remote palliative care among patients with cancer living at home. Our results suggest that RHC may strengthen patients' ability to manage their life-limiting illness at home by providing enhanced routines and control in their daily lives. Personal relationships and close connections with HCPs were considered by patients as prerequisites for illness management. However, over time, patients felt responsible for informing HCPs about details regarding symptoms and experienced the lack of flexibility and deficient tailoring of the RHC content as severe challenges, which further contributed to making the utility of the RHC unclear.

In our study, patients described that RHC facilitated management of their illness at home by contributing to improved routines regarding symptom management. This was facilitated by establishing fixed times for symptom assessments, medical measurements and medication, which aided in symptom control and patients self-governing their illness at home. This result concurs with prior research suggesting that technology-based monitoring and management of symptoms may be both useful and feasible for patients (Bonsignore et al., 2018; Hennemann-Krause et al., 2015; Stern et al., 2012). Furthermore, the patients in our study considered the individual follow-up of HCPs, either via chat, telephone or face-to-face (the cancer coordinator), as pivotal for the experience of a beneficial follow-up. By channelling everything regarding the illness onto the tablet and receiving a response from the HCPs, the illness became less all-consuming and allowed patients to focus on more positive experiences with significant others. Most technology-based communication strategies in cancer care have focused on information exchanges between patients and their providers (Ansari et al., 2022). Introducing technologies to monitor patients' symptoms in the palliative phase at home may provide more information about patients. However, there is a potential risk that HCPs have less time to interact and gain knowledge of the patients, which is considered unfavourable in a PC context in which relationships are key (Payne et al., 2020).

The human component of the RHC was regarded as a facilitator that allowed for the elaboration of symptoms and provided patients with the sense that someone was paying attention to their situation, which enhanced feelings of safety and security at home. Previous research suggests that the possibilities of communicating feelings and problems and the knowledge that someone will respond may be beneficial (Capurro et al., 2014). The significance of the physical presence of HCPs in patients' homes is in accordance with the results of previous studies investigating technology-based communication between patients at home and HCPs (Gorst et al., 2014; Rykkje & Hjorth, 2017; Steindal et al., 2020). However, the establishment of trusting relationships between patients and HCPs and the possibility of providing and receiving a caring touch is challenged when the care is provided remotely (Dorsey & Topol, 2016; Sandsdalen et al., 2015; Steindal et al., 2020). Although patients in our study had regular physical contact with the cancer coordinator in the home care district, they wanted to know more about the HCPs sitting on the 'other side of the tablet' and to have met them in person. Supplementary face-to-face contact and physical follow-ups were highlighted as preferable to video as an addition to the existing RHC service. Thus, great demands are placed on the service when the patient and HCPs do not meet face-to-face to assess, discuss and clarify the reporting of symptoms or other ailments.

The patients in our study experienced complex and fluctuating symptoms that were challenging to describe on an analog scale. To compensate for this challenging deficiency of the RHC, some patients accepted the responsibility and used the chat function in the application to inform the HCPs and elaborate on aspects such as the location and type of pain. Similar results were emphasised a decade ago (Lind et al., 2007; McCall et al., 2008) and summarised in a recent scoping review (Steindal et al., 2020) which stress the importance of welfare technology applications being substantially tested prior to implementation and the need for innovation when planning and designing digital follow-ups of patients living at home.

Although all patients in this study suffered from cancer in the palliative phase, they differed in terms of their life situations, disease burdens, treatments and futures. The patients expressed that their symptoms fluctuated and differed during periods of treatment. Tailored questions for the self-reporting of symptoms and measuring devices were applied when the RHC was installed. However, our results from data collected at various points in time showed that despite the patients' experience of variation in their illness trajectory over time, very few or no adjustments were made to the RHC content, such as questions for the self-reporting of symptoms, settings for aberrant measurements, measuring devices and agreements for telephonic contact. In addition, patients noted that the symptoms they reported were not always detected by HCPs or that they answered questions regarding symptoms that no longer occurred, which in turn led to the unclear utility of the RHC service. For example, patients continued to measure their weight daily even when satisfactory weight gain was achieved. This error in detecting patients' perceived symptoms and changes in clinical signs as time went by and the disease progressed was perceived as a major challenge regarding the use of RHC. Such challenge may further inflict an unnecessary burden on the patient and contrasts with the definition stating that PC promotes quality of life by the comprehensive assessment and management of physical issues, including pain and other distressing symptoms (Radbruch et al., 2020). Furthermore, patients reported experiencing barriers contacting HCPs with matters of a psychosocial nature. Based on the patient's constant changes with regard to the illness, the requirement for RHC changes over time. Emphasis on efforts to facilitate a person-centred approach with continuous, systematic dialogue with the patient is necessary to ensure the continuous relevance of the service (Hansen et al., 2017). Österlind and Henoch (2021) developed a model for person-centred PC, the 6 S-model. With self-image as a central concept, the model encompasses patients' personal experiences of the situation as a starting point for care. The concept of self-image is complemented by the five interrelated concepts of self-determination, symptom relief, social relationships, synthesis and strategies. When developing technologies for remote palliative home care, it would be appropriate to consider models that include a person-centred approach, such as 6 S, rather than pure symptom assessment scales, which may lead to an increased responsibility and burden on patients.

Our results indicate that patients felt responsible for remaining updated on medication and for informing the RHC service team if changes in treatment or medication had been administered. To remedy unsatisfactory documentation systems, patients physically brought their tablets to the hospital or GP to demonstrate trends in the symptom data on the tablet. This finding concurs with Hochstenbach et al. (2016) stating that by accepting technology interventions, HCPs abandon fragments of their present role, previously delivered face-to-face, to the technology itself, but also to patients on which they have to rely for information. As described by Oelschlägel et al. (2021), little is known about RHC among various health service providers involved in the care of patients which has led to communication issues and further shifted the responsibility of significant care aspects, such as an overview of medications, to the patients. Our results show that patients felt strained by the consequences of unpredictability and the heavy burden of having to put on an administrative role to manage appointments, treatment and care. To enable patients to relinquish their perceived responsibilities as administrators and shift the responsibility back to where it belongs, focus must be placed on the digital infrastructure regarding information exchange, available documentation and clear communication between the various levels of healthcare service.

### 5.1 | Limitations

A limitation of this study is that gatekeeping behaviour occurred during the recruitment process. In this context, the term gatekeeping refers to HCPs making their own considerations of the burden that possible participation in the study may entail for the patient (Sharkey et al., 2010; Snowden & Young, 2017). As a result, the sample may have been affected to the extent that patients with a complex life situation or a large degree of burden from the illness may have been excluded. When discovered, actions were implemented to eliminate gatekeeping behaviour, and the inclusion of patients proceeded as planned. Another limitation may be that the interview guide was not pilot tested. The reason for this was partly the limited study population, but also that the participants had an incurable diagnosis with an uncertain life expectancy, which led to a time pressure to complete the data collection. Nevertheless, all included participants had diverse cancer diagnoses with different symptoms and ailments. They also received individualised follow-ups, which meant that they received different questions regarding symptoms, diverse measuring devices and different agreements about contact with the HCPs. These experiences allowed for a large range of topics to be deliberated and for the collection of more comprehensive responses relevant to answering the research questions (Graneheim & Lundman, 2004). Finally, all participants were recruited from the same home care district. It is possible that the experiences of patients living in more rural areas of Norway could have differed from those of the urban patients contributing to this study. Therefore, the transferability of the results to other contexts may be limited.

## 6 | CONCLUSION

Our study on RHC for patients with cancer receiving palliative care at home indicates that patients experience improved daily routines, allowing for aid in symptom control and engaging in a more active role in managing their illness at home. The visual representation of symptoms and clinical signs may enable patients to plan for and anticipate unforeseen events as a result of living with a serious and incurable disease. However, technology is not considered a facilitator in itself; interpersonal care is highly appreciated by patients as pivotal for the experience of satisfactory follow-up and enhanced feelings of safety and security at home. Finally, the lack of continuous adjustments of RHC content and infrastructural glitches regarding data access and sharing may lead to feelings of unsatisfactory utility of the service and represent major challenges with the potential to impose a burden on patients with a limited time to live. These elements should be considered in future research projects exploring the implementation of new technologies to care for patients with severe illness living at home.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The offering of RHC entails a great responsibility for assessing whether the potential burdens outweigh the benefits of palliative homecare. A person-centred approach with close collaboration and routine contact between patients and continuous adjustments in digital applications for remote homecare are crucial for supporting patients with cancer in the palliative phase living at home.

## AUTHOR CONTRIBUTIONS

SAS developed the study design, with contributions from all the authors. SAS, KH, AD and JÖ developed the interview guide. SAS conducted the individual interviews. LO, SAS and VLC contributed to analyses and interpretations. LO drafted the manuscript. All authors (LO, VLC, AM, KH, JÖ, AD and SAS) provided significant intellectual content, constructive comments and revisions in the development of the article manuscript. All authors approved the submitted version.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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LO provided funding for this study.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon reasonable request to the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Paper III

# Implementation of Remote Home Care – assessment guided by the RE-AIM framework

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# Abstract

**Background:** Welfare technology interventions have become increasingly important in home-based palliative care for facilitating safe, time-efficient, and cost-effective methods to support independent living of patients. However, studies evaluating the implementation of welfare technology innovations and the empirical evidence of sustainable models using technology in home-based palliative care remains low. This paper aimed to report on the use of the RE-AIM framework to assess the implementation of RHC, a technology-mediated service for home-living patients in the palliative phase of cancer. Furthermore, we explored areas of particular importance determining the sustainability of technologies for remote palliative home-based care.

**Methods:** A secondary analysis of data collected by semi-structured interviews with patients with cancer in the palliative phase and focus groups and semi-structured interviews with healthcare professionals experienced with remote home care was performed. Data were analyzed with a deductive reflexive thematic analysis, using the RE-AIM dimensions.

**Results:** Five themes illustrating the five RE-AIM dimensions were identified: 1) Reach: Protective actions in recruitment - gatekeeping, 2) Efficacy: Potential to offer person centered care, 3) Adoption: Balancing high touch with high tech, 4) Implementation: Moving towards a common understanding, and 5) Maintenance: Adjusting to what really matters

**Conclusions:** The RE-AIM framework highlighted that the implementation of Remote Home Care for patients in the palliative phase of cancer was influenced by the healthcare professionals' gatekeeping behavior, concerns regarding abandoning palliative care as a high-touch specialty, and a lack of competence in palliative care. Although remote home care facilitated improved routines in the patients' daily lives, it was perceived as a static service that was unable to keep pace with disease progression. Therefore, a person-centered approach that prioritizes individual needs and preferences is necessary for providing optimal care.

While technologies such as remote home care are not a panacea, they can be integrated as support for increasingly strained health services.

**Keywords:** RE-AIM; health care technology, assessment; qualitative; home-based; palliative care

## Background

Palliative care adopts a holistic perspective, aiming to maintain the quality of life of people living with severe illness which are limiting life prognosis such as cancer, by relieving physical, psychosocial, spiritual and existential suffering [1]. Palliative care has evolved from focusing on the care of the dying, to early integration of palliative care for patients with cancer [2]. Palliative care should be delivered based on the patients' personal preferences, which requires a person-centered approach from healthcare professionals (HCPs) associated with their care [3,4]. Current health policies aim to facilitate patients with palliative care needs to live and receive long-term treatment at home [5].

To meet challenges in the increasingly strained health system, where higher workloads and fewer healthcare professionals seem to be the new normal, there is an increased focus on establishing innovative solutions for providing palliative care [6,7]. Many terms can be used to reference technological innovations. In this paper, we refer to the term welfare technology. Welfare technology is an umbrella term, mainly used in Nordic countries, and refers to technologies interacting with individuals involved in the care service; not only to support care, but also alter how care is provided [8]. Remote home care (RHC) is an example of an innovative application of welfare technology as supportive service implemented for home-living patients with cancer in the palliative phase with the intention of enabling patients to stay in their homes for as long as possible. Furthermore, RHC is a tool to provide tailored follow-up, and improve communication between patients and HCPs. The RHC is a non-ambulant service based on three components: i) a tablet device containing individualized questions for self-reporting of symptoms, ii) sensor data via medical measuring devices (such as weight scales, pulse oximeters, blood glucose meters, blood pressure monitors, and electronic drug dispensers), and iii) patient-HCP communication via chat or telephone.

Although empirical evidence of digital interventions beneficial for home-based palliative care is growing [9,10], the adoption of technological innovations in healthcare has been slower than expected in most countries [11]. Moreover, there has been limited prioritization and publication of studies on innovative interventions such as the RHC, indicating a significant gap in knowledge regarding the potential of technology to enhance sustainable patient outcomes in palliative care [12,13]. Without the right tools for evaluation, there is a chance of welfare technology being implemented as an end in itself, rather than as a mean to improved care [14]. Thus, research integrating the effectiveness of interventions with ways to successfully incorporate them into existing organizational context is necessary. This type of research is known by various names in the literature, such as implementation science, dissemination science, translational research, and knowledge transfer [15]. RE-AIM [16] is a useful framework for guiding this type of research.

## The RE-AIM framework

The RE-AIM framework [16] is an acronym referring to five evaluative dimensions describing the overall population-based impact of an intervention like RHC; the individual level (i.e., those who the intervention is intended to benefit), and the staff and setting levels (i.e., the institution applying the intervention) [17,18]. The RE-AIM was developed and deployed to assist in the planning, management, evaluation, and reporting of studies supporting the translation of research or innovations into practice [15]. The framework seeks to balance the traditional focus on internal over external validity and facilitate sustainable adoption and implementation of effective, generalizable, and evidence-based interventions [18]. Table 1 illustrates the dimensions, levels, and definitions of the RE-AIM framework.

**Table 1.** RE-AIM dimensions, levels, and definitions

| **RE-AIM dimension and level** | **Definition** |
|---|---|
| | |
| **Reach**<br>Individual level | Representativeness, rate, and characteristics of individuals who are willing to participate in a given intervention, including potential barriers for participation |
| **Effectiveness**<br>Individual level | Impact of an intervention on individual outcomes, such as positive and negative effects, quality of life, and economic outcomes |
| **Adoption**<br>Institutional level | Representativeness and proportion of settings that implement the intervention |
| **Implementation**<br>Institutional level | Institutional fidelity to the intervention's protocol and includes consistency in intervention delivery, as well as timing and cost of the intervention |
| **Maintenance**<br>Individual + institutional level | The extent to which the intervention has become institutionalized or part of the routine organizational practices and policies. Maintenance also includes an individual level addressing the long-term effects of intervention outcomes following completion of the intervention |
| *RE-AIM: Reach, Effectiveness, Adoption, Implementation and Maintenance* [18] | |

Although the RE-AIM framework has been widely employed for planning, managing, and evaluating a large number of interventions in the past two decades [18], the published literature reveals a shortage of qualitative approaches using RE-AIM [19-21]. The RE-AIM dimensions highlight the need to measure not only traditional clinical outcomes, such as effectiveness, but also implementation outcomes, which are crucial for ensuring widespread public health impact. Holtrop and Rabin [19] argues that qualitative approaches may be helpful to the results and provide answers to why and how implementation processes unfolded the way they did. Thus, qualitative studies using the RE-AIM framework can provide a deeper insight into the intended and unintended outcomes of an implementation. This valuable information can contribute to the translation of relevant interventions into practice [19].

This paper aimed to report on the use of the RE-AIM framework to assess the implementation of RHC, a technology-mediated service for home-living patients in the palliative phase of cancer. Furthermore, we explored areas of particular importance determining the sustainability of technologies for remote palliative home-based care.

## Methods

This paper was based on a secondary deductive reflexive thematic analysis [22] using the RE-AIM framework [16] to assess perspectives on the implementation of RHC to patients in the palliative phase of cancer. The assessment was based on qualitative data obtained through individual and focus group interviews with patients and HCPs and is part of a project exploring patients' and HCPs' experiences with using RHC in palliative homecare [4,23]. The Consolidated criteria for reporting qualitative research (COREQ) checklist guided the reporting of this study [24].

### *Setting and recruitment*

The RHC service team consisted of multidisciplinary HCPs experienced with providing RHC to home living patients with diverse chronic illnesses. The RHC service team were situated at the RHC service center in one city district in a large city in Norway.

The participants were recruited through purposeful sampling [25] from one municipality in Norway, where RHC was introduced to home-living patients with cancer in the palliative phase. The sample consisted of 11 patients and 8 interdisciplinary HCPs employed by the RHC service team [4,23]. Most HCPs were experienced users of RHC, however less experienced with patients with cancer and palliative care. A few HCPs had more experience with cancer and palliative care, however, were less experienced with RHC. All the included HCPs were familiar with different aspects of the RHC service for patients in the palliative phase of cancer and were considered important contributors in this study. The sample characteristics are listed in Table 2. The authors had no relationship with the participants prior to their inclusion in this study.

**Table 2.** Characteristics of the patients in the palliative phase of cancer and interdisciplinary HCPs (N=19)

| **Characteristics of the patients (n=11)** | | **Characteristics of the HCPs (n=8)** | |
|---|---|---|---|
| | | | |
| **Gender** | | **Gender** | |
| Female | 5 | Female | 6 |
| Male | 6 | Male | 2 |
| **Age, years** | | **Age, years** | |
| Mean (range) | 66 (30–94) | Mean (range) | 37 (27–50) |
| **Living-situation** | | **Profession** | |
| Cohabiting | 4 | Specialized nurse[a] | 2 |
| Living alone | 7 | Nurse | 2 |
| **RHC devices provided** | | Social worker | 1 |
| Tablet device | 2 | Physical therapist | 1 |
| Tablet device with self-reporting of symptoms | 9 | Occupational therapist[b] | 2 |
| Weight scale | 6 | **Experience in healthcare** | |

| | | | |
|---|---|---|---|
| Electronic drug dispenser | 2 | Years, mean (range) | 13 (4–27) |
| Blood glucose meter | 1 | **Experience in current position** | |
| Pulse oximetry | 1 | Years, mean (range) | 6 (1–10) |
| Blood pressure monitor | 1 | | |

[a] One specialized nurse operated as cancer care coordinator in the district.

[b] One occupational therapist operated as project manager for implementing RHC.

HCP, healthcare professional; RHC, remote home care.

### *Data collection*

One of the authors (SAS) collected patient data by conducting 35 repeated individual interviews between September 2017 and March 2019. The first interview took place shortly after the RHC home follow-up was established (T1), followed by interviews at weeks 4 (T2), 12 (T3), and 16 (T4) of RHC use. Five patients were interviewed on all occasions, while one patient only participated at baseline. Table 3 presents an overview of the patient interviews.

**Table 3.** Patients participating in which interview

| **Patient** | **Interviewed at baseline (T1)** | **Interviewed at 4 weeks (T2)** | **Interviewed at 12 weeks (T3)** | **Interviewed at 16 weeks (T4)** |
|---|---|---|---|---|
| | | | | |
| Patient 1 | X | X | X | X |
| Patient 2 | X | X | X | X |
| Patient 3 | X | X | X | X |
| Patient 4 | X | X | X | |
| Patient 5 | X | X | X | X |
| Patient 6 | X | X | | X |
| Patient 7 | X | X | X | X |
| Patient 8 | X | X | | |
| Patient 9 | X | X | X | X |

| | | | | |
|---|---|---|---|---|
| Patient 10 | X | | | |
| Patient 11 | X | X | | |
| | | | | |
| Total number of patients per interview | n = 11 | n = 10 | n = 7 | n = 6 |

One of the authors (LO) collected data from the HCPs through focus groups and individual interviews in November 2019. Important topics identified from audio recordings and transcribed material were used to facilitate individual interviews with six of the eight focus group participants. All the interviews were guided by a semi-structured interview guide consisting of open-ended and probing questions covering topics related to the participant's experience with RHC. The interviews were audio recorded, transcribed verbatim, and checked for accuracy by the above-mentioned authors. Interview guidelines are available upon request.

### *Ethics*

The study was approved by the Norwegian Centre for Research Data (NSD) (reference number:429408) and exempted from review by The Norwegian Regional Committee for Medical and Health Research Ethics (REK). All the participants received oral and written information assuring confidential and voluntary study participation, with the opportunity to withdraw from the study at any time. Details of the participants were kept separate and locked. Data were managed and stored securely, following the guidelines set forth by the NSD. Taking anonymization and confidentiality into consideration, this paper mainly refers to the group of HCPs as a whole: The RHC service team.

### Analysis

A deductive reflexive thematic analysis [22], using the RE-AIM framework [16], was applied to assess the perspectives on the implementation of RHC to patients in the palliative phase of cancer. The RE-AIM dimensions Reach, Effectiveness, Adoption, Implementation, and Maintenance (Table 1) guided the analysis of the following six phases:

*Phase 1 (Familiarization with the dataset)*

A deductive approach was initiated by applying the five RE-AIM dimensions to existing patient and HCP datasets. This provided an initial structure, in which the data extracted from the two datasets were assessed and placed within a given RE-AIM dimension. The data extracts were read, re-read, and re-arranged multiple times to determine meanings and patterns across the datasets.

*Phase 2 (Generating codes)*

To capture the meanings in the dataset, the initially structured data extracted from the patients and HCPs were coded using semantic codes. The semantic codes were revised and processed before being labelled with latent codes to capture their implicit meanings [22]. The latent codes were revised and re-arranged according to the five RE-AIM dimensions.

*Phases 3 and 4 (Constructing and reviewing potential themes)*

Using the qualitative RE-AIM data questions suggested by Holtrop and Rabin [19] (Table 4), the latent codes were constructed and revised multiple times before collating into potential and later themes. Visual mapping was employed to provide an overview and explore the association of the potential themes with each other [22] (Figure 1).

*Phase 5 (Defining and naming themes)*

The candidate themes were refined and revised in accordance with the RE-AIM dimensions to ensure that they highlighted important patterns across the dataset. This step, as well as the final step of defining and naming the themes, was performed collaboratively within a group of researchers with diverse research expertise in welfare technology and palliative care (LO, AM, and SAS) to enhance alternative interpretations and intersubjectivity and strengthen the credibility and dependability of the results [25]. The final analysis and interpretation were discussed in its whole.

The first author wrote a text presenting the preliminary results (phase 6), which was thoroughly read and discussed and subsequently revised in collaboration with all the authors. NVivo facilitated data storage and organization.

**Table 4.** Qualitative RE-AIM questions used in the analysis phases 3 and 4

| RE-AIM Dimensions | Questions guiding the analysis |
|---|---|
| **Reach** | What factors contribute to the participation/non-participation of the participants?<br>What might have been done to get more of the target audience to participate? |
| **Effectiveness** | Did the intervention work to affect the outcomes noted?<br>What other factors contributed to the results?<br>Are the outcomes found accurate?<br>Are the results meaningful? |
| **Adoption** | What factors contributed to the organization and its individuals taking up the intervention? What barriers interacted with the intervention to prevent adoption? Was there partial or complete adoption? Why did some staff members in these organizations participate and others did not? |

| | |
|---|---|
| **Implementation** | How was the intervention implemented? By whom and when?<br>What influenced implementation or lack of implementation?<br>What combination of implementation effects affected the outcome results?<br>How and why was the program or policy adapted or modified over time? |
| **Maintenance** | Is the intervention being implemented (and adapted) after the intervention core period?<br>What is sustained, what discontinued, what modified- and why? |

*RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance*

Holtrop and Rabin [19]

(Insert figure 1 here)

The sample size was determined using the theoretical model of information power suggested by Malterud and Siersma [41]. Information concerning the sample size of the relevant datasets are available in two recently published papers [4,23].

## Results

The results of the secondary analysis of the data from the patients and HCPs are presented according to the five themes representing the RE-AIM dimensions as follows:

1. Reach: Protective actions in recruitment - gatekeeping
2. Effectiveness: Potential to offer person centered care
3. Adoption: Balancing high touch with high tech
4. Implementation: Moving towards a common understanding
5. Maintenance: Adjusting to what really matters

### *Reach: Protective actions in recruitment - gatekeeping*

Reach considers the factors contributing to the participants' participation/non-participation in recruitment. Considering RHC, the *Reach* dimension applies to individuals (patients) who meet the inclusion criteria and agree to receive RHC in addition to existing services upon request from the RHC service team. Furthermore, the reach dimension applies to the HCPs involved in patient recruitment.

Patients who were asked to participate were positive and found it meaningful to test a service that potentially could benefit others.

*«I have little expectations. I was thinking that this was something I could do for you. To the benefit of others later. »*
*Patient 10_ T1*

HCPs in the RHC service team who were experienced of using RHC on patients with Chronic Obstructive Lung Disease (COPD) and diabetes, wanted to use the opportunities in RHC to get closer to patients living at home with cancer in the palliative phase. However, some HCPs were less experienced with RHC and were skeptical of introducing high-tech services to care for these patients. This was evident in the recruitment of patients to RHC, where HCPs who were less experienced with RHC felt a responsibility not to impose unnecessary stress and burden on patients, and therefore failed to introduce RHC to patients they perceived to be very frail.

*«I felt it was wrong to expose patients with cancer to this [RHC and research participation] in addition to everything else. »*

*HCP 4_focus group 1*

Furthermore, the HCPs involved in the recruitment expressed that it was challenging to anticipate and decide which patients could benefit from receiving RHC, and when in the palliative phase and disease trajectory it was appropriate to introduce RHC, although the inclusion criteria were specified. These protective actions or gatekeeping behaviors in HCPs may have led to eligible patients missing the opportunity to receive RHC.

With the passage of time, HCPs became more aware that their job was not so much to act but more to provide safety and stability to patients and pass on important information to others responsible for the medical follow-up of the patient. HCPs experienced RHC as more beneficial to patients than initially anticipated and became more eager to introduce RHC to patients.

### *Effectiveness: RHC potential to offer person centered care*

The *Effectiveness* dimension considers any impact of RHC on the patients' individual outcomes.

Patients stated that the RHC devices and statistics provided on the tablet computer provided an overview of symptom development, which improved their daily routines and contributed to enhanced feelings of security and reassurance that someone was paying attention to their situation. During the interviews at T1 and T2, most patients were satisfied with the training and information they received from the RHC service teams. However, during the period of using RHC, several patients experienced changes in their conditions without the content of the RHC being updated or adjusted accordingly. This was considered discouraging, and patients became less inspired to submit their scores and measurements. Patients shared feelings of despair and uncertainty regarding their future. Some questioned how the RHC would benefit their situation if not adjusted to their altered conditions and preferences. At T4, several patients expressed confusion regarding the use of RHC.

*«When I spoke to you and the project manager, I felt it was very difficult to understand what you really want with these questions and all that stuff. »*
*Patient 7_ T4*

Most patients sought more opportunities to communicate face-to-face and expressed the need to communicate their needs in person, and not merely by providing scores and statistics. Some patients expressed a desire to get to know another person on "the other side of the tablet computer." In relation to face-to-face contact, the HCPs were divided. Some HCPs felt that it was important to visit the patient once to assess the submitted data, whereas others felt that it was possible to make assessments based on the submitted data and telephone conversations.

### ***Adoption: Balancing high touch with high tech***

The *Adoption* dimension considers the representativeness and willingness to initiate the intervention, which, in this context, refers to both the patients and HCPs who used the RHC.

Patients expressed great self-confidence concerning the usability of the RHC and related this to personal experiences with smartphone technology. Most patients seemed satisfied with the user-friendliness of the RHC, and the initial training and information provided by the RHC service team. However, there were barriers making full *Adoption* of the RHC challenging. Some patients experienced a fragmented health service, especially if their health situation required involvement of many health service actors. Some patients contacted the RHC service team with everyday problems, only to have then been told by the RHC service team to contact others. This fragmentation was experienced as problematic as patients did not seem to know how the RHC team defined their service and lacked knowledge of which service was responsible for what. For these patients, RHC represented yet another service that contributed to a corresponding increase in service complexity.

*«I had feedback in relation to poor cleaning but was told that they [the RHC service team] couldn't help me with it. I got a phone number, but I don't know what's going on. If there's anyone who can help me at all. »*
*Patient 1_T3*

Most HCPs were experienced providers of RHC and had positive attitudes towards technology. Some stated that a positive attitude towards providing care through technology was essential for receiving an offer of employment from the RHC service team. However, the inclusion of patients in the palliative phase of cancer added care requirements and led to changes in the HCPs' attitudes. The HCPs experienced with palliative care expressed skepticism concerning the introduction of RHC to patients in the palliative phase of cancer, especially owing to the lack of physical proximity.

*«Palliative care is about meeting and seeing. You have to touch and feel and interpret. It cannot be done remotely. It can create anxiety in the patient. My experience says you can't do that. »*
*HCP 4_Focus group 1*

Most HCPs were experienced in providing RHC to other patient groups; however, they had no prior training or experience with either palliative care or cancer care. They experienced that patients with cancer reported unexpected and fluctuating symptoms and measurements; moreover, HCPs described feelings of anxiety and an increased sense of responsibility.

### *Implementation*: *Moving towards a common understanding*

The *Implementation* dimension of the RHC addresses facilitators and barriers regarding consistency in service delivery in the context of the HCPS employed at the RHC service team.

The RHC was designed with a high level of flexibility allowing for HCPs to tailor and adjust the service accordingly to each patient's unique situation. The HCPs previous experience of using RHC in the follow-up of patients with COPD was that these patients often had a COPD Action Plan for self-treatment that could support the HCPs when making decisions and assessments. However, that was not the case with the patients with cancer in the palliative phase. The question concerning pain was considered particularly challenging. HCPs highlighted a need for branched questions allowing for patients to proceed with in dept explanations for symptoms, and especially pain.

*«If I have pain, I don't get to elaborate on where the pain is when I tick the form. Shouldn't that be somewhat important for the person who is going to assess the pain? Because otherwise they have to call me and find out where I'm in pain. I can probably describe the pain by sending an additional message. »*

*Patient 6_T1*

Furthermore, HCPs learned that the sensor data, such as weight, provided little valuable information and questioned the purpose of collecting data from a patient group where, for example, the weight is expected to decrease, without the opportunity or mandate to act and take necessary action. These challenges became more prominent as the patients' condition changed, and assessments had to be made which is in line with patients' experiences of RHC as a static service unable to keep up when their needs changed (*Effectivity*). The HCPs often had no other option than to refer patients to the emergency room or general practitioners.

*«If there's a need for pain relief beyond the usual, we contact the patient's doctor to notify.*
*HCP 5_individual interview»*

HCPs constantly experienced challenges in gaining access to patient information, which resulted in much valuable time being spent on telephonic conversations attempting to obtain the necessary information. Several patients had general practitioners who had not heard of RHC, rendering collection of the necessary information, such as patient medication, challenging. Consequently, HCPs had to rely on the patients to provide them with information.

*«We're not notified of changes in treatment unless the patient tells us about it. We can recommend something they shouldn't do anymore, so we pay close attention and time and ask the patient. It can be risky business. »*
*HCP 1_individidual interview*

Our results indicate that RHC lacked anchoring in the healthcare service and that sufficient adaptations had not been made before patients with cancer in the palliative phase were included. HCPs expressed doubts about how they should act when patients reported unexpected measurements and described limited possibilities for help. In situations where patients' situations were perceived as unclear, several HCPs experienced that it could be difficult for them to leave work.

### ***Maintenance: Adjusting to what really matters***

RHC was continued as a service for patients in the palliative phase of cancer. The experiences of the HCPs resulted in a more person-centered approach where the objective measurements were given less attention, and increased focus on personalizing the questions for symptom mapping was applied.

*«We managed to achieve a better follow-up by using individualized questions and chat rather than relying on objective measurements of weight and saturation [... ] We removed questions that were perceived as unnecessary. »*
*HCP 5 and 6_focus group 2*

The HCPs experienced good internal cooperation in the RHC service team and strived for openness with each other with respect to the challenges, skepticism, and lack of competence. However, a counselling service, in which all the HCPs in the RHC service team could communicate and receive guidance from a person with broad expertise in cancer and palliative care, was established to account for the lack of expertise. This guidance was perceived as pivotal for HCPs and represented a significant facilitator of the *Adoption*, *Implementation, and Maintenance* of RHC as a satisfactory follow-up for patients in the palliative phase of cancer.

## Discussion

This paper reported on the use of the RE-AIM framework to assess the implementation of RHC, a technology-mediated service for home-living patients in the palliative phase of cancer. Furthermore, we explored areas of particular importance determining the sustainability of technologies for remote palliative home-based care.

Our results demonstrated that initially, HCPs felt responsible for not imposing unnecessary stress on patients, which resulted in gatekeeping behavior influencing the introduction of RHC *Reach*. RHC demonstrated *Effectivity* by providing patients with an overview of symptom development. However, patients missed opportunities for face-to-face communication when their condition and symptoms changed. HCPs were skeptical about RHCs' ability to provide palliative care and struggled to balance high-touch with high-tech, while patients experienced poor integration and increased service complexity, both hindering *Adoption*. A major issue concerning *Implementation* of RHC was a lack of competence in palliative care in the HCPs. Considering *Maintenance*, measures such as tailoring the RHC and securing HCP-competence in palliative care was applied.

### *Gatekeeping*

Our results suggest that HCPs experienced with cancer and palliative care distrusted the potential in RHC for providing palliative care without being physically close to the patients and felt a great responsibility to not impose unnecessary stress and burden on patients who they perceived to be very frail. These HCPs were troubled with the idea of abandoning palliative care as a high-touch, not high-tech specialty, which greatly affected both *Reach* and *Adoption* of RHC. These results can be referred to as "gatekeeping" behavior [26,27] in terms of preventing eligible patients' access to RHC. A review found that the fear of burdening patients was the most frequent reason for gatekeeping behavior [26]. Research indicates that HCPs may be hesitant and concerned that welfare technology in home-based palliative care could have a negative effect on contact with patients and result in an increased focus on the patients' physical problems [28,29], leaving the patients' psychosocial, spiritual, and existential needs unattended. Furthermore, research argues that a prevailing opinion is that clinical care is either high-tech or high-touch with each of these considered antithetical to the other [31]. However, research highlights the benefits of patients and HCPs using technology in palliative care [9, 10], indicating that high-tech not necessarily excludes high-touch. Technology cannot completely replace personal interactions [31,32]; however, combining remote and in-person care may be preferable for patients in the palliative phase [10].

Our results highlighting HCPs initial skepticism of introducing RHC in home-based palliative care emphasize the continued requirement to raise awareness about the benefits of integrating technology in home-based palliative care, and further highlights a demand for an ongoing effort to alter negative attitudes towards combing palliative care and technology. Furthermore, patients in the palliative phase may be interested in and willing to engage in new interventions [9,33], despite the concerns of HCPs. Our results suggest that once referred to RHC, patients had positive expectations regarding RHC and found it meaningful to contribute to the development of a new service that could potentially benefit others.

### *Person centered care as a key to symptom management and quality of life*

RHC supports patients by facilitating an overview of the development of their symptoms, leading to improved routines in daily life, which may be substantial for patients in the palliative phase, as symptom management is a prerequisite for maintaining the patients' sense of self, improve overall well-being and quality of life and the ability to participate in daily activities [2]. Furthermore, in line with previous reviews [35], our results implies that RHC provided patients with feelings of safety at home and a security that someone paid attention to their needs. However, as their illness progressed and symptoms changed, patients considered RHC a static service with limited assessment of their actual needs, and they experienced missed opportunities to communicate these needs face-to-face. These results are contradictory to a person-centered palliative care approach that considers the individual's needs and preferences as the foundation of care [35] and indicate a barrier to RHC *Effectiveness* and a key to *Maintenance* of RHC for patients in the palliative phase. To accommodate this barrier of RHC *Effectiveness*, measures to ensure a person-centered approach, such as the facilitation of continuous dialogue that allows patients to express what could contribute to meaning, dignity, relief, and confirmation of beliefs and values during the palliative phase, need to be considered [10,35]. The 6S-dialogue tool assesses the patients' needs in key areas of person-centered care, including self-image, symptom relief, social relationships, self-determination, and finally synthesis and choice of strategies concerning existential and spiritual needs [35,36]. These six key areas align with the World Health Organization's view of palliative care as a holistic approach that addresses the emotional, spiritual, and practical needs of both the patients and their families [1]. The 6S-dialogue tool could be used by the RHC service team to facilitate continuous dialogue and assessment of patients' needs, which may contribute to improving RHC *Effectiveness* and facilitate RHC *Maintenance* in terms of person-centered palliative care.

### *Integrating RHC in palliative care*

Palliative care is a complex practice that requires a wide range of competencies from those practicing it [37], and HCPs' remote assessments of patient-reported symptoms depend on their knowledge and experience with the individual patient [29]. Although most HCPs had limited experience and training in cancer and palliative care, no competence-raising measures were carried out prior to the implementation of RHC for patients in the palliative phase of cancer. This influenced RHC *Implementation* in terms of HCPs having difficulty in assessing information transmitted by patients and doubts regarding how to act when the patients' conditions worsened. In addition, the lack of knowledge influenced the dimensions of *Reach* (gatekeeping behavior) and *Adoption* (distrust in RHCs potential for providing palliative care). These results emphasize the importance of offering an educational component that ensures adequate palliative care competence in HCPs before RHC is implemented in home-based palliative care [4,29].

Patients living at home with severe illness, such as cancer in the palliative phase, frequently need health care from different professionals and across care settings [38], which require integrated care that is streamlined and easy to navigate to facilitate access to care [39]. However, healthcare is commonly organized into silos of primary, secondary, and tertiary levels of care, which may cause patients to experience great difficulty in navigating within and between each of these silos [2]. Although RHC was introduced to patients with the intention of providing an assembling service, our results suggest that to some patients, RHC became an additional silo, contributing to an increased experience of service complexity, poor integrated care, and uncertainty concerning the allocation of responsibilities of those involved in their healthcare. This became a barrier to integration of RHC in home-based palliative care. These results are closely connected to the HCPs' experiences of struggles gaining access to relevant patient information necessary for the provision of remote palliative care, which was a challenge for *Implementing* RHC. Access to relevant, accurate, and timely information is a prerequisite for providing high-quality and safe health care [40]. RHC has the potential to improve integrated care for patients in the palliative phase of cancer; however, the necessary digital infrastructure is still missing. There is an urgent need to establish clear lines of responsibility and a digital infrastructure that can facilitate welfare technology in home-based palliative care, such as RHC.

### *Limitations*

A possible limitation is that this paper was based on a secondary analysis of a qualitative dataset of patients and HCPs' experiences using RCH, and specific questions related to the RE-AIM were not included in the interview guides. This is likely to have produced different data than if specific questions had been included. However, such specific questions could also have acted as blinders in the interpretation, and concepts that were not obvious factors for implementation, but not specifically targeted by the RE-AIM questions, could have been overlooked. The extent and accessibility of healthcare facilities in Norway are not uniform; therefore, the outcomes and data generated from the implementation of RHC in rural regions may vary. This may limit the transferability of the results to other settings. Another limitation could be that the gatekeeping behavior of the HCPs responsible for recruiting patients to the RHC might have resulted in a smaller sample size than originally planned. However, it is unclear whether a larger sample size would increase the richness of the data. The willingness of participants to share their diverse experiences contributed to the depth and variety of data [41].

## Conclusions

Our results suggest that the HCPs' gatekeeping behavior, concerns about abandoning palliative care as a high-touch specialty, and lack of competence in palliative care affected the implementation of RHC in patients in the palliative phase of cancer. Although RHC facilitated improved routines in patients' daily lives, patients experienced it as a static service unable to keep up as the disease progressed, highlighting the need for a person-centered approach that prioritizes the individual’s needs and preferences as the basis for providing care. Technologies, such as RHC, are not a panacea, but rather an aid that must be integrated as support for an increasingly strained health service. Emphasis must be placed on establishing a digital infrastructure that supports this integration and secures sustainability in welfare technologies, such as the RHC. The results of this paper could be of importance to others implementing technologies for remote care of patients in a palliative phase, regardless of disease.

The RE-AIM dimensions provide significant insight into areas of particular importance to ensure the sustainability of welfare technologies, such as the RHC in future healthcare. In future studies of implementation of welfare technology for home-based palliative care, we suggest that the RE-AIM as a framework guiding the process, should be applied already in the planning of the implementation. Furthermore, future research should investigate the ethical considerations when welfare technologies for home-based palliative care are implemented, as these patients comprise a particularly vulnerable group that could face additional burdens when using such services.

**List of abbreviations:**

COPD - chronic obstructive pulmonary disease

HCP – healthcare professionals

RHC – remote home care

RE-AIM: Acronym for: Reach Effectiveness Adoption Implementation Maintenance

## Declarations

### Ethics approval and consent to participate

The study was approved by the Norwegian Centre for Research Data (NSD) (reference number: 429408), which concluded that the management of personal data was in accordance with privacy legislation. The study was not categorized as medical or health research (defined as research on humans, human biological material, and personal health information aimed at generating new knowledge about diseases and health) and was thereby exempted from review by The Norwegian Regional Committee for Medical and Health Research Ethics (REK). All the participants received oral and written information assuring confidential and voluntary study participation, with the opportunity to withdraw from the study at any time. Details of the participants were kept separate and locked. Data were managed and stored securely, and all methods were performed in accordance with the relevant guidelines and regulations set forth by the NSD.

### Consent for publication

Not applicable

### Availability of data and materials

Data are available upon reasonable request to the corresponding author.

### Competing interests

The authors declare that they have no competing interests.

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## Authors' contributions

LO, AM and SAS developed the study design, with contributions from all other authors (VLC, AD, KH, and JÖ). SAS conducted individual interviews with patients. LO and SAS conducted focus group interviews with HCPs, and LO conducted individual interviews with HCPs. LO, AM, and SAS contributed to analyses and interpretations. LO drafted the manuscript. All authors provided important intellectual content, constructive comments, and revisions for the manuscript development. All the authors have approved the submitted version. LO provided the funding for this study.

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## Authors' information (optional)

Not applicable

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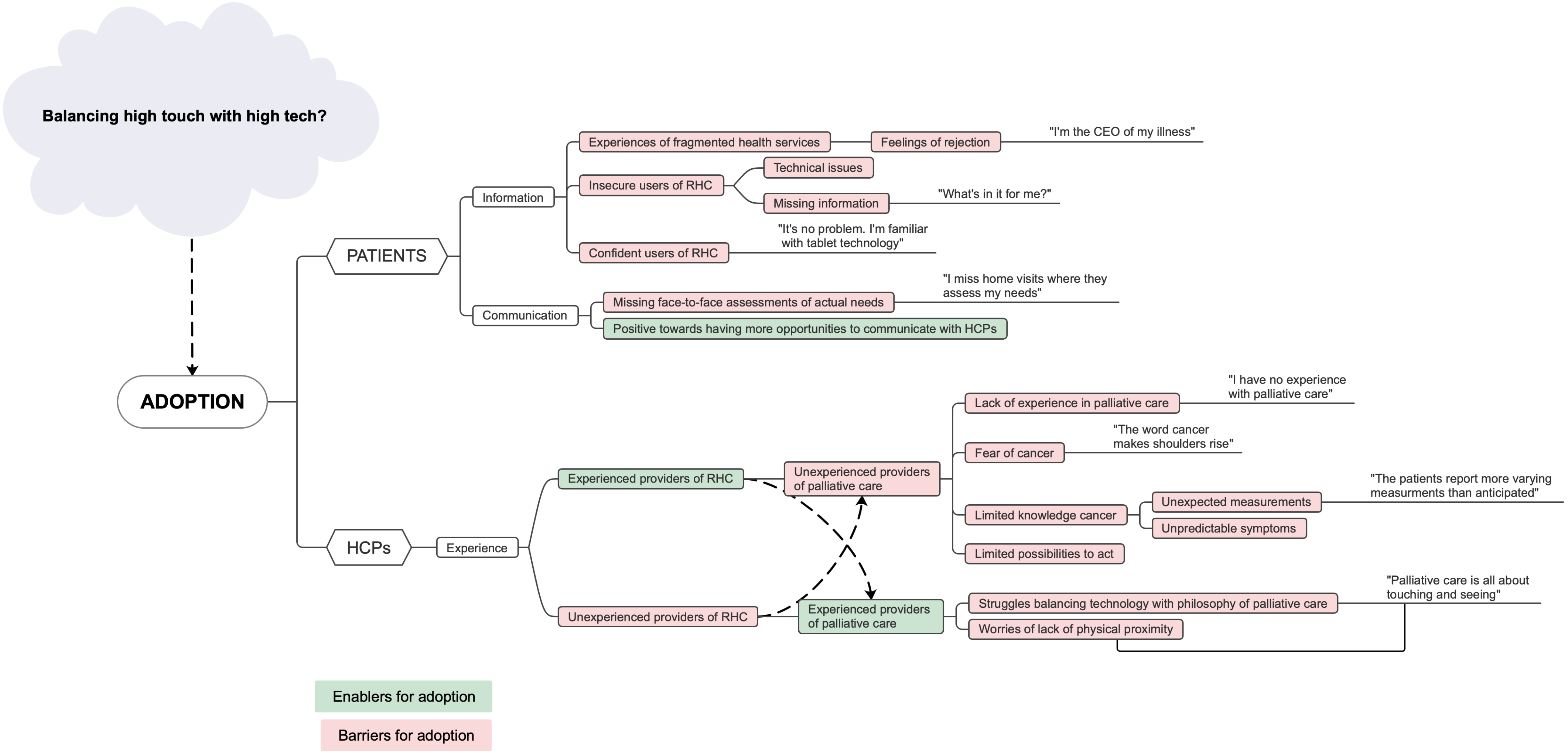
## Figure Legends

**Figure 1.** Example of visual mapping exploring themes related to Adoption.


Balancing high touch with high tech?
ADOPTION
PATIENTS
Information
Experiences of fragmented health services
Feelings of rejection
"I'm the CEO of my illness"
Insecure users of RHC
Technical issues
Missing information
"What's in it for me?"
Confident users of RHC
"It's no problem. I'm familiar with tablet technology"
Communication
Missing face-to-face assessments of actual needs
"I miss home visits where they assess my needs"
Positive towards having more opportunities to communicate with HCPs
HCPs
Experience
Experienced providers of RHC
Unexperienced providers of palliative care
Lack of experience in palliative care
"I have no experience with palliative care"
Fear of cancer
"The word cancer makes shoulders rise"
Limited knowledge cancer
Unexpected measurements
"The patients report more varying measurments than anticipated"
Unpredictable symptoms
Limited possibilities to act
Unexperienced providers of RHC
Experienced providers of palliative care
Struggles balancing technology with philosophy of palliative care
Worries of lack of physical proximity
"Palliative care is all about touching and seeing"
Enablers for adoption
Barriers for adoption

# Appendices

I. Information letter for **HCP**s containing information regarding the study, inclusion criteria and study participation. The information letter also includes an option to sign written informed consent.

II. Information letter for **patients** containing information regarding the study, inclusion criteria and study participation. The information letter also includes an option to sign written informed consent.

III. Semi-structured interview guide for the focus group interviews with interdisciplinary **HCP**s.

IV. Semi-structured interview guide for the individual interviews with interdisciplinary **HCP**s.

V. Semi-structured interview guide for individual interviews with **patients** at baseline, 4-, 12-, and 16-weeks of using RHC.

# Appendix I

**Forespørsel om å delta i forskningsprosjektet:**

# Velferdsteknologi i oppfølgingen av hjemmeboende pasienter med kreft i palliativ fase

**Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å** få kunnskap om helsepersonell i kommunehelsetjenesten sine erfaringer med å benytte velferdsteknologi hos hjemmeboende pasienter med kreft i palliativ fase. Prosjektet vil også bidra til kunnskap om hvordan teknologiske hjelpemidler best kan innføres i praksis. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

**Formål**
Vi vil undersøke helsepersonell i kommunehelsetjenesten sine erfaringer med å bruke velferdsteknologi i oppfølgingen av hjemmeboende pasienter med kreft i palliativ sykdomsfase. Målet er å frembringe kunnskap av betydning når man skal implementere velferdsteknologi som et ledd i oppfølgingen av svært alvorlig syke pasienter som bor hjemme.

**Hvem er ansvarlig for forskningsprosjektet?**
Lovisenberg diakonale høgskole er ansvarlig for prosjektet. Doktorgradsstipendiaten er også tilknyttet Universitetet i Oslo.

**Hvorfor får du spørsmål om å delta?**
Du får spørsmål om å delta i studien fordi du er ansatt i en bydel i Oslo kommune som bruker velferdsteknologi og har erfaring med å benytte velferdsteknologi i oppfølgingen av hjemmeboende pasienter med kreft i palliativ fase eller har erfaring med å følge opp hjemmeboende pasienter med kreft i palliativ fase som bruker velferdsteknologi.

**Hva innebærer det for deg å delta?**
Dersom du ønsker å delta i studien vil du bli invitert til å delta i ett fokusgruppeintervju med 4-6 av dine kollegaer, samt ett individuelt intervju. Fokusgruppeintervjuet vil finne sted på din arbeidsplass på et tidspunkt som kan passe alle aktuelle deltakere. Fokusgruppeintervjuet vil vare inntil 90 minutter. Det individuelle intervjuet vil holdes i etterkant av fokusgruppeintervjuet på arbeidsplassen din og på et tidspunkt som passer deg. Intervjuet vil vare inntil 60 min. Intervjuene vil omhandle dine erfaringer med å følge opp hjemmeboende pasienter med kreft i palliativ fase ved bruk av velferdsteknologi eller dine erfaringer med å følge opp hjemmeboende pasienter med kreft i palliativ fase som har brukt velferdsteknologi. Intervjuene vil bli tatt opp på lydbånd for senere å bli skrevet ut på papir.

**Det er frivillig å delta**
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

**Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Prosjektleder/hovedveileder og biveiledere samt doktorgradsstipendiaten vil ha tilgang på datamaterialet. Den øvrige prosjektgruppen vil ha tilgang på anonymisert materiale.
- Før intervjuene ønsker vi å samle noen bakgrunnsopplysninger om deg som kjønn, alder, utdanning og arbeidserfaring. Disse vil bli presentert på en slik måte at det ikke er mulig å

gjenkjenne deg. Eventuelle kjennetegn som fremkommer spontant gjennom intervjuene vil bli anonymisert.

- Lydopptakene og transkriberte data lagres på kryptert minnepinne som låses inn i et skap på et låst kontor.
- Resultatene vil bli presentert i vitenskapelige artikler, fagartikler og doktorgradsavhandling, samt på konferanser.

Alle data vil bli avidentifisert, og ingen svar vil kunne tilbakeføres til deg som person når resultater presenteres. Alle data vil bli behandlet i samsvar med gjeldende lovverk.

**Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?**
Prosjektet skal etter planen avsluttes 01.01.2024. Informasjonen om deg vil bli anonymisert når prosjektet avsluttes.

**Dine rettigheter**
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

**Hva gir oss rett til å behandle personopplysninger om deg?**
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Lovisenberg diakonale høgskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

**Hvor kan jeg finne ut mer?**
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Lovisenberg diakonale høgskole (LDH) ved:
  Doktorgradsstipendiat Lina Oelschlägel, lina.oelschlägel@ldh.no, tlf: 452 68 036
  Prosjektleder Simen A. Steindal, simen.alexander.steindal@ldh.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.
- Den enkelte forsker ved LDH har et selvstendig ansvar for å sikre at egen forskning organiseres og utøves forsvarlig i henhold til anerkjente forskningsetiske normer.
- LDH har ansvar for oversikt, kompetansekrav og internkontroll med forskning ved institusjonen. Ansvaret ligger hos daglig leder.
- NSD er saksbehandlende instans i saker som omhandler personvern ved LDH.

Med vennlig hilsen

| | |
|---|---|
| Simen A. Steindal | Lina Oelschlägel |
| Førsteamanuensis, prosjektansvarlig | Doktorgradsstipendiat |
| Lovisenberg diakonale høgskole | Lovisenberg diakonale høgskole |

# Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *Velferdsteknologi i oppfølgingen av hjemmeboende pasienter med kreft i palliativ fase*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i *fokusgruppeintervju og individuelt intervju*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet 01.01.2024.

--------------------------------------------------------------------------------------------------------------
(Signert av prosjektdeltaker, dato)

# Appendix II

LOVISENBERG
DIAKONALE HØGSKOLE

# Forespørsel om deltakelse i forskningsprosjektet "Pasienter med kreft og pårørendes erfaringer med bruk av velferdsteknologi i lindrende oppfølgning i hjemmet"

## Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Hensikten er å få mer kunnskap om bruk av velferdsteknologi i omsorg til pasienter med kreftsykdom som bor hjemme. Velferdsteknologi er ulike teknologiske hjelpemidler som brukes til helseoppfølgning i hjemmet. Målet med forskningsprosjektet er å utvikle et tilbud for bruk av velferdsteknologiske hjelpemidler i oppfølgning og omsorg til pasienter med kreft.

Du får denne forespørselen fordi du er alvorlig kreftsyk og bor i bydel [redacted] Lovisenberg diakonale høgskole er ansvarlig for å gjennomføre forskningsprosjektet.

## Hva innebærer prosjektet?

Du vil over en 5 måneders periode få bruke teknologiske hjelpemidler tilpasset dine behov. Dette kan for eksempel være et nettbrett, mobil trygghetsalarm, elektronisk medisindispenser, måleinstrumenter som blodtrykksmåler, blodsukkermåler, termometer, vekt og pulsoxymeter (måler oksygenverdien i blodet) og/eller digitalt tilsyn. På nettbrettet kan du svare på individuelt tilpassede spørsmål og kommunisere med helsepersonell fra Oppfølgningssenteret for avstandsoppfølgning i bydel [redacted] Målingene du gjør vil bli registret på nettbrettet og sendt inn til Oppfølgningssenteret. Helsepersonell ved Oppfølgningssenteret vil følge med på målingene dine og ved endringer gjøre eventuelle tiltak. Det er viktig å presisere at prosjektet ikke er en akutt tjeneste, og om det oppstår plutselige forverringer i helsetilstanden din, må du kontakte lege og/eller ambulanse.

Du vil bli intervjuet fire ganger av en forsker, som også er utdannet sykepleier, om erfaringene dine med å bruke teknologiske hjelpemidler hjemme når du blir med i prosjektet og etter 4, 10 og 16 uker. Intervjuene vil vare mellom 15 og 60 minutter per gang. Du kan selv velge hvor samtalene skal foregå, enten hjemme hos deg, på telefon eller på et annet rolig egnet sted som du synes kan være passende for deg. Tidspunkt vil bli avtalt i samarbeid med deg. Samtalene vil bli tatt opp på lydbånd for senere å bli skrevet ut på papir. Etter at intervjuene er skrevet ut, vil lydfilene bli slettet. Alle opplysninger som kan føre til gjenkjenning vil bli fjernet. Du vil i tillegg fylle ut ESAS som er et selvrapporteringsskjema for noen av de vanligste symptomene kreftpasienter kan oppleve. Du vil fylle ut ESAS når du blir med i prosjektet og ved hvert intervjutidspunkt. Det tar 5-10 minutter å fylle ut ESAS.

Deltakelse i prosjektet innebærer også at din pårørende vil bli forespurt om å bli intervjuet en gang. Intervjuet vil omhandle din pårørende sine erfaringer med at du bruker teknologiske hjelpemidler for helseoppfølgning i hjemmet.

## Mulige fordeler og ulemper

En fordel ved å delta i prosjektet er at du får være med å utvikle en tjeneste for omsorg og oppfølgning ved bruk av velferdsteknologi for pasienter med kreft som bor hjemme. En ulempe kan være at det kan oppstå tekniske problemer med hjelpemidlene. Om det skulle oppstå slike problemer, vil disse bli løst så raskt som mulig. Noen kan oppleve tidsbruk ved å bli intervjuet som en belastning. Det vil bli tatt hensyn til din helsetilstand under intervjuene.

**Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt og skal kun brukes slik som beskrevet i hensikten med prosjektet. En kode knytter deg til dine opplysninger gjennom en navneliste, og det er kun forsker Simen A. Steindal som har adgang til navnelisten og kan finne tilbake til deg. Forskeren har taushetsplikt. Datamateriale vil bli lagret på datamaskin som er passord beskyttet.

Resultatene vil bli publisert i vitenskapelig artikler. Datamaterialet vil bli anonymisert slik at det ikke er mulig å identifisere enkeltpersoner. Prosjektet skal etter planen avsluttes 30.06.2019. Informasjonen om deg vil bli anonymisert når prosjektet avsluttes.

**Frivillig deltakelse**
Det er frivillig å delta i forskningsprosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på den siste siden. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for videre oppfølgning du får fra bydel [redacted]. 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 kreftkoordinator i bydel [redacted], eller forsker og prosjektleder for forskningsprosjektet Simen A. Steindal, telefonnummer 926 604 22.

Forskningsprosjektet er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

LOVISENBERG
DIAKONALE HØGSKOLE

**Samtykke til deltakelse i prosjektet**
Jeg er villig til å delta i prosjektet.

---

| | |
|---|---|
| Sted og dato | Deltakers signatur |
| | ---------------------------------------- |
| | Deltakers navn med trykte bokstaver |

# Appendix III

## Intervju med helsepersonell

Det er hensikten at samtalene skal være fri, og intervjuguiden vil bli brukt for å fremme diskusjon og at deltakere diskuterer tema som er relevant for studien.

Før intervjuet starter vil moderator gjenta informasjon om hensikten med studien og deltakernes rettigheter ved å delta.

- **Hensikten** med studien er å få kunnskap om helsepersonells erfaringer med velferdsteknologi i palliativ oppfølgning i hjemmet og å få kunnskap om aspekter som vil være av betydning når teknologi skal implementeres på en sårbar pasientgruppe.

- **Anonymitet og konfidensialitet** – intervjuer har taushetsplikt og resultater fra studien vil presenteres anonymisert. Resultater som presenteres for bydelen vil også være anonymisert og avidentifisert. Det er frivillig å delta og vedkommende kan trekke seg når som helst uten å oppgi grunn. Dette vil ikke få noen konsekvenser for deres forpliktelser eller arbeidsforhold i bydelen

- Deltakerne fyller ut et skjema med bakgrunnsopplysninger før lydopptakeren skrus på og intervjuet starter.

- Deltakerne vil bli oppfordret til å ikke bruke navn dersom snakker om andre enn de som deltar i intervjuet

- Det understrekes at det ikke finnes riktige eller gale svar- det er deres erfaringer vi ønsker å høre om

- Deltakerne vil få mulighet til å stille spørsmål før lydopptakeren startes.

Intervjuguide fokusgruppe:

*Lydopptaker startes*

Dette fokusgruppeintervjuet handler om bruk av velferdsteknologi i oppfølgingen av hjemmeboende pasienter med kreft i palliativ fase.

Jeg vil gjerne begynne med at dere forteller litt om hvordan dere bruker teknologi i den palliative oppfølgingen av hjemmeboende pasienter med kreft?

Hvilke forventninger hadde dere til å ta i bruk velferdsteknologi til hjemmeboende kreftpasienter i palliativ fase?

Kan dere beskrive hvordan teknologien brukes i praksis?

Hvordan behandler dere rapporter / henvendelser som kommer inn fra de hjemmeboende pasientene med kreft i palliativ fase?

Hvordan oppleves det å bruke teknologi til å få informasjon om pasienten i forhold til å møte vedkommende ansikt til ansikt?

Kan dere fortelle om hvordan det oppleves å følge opp pasienter i palliativ sykdomsfase med bruk av velferdsteknologi sammenlignet med andre pasienter dere har ansvaret for?

Kan dere fortelle om hvordan teknologi i oppfølging av pasientene påvirker arbeidshverdagen deres?

Kan dere si noe om hvordan bruken av teknologi påvirket samarbeidet i bydelen?

Hvilke fordeler har dere opplevd ved å bruke teknologi i oppfølgingen av hjemmeboende kreftpasienter i palliativ fase?

Hvilke utfordringer har dere opplevd ved å bruke teknologi i oppfølgingen av hjemmeboende kreftpasienter i palliativ fase?

Er det noe mer dere ønsker å fortelle om?

Tusen takk for at dere har sagt ja til å være med i prosjektet og til å bli intervjuet!

# Appendix IV

## Intervjuguide helsepersonell

Det er hensikten at samtalene skal være fri, og intervjuguiden vil bli brukt for å danne rammer for en samtale som i utgangspunktet skal gå fritt.

Før intervjuet starter vil moderator gjenta informasjon om hensikten med studien og deltakerens rettigheter ved å delta.

- **Hensikten** med studien er å få kunnskap om helsepersonells erfaringer med velferdsteknologi i palliativ oppfølgning i hjemmet og å få kunnskap om aspekter som vil være av betydning når teknologi skal implementeres på en sårbar pasientgruppe.

- **Anonymitet og konfidensialitet** – intervjuer har taushetsplikt og resultater fra studien vil presenteres anonymisert. Resultater som presenteres for bydelen vil også være anonymisert og avidentifisert. Det er frivillig å delta og deltaker kan trekke seg når som helst uten å oppgi grunn. Dette vil ikke få noen konsekvenser for vedkommendes forpliktelser eller arbeidsforhold i bydelen

- Deltaker vil bli oppfordret til å ikke bruke navn om de snakker om andre enn de som deltar i intervjuet

- Det understrekes at det ikke finnes riktige eller gale svar- det er vedkommendes erfaringer vi ønsker å høre om

- Det vil uttrykkes at det er deres (helsepersonellets) erfaringer som er i fokus. Ikke pasientenes opplevelser.

- Deltaker vil få mulighet til å stille spørsmål før lydopptakeren startes.

### Intervjuguide individuelle intervju:

*Tematikken i de individuelle intervjuene vil i all hovedsak baseres på tematikk som fremkommer i preliminære analyser av fokusgruppeintervjuene. Det er samtidig ønskelig å utforske tematikk presentert nedenfor:*

*Lydopptaker startes*

**Var det noe som kom frem da vi snakket sammen i gruppe som du ønsker å si noe mer om nå?**

**Fortell om en situasjon der du opplevde at teknologien var til hjelp for pasienten.**

**Fortell om en situasjon der du opplevde at teknologien ikke kunne bidra til å hjelpe pasienten.**

**Kan du fortelle hvordan du opplever at bruken av teknologi fremmer oppfølgingen av hjemmeboende pasienter med kreft i palliativ fase?**

- Har du opplevd situasjoner der teknologien har hemmet oppfølgingen?

**Hva er dine tanker om hvordan bruk velferdsteknologi kan påvirke helsepersonell som følger opp hjemmeboende pasienter med kreft i palliativ fase?**

- Personlig plan
- Organisatorisk plan

**Hva er dine tanker om pasientens livssituasjon med tanke på at de skal bruke teknologi?**

- Palliativ fase
- Begrenset forventet levetid

**Kan du fortelle om dine erfaringer i forhold til muligheter for å kunne tilby pasienter hjelpen de oppfatter at de trenger?**

- Faktorer som påvirker mulighetene

**Hva er dine tanker meninger om bruk av denne typen teknologi i oppfølging av hjemmeboende pasienter med kreft i palliativ fase i fremtiden?**

- Er det noe som bør gjøres annerledes?

**Kan du fortelle noe om hvordan innføringen av teknologi i palliativ oppfølging av hjemmeboende pasienter med kreft har påvirket din arbeissituasjon?**

**Er det noe mer du vil fortelle?**

# Appendix V

## Intervjuguide pasienter

Første intervju:

- **Hensikten** med studien er å få kunnskap og innsikt i kreftpasienter erfaringer med velferdsteknologi i oppfølgning i hjemmet og å få kunnskap om hvordan bruk av velferdsteknologi kan optimalisere samhandlingen mellom kreftpasienter og helsepersonell fra kommune- og spesialisthelsetjenesten.

- Om mulig ønsker jeg å snakke med deg fire ganger. Det er f**rivillig** å delta og du kan trekke seg når som helst uten å oppgi grunn og det vil ikke få noen konsekvenser for oppfølgningen og helsehjelp fra bydelen.

- **Anonymitet og konfidensialitet** – jeg har taushetsplikt, jeg jobber ikke i bydelen, men jobber ved Lovisenberg diakonale høgskole, så jeg forsker og sykepleier. Resultatene fra studien vil presenteres anonymisert, resultater som presenteres for bydelen vil også være anonymiser og avidentifisert

- **Noen spørsmål?**

*Sett på lydopptaker*
*Pasienten fyller ut ESAS først – snakk litt om ESAS scorene*

**Hvordan innvirker symptomene og plagene inn på dagliglivet/hverdagen?**
- Det du kan gjøre i hverdagen?

**Fortelle litt om hvordan hverdagen din er?**
- Hva gjør du på om dagen? Hvordan er hjemmesituasjonen din?

**Hvordan er helsetilstanden din om dagen?**

**Hva er viktig for deg for å kunne ha en god hverdag?**

**Hvilke teknologiske hjelpemidler for helseoppfølgning fikk du da du ble med i dette prosjektet?**

**Fortell litt om opplæringen du fikk i bruk av de teknologiske hjelpemidlene?**
- Hva slags informasjon fikk du?
- Hva var du fornøyd med?
- Var det noe som kunne vært gjort annerledes?
- Noe du savnet?

**Hvilke forventninger har du til nettbrettet med spørsmål /de teknologiske hjelpemidlene du skal bruke?**

**Fortell litt om hvordan du bruker de teknologiske hjelpemidlene?**

- Når bruker du dem?
- Fortell om en situasjon der du de teknologiske hjelpemidlene

*Nettbrettet:*

- Hva slags spørsmål har du?
- Hvor ofte svarer du?
- Hva synes du om å svare på spørsmålene?
- Er det noen spørsmål du savner?
- Har du skrevet noen meldinger til sykepleierne i bydelen?
    - Hva opplever du som positivt med å bruke dem?
    - Hvilke utfordringer opplever du med å bruke dem?
    - Hvilke ulemper opplever du med å bruke dem

**Fortell litt om hva som gjør at du ikke bruker de teknologiske hjelpemidlene?**

**Hva skal til for at du skal bruke de teknologiske hjelpemidlene?**

**Hvilken betydning har bruk av de teknologiske hjelpemidlene for hverdagen din?**

**Hva slags hjelp og tjenester får du fra bydelen?**

**Hva slags oppfølgning får du fra sykehus?**

**Hva slags oppfølgning får du fra fastlegen? Vet fastlegen at du er med i dette prosjektet?**

**Hvordan har helsepersonell fulgt deg opp mens du har brukt de teknologiske hjelpemidlene?**

- Har de tatt kontakt med deg? (KREFTKOORDINATOR?)
- Fått meldinger fra deg?

Andre intervju (etter 4 uker)

- **Hensikten** med studien er å få kunnskap og innsikt i kreftpasienter erfaringer med velferdsteknologi i oppfølgning i hjemmet og å få kunnskap om hvordan bruk av velferdsteknologi kan optimalisere samhandlingen mellom kreftpasienter og helsepersonell fra kommune- og spesialisthelsetjenesten.

- **Anonymitet og konfidensialitet** – jeg har taushetsplikt, jeg jobber ikke i bydelen. Resultatene fra studien vil presenteres anonymisert, resultater som presenteres for bydelen vil også være anonymiser og avidentifisert

- **Frivillig** å delta kan trekke seg når som helst uten å oppgi grunn og vil ikke få noen konsekvenser for oppfølgningen fra bydelen

*Pasienten fyller ut ESAS først*
*Sett på lydopptaker*

**Kan du fortelle litt om hvordan hverdagen din har vært den siste tiden?**

**Fortell litt om hvordan helsetilstanden din har vært siden vi snakket sammen sist?**

**Har du fått noen nye teknologiske hjelpemidler for helseoppfølging siden jeg var hos deg sist?**
- Hva slags opplæring fikk du?
- Hvordan var informasjonen som du fikk

**Kan du fortelle litt om hvordan du har bruk de teknologiske hjelpemidlene siden sist?**
- Når bruker du dem? Fortell om en situasjon der du de teknologiske hjelpemidlene
- Har du fått noen nye spørsmål på nettbrettet som du svarer på?
- Hvor ofte svarer du?
- Hva synes du om å svare på spørsmålene?
- Er det noen spørsmål du savner?
- Har du skrevet noen meldinger til sykepleierne i bydelen?
- Hva opplever du som positivt med å bruke dem?
- Hvilke utfordringer opplever du med å bruke dem?
- Hvilke ulemper opplever du med å bruke dem

**Kan du fortelle om hvordan hverdagen din er mens du bruker de teknologiske hjelpemidlene?**
- Hva har det å si for din mulighet til å håndtere hjemmesituasjonen?
- Hva har det å si for din mulighet til å håndtere kreftsykdommen?
- Hvilken betydning har det for forholdet til ektefelle/ samboer og resten av familien
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?

**Lever de teknologiske hjelpemidlene opp til forventingene dine? Fortell?**
- Hva er det som gjør at de ikke lever opp til forventingene?

**Hva slags ansvar opplever du har for oppfølgning av helsen din mens du bruker de teknologiske hjelpemidlene?**

**Hva slags ansvar opplever du at helsepersonell i bydelen har for helsen din mens du bruker de teknologiske hjelpemidlene?**

**Hvordan har helsepersonell i bydelen fulgt deg opp mens du har brukt de teknologiske hjelpemidlene?**

  - o Har de tatt kontakt med deg?
  - o Hvordan synes du oppfølgningen har vært?
  - o Hvilke forventinger har du til oppfølgningen
- Hva har oppfølging å si for at du skal håndtere hjemmesituasjonen?
- Hva har det å si for din mulighet til å håndtere kreftsykdommen?
- Hvilken betydning har det for forholdet til ektefelle/samboer og resten av familien
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?
- Hva har vært positivt med oppfølgningen?
- Hvilke utfordringer har du opplevd med oppfølgningen?

**Hva slags hjelp og tjenester har du fått fra bydelen den siste tiden?**

- Hva slags oppfølgning har du fått fra sykehuset den siste tiden?
- Hva slags oppfølgning har du fått fra fastlegen? Har du snakket om pasientlegen at du svarer på spørsmål på nettbrett
- Noen andre?

Tredje intervju (etter 12 uker):

- **Hensikten** med studien er å få kunnskap og innsikt i kreftpasienter erfaringer med velferdsteknologi i palliativ oppfølgning i hjemmet og å få kunnskap om hvordan bruk av velferdsteknologi kan optimalisere samhandlingen mellom kreftpasienter og helsepersonell fra kommune- og spesialisthelsetjenesten.

- **Anonymitet og konfidensialitet** – jeg har taushetsplikt, jeg jobber ikke i bydelen. Resultatene fra studien vil presenteres anonymisert, resultater som presenteres for bydelen vil også være anonymiser og avidentifisert

- **Frivillig** å delta kan trekke seg når som helst uten å oppgi grunn og vil ikke få noen konsekvenser for oppfølgningen fra bydelen

*Pasienten fyller ut ESAS først*
*Sett på lydopptaker*

**Kan du fortelle litt om hvordan hverdagen din har vært siden vi snakket sammen sist?**

**Fortell om hvordan helsen din har vært i den siste tiden?**

**Hva er viktig for deg for å kunne ha en god hverdag?**

**Har du fått noen nye teknologiske hjelpemidler siden vi snakket sammen sist?**

**Nå har hatt disse hjelpemidlene en lang stund, fortell litt om hvordan du har brukt dem den siste tiden.**

**Har det vært noen endringer i måten du bruker de teknologiske hjelpemidlene på?**
- Når bruker du dem? Fortell om en situasjon der du har bruk hjelpemidlene
- Hva opplever du som positivt med å bruke dem?
- Hvilke utfordringer opplever du med å bruke dem?
- Er det noen ulemper ved å bruke dem?

**Hvordan har du brukt nettbrettet i den siste tiden?**
- Har det vært noen endringer i måten du bruker nettbrettet?
- Har du fått noen nye spørsmål du skal svare på?
- Er det noen spørsmål du savner?
- Hvordan har du blitt fulgt opp av helsepersonell når du har svart på spørsmål?
- Har du kommunisert via melding med helsepersonell i bydelen den siste tiden? Fortell

**Hvordan innvirker bruk av de teknologiske hjelpemidlene innvirket på hverdagen din?**
- Har det vært noen endringer?

- Hva har de teknologiske hjelpemidlene å si for din mulighet til å håndtere kreftsykdommen?
- Hvilken betydning har det for forholdet til familien
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?

**Har det vært noen endringer i forventingene dine til de teknologiske hjelpemidlene?**

**Er det noen andre hjelpemidler eller tjenester du heller hadde hatt behov for, for å ha en ha god hverdag?**

**Når du bruker de teknologiske hjelpemidlene**

- Hva slags ansvar opplever du for din egen helse og kreftsykdommen?
- Hva slags ansvar opplever du at bydelen har for helsen din og kreftsykdommen din?

**Kan du fortelle litt om hvordan helsepersonell har fulgt deg opp i den siste tiden?**

- Har det vært noen endringer i måten du blir fulgt opp på?
- Har du fått noen nye tjenester fra bydelen?
- Har du pratet med fastlegen om at du bruker de teknologiske hjelpemidlene?
- Hva har helsepersonellets oppfølging å si for å håndtere hjemmesituasjonen?
- Hvilken betydning har det for forholdet familien?
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?

Fjerde intervju (etter 16 uker):

- **Hensikten** med studien er å få kunnskap og innsikt i kreftpasienter erfaringer med velferdsteknologi i palliativ oppfølgning i hjemmet og å få kunnskap om hvordan bruk av velferdsteknologi kan optimalisere samhandlingen mellom kreftpasienter og helsepersonell fra kommune- og spesialisthelsetjenesten.

- **Anonymitet og konfidensialitet** – jeg har taushetsplikt, jeg jobber ikke i bydelen. Resultatene fra studien vil presenteres anonymisert, resultater som presenteres for bydelen vil også være anonymiser og avidentifisert

- **Frivillig** å delta kan trekke seg når som helst uten å oppgi grunn og vil ikke få noen konsekvenser for oppfølgningen fra bydelen

*Pasienten fyller ut ESAS først*
*Sett på lydopptaker*

**Kan du fortelle litt om hvordan hverdagen din har vært siden vi snakket sammen sist?**

**Fortell om hvordan helsen din har vært i den siste tiden.**

**Har du fått noen nye teknologiske hjelpemidler siden vi snakket sammen sist?**

**Nå har hatt disse hjelpemidlene en stund, fortell litt om hvordan du har brukt dem den siste tiden.**

**Har det vært noen endringer i måten du bruker de teknologiske hjelpemidlene på?**
- Når bruker du dem? Fortell om en situasjon der du har bruk hjelpemidlene
- Hva opplever du som positivt med å bruke dem?
- Hvilke utfordringer opplever du med å bruke dem?
- Er det noen ulemper ved å bruke dem?

**Hvordan har du brukt nettbrettet i den siste tiden?**
- Har det vært noen endringer i måten du bruker nettbrettet?
- Har du fått noen nye spørsmål du skal svare på?
- Er det noen spørsmål du savner?
- Hvordan har du blitt fulgt opp av helsepersonell når du har svart på spørsmål?
- Har du kommunisert via melding med helsepersonell i bydelen den siste tiden? Fortell

**Hva slags ansvar opplever du har for helsen din mens du bruker de teknologiske hjelpemidlene?**

**Hva slags ansvar opplever du at helsepersonell i bydelen har for helsen din mens du bruker de teknologiske hjelpemidlene?**

**Hvordan innvirker bruk av de teknologiske hjelpemidlene innvirket på hverdagen din?**

- Har det vært noen endringer?
- Hva har de teknologiske hjelpemidlene å si for din mulighet til å håndtere kreftsykdommen?
- Hvilken betydning har det for forholdet til familien
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?

**Har det vært noen endringer i forventingene dine til de teknologiske hjelpemidlene?**

**Er det noen andre hjelpemidler eller tjenester du heller hadde hatt behov for, for å ha en ha god hverdag?**

**Når du bruker de teknologiske hjelpemidlene**

- Hva slags ansvar opplever du for din egen helse og kreftsykdommen?
- Hva slags ansvar opplever du at bydelen har for helsen din og kreftsykdommen din?

**Kan du fortelle litt om hvordan helsepersonell har fulgt deg opp i den siste tiden?**

- Har det vært noen endringer i måten du blir fulgt opp på?
- Har du fått noen nye tjenester fra bydelen?
- Har du pratet med fastlegen om at du bruker de teknologiske hjelpemidlene?
- Hva har helsepersonellets oppfølging å si for å håndtere hjemmesituasjonen?
- Hvilken betydning har det for forholdet familien
- Hvilken betydning har det når det gjelder det å føle seg trygg hjemme?

Erratliste

Navn kandidat: Lina Oelschlägel

Avhandlingens tittel: Implementing welfare technology in palliative homecare - A study exploring the experiences of patients with cancer and health care professionals.

| Side | Linje | Originaltekst | Type rettelse | Korrigert tekst |
|---|---|---|---|---|
| VI | 32-33 | ... and follow-up. In addition, the introduction... | Satt inn manglende setning for å samsvare med norsk abstrakt. | ... and follow-up. RHC was not suitable for addressing the patient's spiritual and existential needs, which is in striking contrast to person-centered, palliative care. In addition, the introduction... |
| VIII | 20 | ... med tverrfaglig helsepersonell (Paper II), samt gjentatte... | Korrektur | ... med tverrfaglig helsepersonell (Paper I), samt gjentatte... |
| VIII | 21 | ... kreft i palliativ fase som bor hjemme (N = 11) (Paper I). | Korrektur | ... kreft i palliativ fase som bor hjemme (N = 11) (Paper II). |
| VIII | 22 | ... kvalitativ innholdsanalyse som foreslått av Graneheim and Lundman (2004). | Referanse tatt ut for å samsvare med engelsk abstrakt. | ... kvalitativ innholdsanalyse. |
| VIII | 25 | ... tematisk analyse (TA) inspirert av Braun og Clarke (2022). | Referanse tatt ut for å samsvare med engelsk abstrakt. | ... tematisk analyse. |