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# Person-centered care supported by an interactive app for patients with pancreatic cancer following surgery

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**PERSON-CENTERED CARE  
SUPPORTED BY AN INTERACTIVE  
APP FOR PATIENTS WITH  
PANCREATIC CANCER  
FOLLOWING SURGERY**

Tina Gustavell



**Karolinska  
Institutet**

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# Person-centered care supported by an interactive app for patients with pancreatic cancer following surgery

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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## ABSTRACT

**Background:** Patients with pancreatic or periampullary cancer experience severe symptoms and have poor prognosis even after intentionally curative surgery. To meet patients' needs healthcare professionals are required to form partnerships with patients. Routine collection and management of symptoms with support of mHealth have shown promising results on improved health-related quality of life and decreased symptom distress for patients with cancer.

**Aim:** To evaluate if collection and management of patient-reported outcomes in clinical practice, with support of an interactive app (Interaktor), can enable person-centered care and improve outcomes for patients who have undergone pancreaticoduodenectomy due to cancer.

**Methods:** Through Interaktor patients reports symptoms, which are monitored and responded to by clinical nurses. In the app patients can also view graphs over their previous reports and read self-care advice. The Medical Research Council's framework for complex interventions was used to develop and evaluate the app. In **Phase I** the content in the app was developed by interviews with patients (n=14) and healthcare professionals (n= 10). In **Phase II** the app was tested for feasibility by patients (n=6) during one month. In **Phase III** the app was evaluated by analyzing the impact of symptoms and self-care activity in patients (n=26) using the app for six months, compared with a historical control group of patients (n=33) not using the app, by analysis of patients' (n=26) logged data in the app, and through interviews with patients (n=25) using the app.

**Results:** The results in **Phase I** contributed to knowledge on important symptoms to assess and some self-care advice and strategies to manage these symptoms which formed the content in the Interaktor app. The results in **Phase II** showed that the app was feasible and had relevant content. The patients felt reassured and taken cared of at home and got support for symptom management. The results in **Phase III** showed that using the app decreased symptoms and increased self-care activity after pancreaticoduodenectomy. Further, patients using the app had high adherence to report symptoms as intended, and felt that they could have their voices heard through the app, and that they had an extended arm to healthcare and learned about their own health.

**Conclusion:** The thesis shows that an interactive app like Interaktor can support patients with severe symptoms and poor prognosis. Person-centered care can be enabled by making the patients active partners in care and by timely identification of symptoms important to patients.

## LIST OF SCIENTIFIC PAPERS

- I. **Gustavell, T.**, Sundberg, K., Frank, C., Wengström, Y., Browall, M., Segersvärd, R., Langius-Eklöf, A. (2017). Symptoms and self-care following pancreaticoduodenectomy: Perspectives from patients and healthcare professionals – Foundation for an interactive ICT application. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*, 26, 36-41.
- II. **Gustavell, T.**, Langius-Eklöf, A., Wengström, Y., Segersvärd, R., Sundberg, K. (2019). Development and Feasibility of an Interactive Smartphone App for Early Assessment and Management of Symptoms Following Pancreaticoduodenectomy. *Cancer Nursing*, 42, (3).
- III. **Gustavell, T.**, Sundberg K., Segersvärd, R., Wengström, Y., Langius-Eklöf, A. (2019). Decreased symptom burden following surgery due to support from an interactive app for symptom management for patients with pancreatic and periampullary cancer. *Acta Oncologica*. Submitted.
- IV. **Gustavell, T.**, Sundberg, K., Langius-Eklöf, A. (2019). Being seen as a person when using an interactive app for symptom reporting and management: A descriptive study. *Manuscript*.

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## **LIST OF ABBREVIATIONS**

App	Application for smartphone and tablets
PD	Pancreaticoduodenectomy
NET	Neuroendocrine tumours
IPMN	Intraductal papillary mucinous neoplasm
HRQoL	Health-related quality of life
PRO	Patient-reported outcome
PROM	Patient-reported outcome measures
ICT	Information and communication technology
MRC	Medical Research Council
EORTC QLQ	European Organisation for Research and Treatment on Cancer Quality of Life Questionnaire
SOC	Sense of coherence
ASA	Appraisal of self-care agency
ANOVA	Analysis of Variance



# 1 INTRODUCTION

When writing my master thesis, which concerned assessments to find early signs of complications after pancreatic surgery, I found that the patients' judgements of their general health could predict an upcoming complication just as well as objective signs. My conclusion was that for this vulnerable group of patients, their own health assessments should be included in the postoperative assessments. At that time the clinic where I was working (and still do), was focusing on supporting patients' self-care ability based on needs attributed to their disease or treatment. The concept of person-centered care and incorporating the patient's narrative in the care plan was not yet established. Since I wanted to continue to explore how the patients' voices could be more incorporated in clinical care, I got in contact with the newly installed professor of nursing at Karolinska Institutet. She shared her ideas about an interactive mobile app, later called Interaktor, where patients would self-report symptoms that were acted upon by healthcare professionals. I instantly felt that her views of a model where care was given in collaboration with fully active participating patients was just what I was looking for. Since the idea with the interactive app was to make patients participate in care by reporting symptoms, interact with nurses and have access to self-care advice, the app was considered to be complex. At that time the Medical Research Council in UK had just authored their updated framework for development and evaluation of complex interventions. The framework was found to be suitable for developing and evaluating the app and that is how this doctoral project was initiated.

My hope is that the findings will contribute to a care system where the needs of patients with pancreatic cancer are known to and supported by healthcare professional even when patients are at home. Further, I hope that care will be based on patients' individual needs rather than the needs of the healthcare organization.

## 2 BACKGROUND

### 2.1 Pancreaticoduodenectomy and cancer

In Sweden, 1500 individuals, equally distributed between men and women, are diagnosed each year with cancer in the pancreas or periampullary region, the latter includes the duodenum, extrahepatic bile ducts and the ampulla of Vater. The disease is associated with vague and unspecific symptoms and is therefore often diagnosed at an advanced stage, which contributes to patients mostly being offered different types of palliative treatments. The disease has poor prognosis and only about 8 percent of patients are alive 5 years after receiving their diagnose, regardless of treatment (The National Board of Health and Welfare & The Swedish Cancer Society, 2018) . The only hope for cure is surgical resection, which can be offered to less than 20% of the patients (Kleeff et al., 2016). After surgery eligible patients are offered adjuvant chemotherapy. Even after intentionally curative surgery and adjuvant chemotherapy the prognosis is poor, with a median survival of 2 and 4 years in pancreatic and periampullary cancer respectively (Neoptolemos et al., 2012; Neoptolemos et al., 2010). Most resectable tumors are located in the head of the pancreas or periampullary region and for these the standard treatment is pancreaticoduodenectomy (PD). The surgery includes removal of the pancreatic head, duodenum, distal common bile duct and gall bladder, with or without preserving the gastric antrum and pylorus (Pappas, Krzywda, & McDowell, 2010). In addition to those with pancreatic and periampullary tumors, PD is also offered to patients with neuroendocrine tumors (NET) and intraductal papillary mucinous neoplasm (IPMN), which can either be premalignant or carry invasive cancer.

The recovery period can be long and problematic, since half of patients will suffer from postoperative complications such as delayed gastric emptying, pancreatic fistula, abdominal abscess, wound infection or cardiopulmonary problems (Winter et al., 2006). Furthermore, quality of life is reported to be considerably impaired after PD but is gradually regained within the first 6 to 24 months (Chan et al., 2012; Gerstenhaber et al., 2013; Kostro & Sledzinski, 2008; Nieveen van Dijkum et al., 2005; Pezzilli et al., 2011; Schniewind et al., 2006). After surgery, patients usually experience symptoms like pain, fatigue, diarrhea and appetite loss (van Dijk et al., 2018). Patients describe how the symptoms can lead to social isolation, but they can be managed using self-care strategies as well as support from their families (Andersson, Falk, Bjerså, & Forsberg, 2012; Carey, Laws, Ferrie, Young, & Allman-Farinelli, 2013). However, after PD patients sometimes have inadequate strategies to manage symptoms. One example is the lack of knowledge about how to prevent malnutrition and diarrhea by taking pancreatic enzyme supplements with every meal (Carey et al., 2013). Also, patients may resign to their symptoms and are therefore unlikely to complain, which requires a healthcare system where professionals are more vigilant for symptoms (Carey et al., 2013). In fact, patients

have expressed experiences of no longer feeling cared for, lack of someone to discuss symptoms and self-care strategies with, and have underlined the importance of support from healthcare professionals even after discharge (Andersson et al., 2012). Unmet supportive care needs, especially of a physical and psychological nature, but also regarding information from the healthcare system, are prominent in patients affected by pancreatic cancer. It has been concluded that future research and efforts need to focus on changing the healthcare system and services so that these needs are met (Beesley et al., 2016).

## **2.2 Person-centered care**

To achieve the best care for patients with advanced cancer, the integration of a disease-specific approach and focus on the person behind the disease are vital components (Kaasa et al., 2018). Within nursing, the concept of person-centered care is visible even in the work of Florence Nightingale (1860) who distinguished nursing from medicine by focusing on the sick person rather than the disease. A person-centered approach was early described as central in caring for another person and emphasized as an understanding of a person's perspective and experience of a situation. Further, each person was theorized to be able to draw strength from available resources and find a way to aid difficulties as long as a facilitating environment is present (Rogers, 1961). Within the frame of person-centered care the use of the term person instead of patient are suggested to clarify the focus on the needs and preferences of the person and not solely the disease (Kristensson Uggla, 2015). However, it has been argued that it is still relevant to use the term patient when discussing person-centered care to clarify the patients role as separate from the healthcare professionals legal obligations (Kristensson Uggla, 2015). Therefore, the participating patients throughout this thesis are referred to as patients.

Person-centered care emphasizes the patients' perspective and involvement, resulting in a shift from a model where patients are objects of care to a model where the patient is involved as an active partner in their own care and the decision-making process (Lepleg et al., 2007). Patients' involvements in care has been stipulated in Swedish law, which states that patients should be given the opportunity to participate in their own health management with a focus on decision making (The Swedish Riksdag, 2014). For patients to be active participants in the decision-making process they need to have sufficient and relevant knowledge which can only be provided by continuous person-centered information (Kaasa et al., 2018). This requires interactions with healthcare professionals where patients' needs and wishes are systematically assessed (Kaasa et al., 2018).

Aside from partaking in the decision-making process, patient participation has been described to also include; mutual communication with healthcare professionals where patients are listened to and their knowledge is respected; shared knowledge

where patients get explanations for symptoms and procedures and also can tell professionals about their symptoms; and patients knowing how to manage their symptoms and provide self-care (Eldh, Luhr, & Ehnfors, 2015). To achieve patient participation in nursing care the relationship between the patient and the nurse is crucial. A relationship which requires time to grow stronger, and the patients situation should be considered a source of information that can be transferred into knowledge and understanding (Angel & Frederiksen, 2015).

Even though the notion of person-centered care has been a paradigm shift in healthcare and especially in nursing during the last decades, patients are still navigated through a healthcare system that is adapted to the routines and needs of organizations and professionals, rather than focusing on the individual patient's needs, preferences and values (Ekman et al., 2011). To shift focus, the patient's narrative must lay the ground for the partnership in care, which focuses on the sick person's experiences of his/her illness, symptoms and impact on daily life. To ask for a patient's narrative means that their experiences, feelings, beliefs, preferences, and resources for self-care are important for consideration and the shift from the disease to the person with the illness can be enabled (Ekman et al., 2011). The implementation of different types of person-centered care approaches in Swedish care facilities have been evaluated and shown to reduce hospital stays and healthcare costs (Ekman et al., 2012; Hansson et al., 2016), a more welcoming environment and improved working environments (Edvardsson, Sandman, & Borell, 2014). In the out-patient setting the health-related quality of life (HRQoL) increased while symptoms were reduced (Brännström & Boman, 2014; Feldthusen, Dean, Forsblad-d'Elia, & Mannerkorpi, 2016), disease control improved (Jutterström, Hornsten, Sandström, Stenlund, & Isaksson, 2016) and self-efficacy increased (Fors et al., 2018). Most studies have been focusing on care for patients with chronic conditions such as dementia, heart failure, chronic obstructive pulmonary disease, diabetes and rheumatoid arthritis while few include patients with severe cancer diagnosis. Patients with head and neck cancer, who had a clinical meeting with a nurse before start of treatment where a person-centered care plan was designed, showed decreased disease-related symptoms during treatment compared to a control group (Hansson, Carlström, Olsson, Nyman, & Koinberg, 2017). There is a need for knowledge on how the patient's narrative can be continuously incorporated in the care process when patients with severe cancer diagnosis are cared for at a distance, namely as out-patients. One way can be to make the patients' voices heard by assessing patient-reported outcomes in clinical care, such as health-related quality of life, including symptoms and functions (Kaasa et al., 2018). Further, for healthcare professionals to establish partnership with patients and thereby enable realistic goals to be drawn up in care plans, enhancing patients self-care is required (McCorkle et al., 2011).

## 2.3 Self-care

Self-care was introduced as an element of nursing by Dorothea Orem who theorized that self-care is a learnt human behavior and a conscious, deliberate and self-initiated action that the individual performs in daily life (Orem, Taylor, & Renpenning, 2001). Every person has the ability and motivation to perform actions to promote their own health, wellbeing and personal development and to prevent sickness. Preconditions for self-care are that the person is mature and has developed abilities to take care of oneself in the environment and situation in which he/she lives. To be able to perform self-care, a person needs to have knowledge and understanding of what the actions mean (Orem et al., 2001). A closely related term to self-care is self-management. Self-management has been defined as “those tasks that individuals undertake to deal with the medical, role and emotional management of their health condition” and strive to help patients to take an active role in preventing and managing symptoms, during and after treatment (McCorkle et al., 2011). The terms self-care and self-management are often used interchangeably (Peeters, Wieggers, & Friele, 2013) and sometimes in combination, namely self-care management (Hammer et al., 2015). Similarly defined self-care and self-management include tasks, skills, and competences used to cope with an illness and its integration on a person’s life (Peeters et al., 2013).

In today’s cancer care, with shortened hospital stays and treatments given at out-patient units and where cancers in many cases are considered to be long-term conditions, patients are expected to shoulder a greater role in managing consequences of treatment and everyday life (McCorkle et al., 2011). When patients with cancer were asked about their attitudes towards self-care, a majority reported a positive attitude in their ability to take own actions to improve their health (Jansen, van Uden-Kraan, van Zwieten, Witte, & Verdonck-de Leeuw, 2015). Nevertheless, about half of the patients felt unable to judge whether their symptoms were serious and only a small part were positive towards controlling their own health rather than visit a physician (Jansen et al., 2015). Nursing interventions to enhance self-care for patients with cancer have been focusing on relieving symptoms and improving quality of life by education, counseling, exercise, or complementary and alternative medicine therapies (Hammer et al., 2015). Many interventions have shown favorable outcomes and positive trends, such as improved overall quality of life and symptom management. However, findings have rarely shown statistical significance (Hammer et al., 2015). Using the internet to get advice on how to handle or cope with own illness or to monitor symptoms has been perceived as positive by patients with cancer (Jansen et al., 2015).

## 2.4 Patient-reported outcomes

A patient-reported outcome (PRO) is defined as any report of the status of a patient's health condition that comes directly from the patient, without interpretation by a clinician or anyone else. A PRO can be measured in absolute terms, for instance severity of a symptom or as a change from a previous measure (U.S. Department of Health and Human Services FDA, 2006). Self-reported assessments of HRQoL, including symptoms and functional status, are grouped under the umbrella term patient-reported outcome measures (PROM) (Kaasa et al., 2018).

The term HRQoL is often used in clinical trials to distinguish between general senses of quality of life. Hence, the term also comprises symptoms and functions that are affected or not affected due to an illness (Fayers & Machin, 2007). There are many questionnaires that assess HRQoL, some instruments intended for general use, irrespective of a patient's illness or condition, and some disease-specific instruments used to detect differences that arise as a consequence of specific treatments or interventions (Fayers & Machin, 2007). It has been noted that quality of life measurements are not always sensitive enough to detect changes during a symptom-management intervention as compared to measurements of patients' symptom experiences (Molassiotis et al., 2009). Further, while symptom burden decrease over time for patients with cancer, quality of life has been found to be stable (Deshields, Potter, Olsen, & Liu, 2014). A symptom has been defined as an individual's subjective experience of changes in functions, feelings or perceptions and cannot be objectively identified (Dodd et al., 2001). The symptom experience can be described in several dimensions, such as prevalence, frequency, severity, bother, intensity and distress (Hench, Olsson, Larsson, & Ahlberg, 2018). To assess a patient's frequency, severity and distress of a symptom has been shown to be valuable measurements both in research and clinical settings (Browall, Kenne Sarenmalm, Nasic, Wengström, & Gaston-Johansson, 2013). However, there is no consensus as to which dimensions affect patients' well-being the most and thereby which data best to collect, when evaluating interventions to improve patients symptom experience (Hench et al., 2018). Patients with cancer, cared for as outpatients, often experience multiple symptoms and if these are not identified and managed they will impact the patient's HRQoL and recovery (Pachman, Barton, Swetz, & Loprinzi, 2012). Symptom management is a key element in supporting care of patients with advanced cancer (Kaasa et al., 2018). Recent recommendations are that patients with pancreatic cancer are offered thorough symptoms management and advance care planning at an early stage of their illnesses (Rabow, Petzel, & Adkins, 2017). Even so, symptom assessments are rarely systematically collected and routinely incorporated in clinical cancer care (Kaasa et al., 2018).

Evidence suggests that using PROM as a routine in clinical practice can facilitate detection of symptoms and concerns, enhance communication between patients and healthcare professionals regarding experienced and distressing symptoms,

inform on impact of treatment, promote shared decision making, and improve patient satisfaction (Howell et al., 2015; Kotronoulas et al., 2014; Valderas et al., 2008). Traditionally, PROM have been collected through paper-based questionnaires, but the rapid advancements in information and communication technology has promoted the development of electronic tools (Kaasa et al., 2018). Thereby, there are possibilities to create new care models in which PROM can be integrated and patients monitored at a distance (Kaasa et al., 2018).

## **2.5 Information and communication technology**

Modern information and communication technologies (ICT) are believed to enable patient participation in own care and to support contact between patients and healthcare (Swedish Government & Swedish Association of Local Authorities, 2016). The use of ICT for health is described under the term eHealth by the World Health Organization, and when ICT are mobile and wireless they are described as mHealth (World Health Organization, 2011). mHealth has the potential to change the delivery of healthcare due to the rapid advances in mobile technologies, the improvements in possibilities to integrated mHealth into existing eHealth services, and the growing mobile coverage (World Health Organization, 2011). The growing mobile coverage is evident in Sweden as 94% of households now have internet access (European Union, 2016). Also, 85% have reported to use the internet daily and over 64% are using the internet to search for information on health (European Union, 2016). This shows the interest of using eHealth in the Swedish population. In 2016 the Swedish Government and the Swedish Association of Local Authorities and Regions jointly decided on a vision for eHealth policy (Swedish Government & Swedish Association of Local Authorities, 2016). The vision is that by 2025, Sweden aims to be the best country in the world at using the opportunities offered by digitalization and eHealth in both health and welfare to achieve a good and equal health amongst individuals and to enhance their own resources for increased independence and participation (Swedish Government & Swedish Association of Local Authorities, 2016). It is important to bring this goal into clinical healthcare and nursing through new eHealth solutions that enable person-centered care.

Promising results are beginning to show that mHealth can support patients with chronic conditions in participating in their own health and in making them feel secure and taken care of even outside the hospital (Wang et al., 2014). Using mHealth to deliver different self-care interventions to patients with long-term conditions, like motivating and advisory automatic messages connected to a reported symptom or disease-related sign, show a potential to improve patients' symptom management (Whitehead & Seaton, 2016). However, these evaluated self-care interventions have not targeted patients with cancer, and most have not provided real-time interactions with healthcare professionals (Whitehead & Seaton, 2016).

It has been proven to be feasible and a well-accepted method to offer patients with cancer undergoing treatment to interact with healthcare professionals by self-reporting symptoms via different kinds of eHealth systems (Basch et al., 2007; Denis et al., 2014; Judson et al., 2013; McCann, Maguire, Miller, & Kearney, 2009; Sundberg, Eklöf, Blomberg, Isaksson, & Wengström, 2015; Weaver et al., 2014). Common for these systems is that patients regularly submit reports between planned hospital visits and predefined alerts are immediately sent to either a nurse or an oncologist who then respond by contacting the patient. Studies are now showing that eHealth systems where patients report symptoms which are then discussed at their next hospital visit are effective in terms of fewer visits to the emergency room, patients staying on chemotherapy for a longer period (Basch et al., 2016), less symptom distress, fewer symptoms in need of symptom management support over time (Ruland et al., 2010), improved HRQoL and one year survival (Basch et al., 2016; Denis et al., 2017) compared to patients not using such systems or where reports were not discussed at visits. Patients in these studies have had a wide range of cancer diagnoses, namely; breast, colorectal, genitourinary, gynecologic, lung, lymphoma, prostate or multiple myeloma. Also, some evidence exists that when patients are also offered written feedback comprising of self-care advice, patients feel more in control and confident in their abilities to self-manage their illnesses (Weaver et al., 2014), and symptom burdens can be reduced (Kearney et al., 2009; Sundberg et al., 2017).

In summary, there are indications that collecting PRO for regular use in clinical care enhance patient participation, lessen symptom burden, increase HRQoL and even survival for patients with cancer. Further, most studies have been performed during the period of active treatment while only a few during follow-up, which affects the possibility to understand how using mHealth care contributes to the creation of new care models throughout the whole cancer continuum (Nasi, Cucciniello, & Guerrazzi, 2015).

### **3 RATIONALE**

Patients with pancreatic or periampullary cancer have poor prognosis even after intentionally curative surgery. The surgery usually results in severe symptoms and impaired quality of life for a long time. Patients have reported that they often lack sufficient knowledge about how to manage their illnesses and that they experience unmet supportive care needs. Hence, innovations where these patients can communicate with healthcare professionals and get support for self-care are needed. By routinely collecting PRO in clinical practice, early detection of symptoms can be facilitated, communication between patients and healthcare professionals is enhanced, information on impact of treatment is improved, shared decision making is promoted, and patient satisfaction is improved. In today's cancer care, patients themselves must shoulder a great role in managing consequences of treatment and everyday life. To be able to do so, patients need to have knowledge and understanding about self-care, which requires healthcare professionals to form partnerships with patients. Using mHealth has shown promising results in supporting patients with cancer to participate in their own health management. Further, promising results on improved HRQoL, decreased symptom distress, fewer symptoms in need for symptom management and improved one year survival have been shown after routinely reporting symptoms to healthcare with support of mHealth. However, only a few of evaluated systems where PROs are collected comprise written self-care advice. Based on previous research, it is reasonable to believe that routine collection and management of relevant patient-reported symptoms can enable person-centered care for patients with pancreatic- and periampullary cancer since it makes patients active participants in their own care. Also, supportive care needs can be identified for the right patient at the right time.

## **4 AIM**

The overall aim of the thesis is to evaluate if collection and management of patient-reported outcomes in clinical practice, with support of an interactive app (Interaktor), can enable person-centered care and improve outcomes for patients who have undergone pancreaticoduodenectomy due to cancer.

### **Study I**

With the goal of developing the content of the interactive ICT application, the aim was to explore common symptoms and self-care in the first six months after pancreaticoduodenectomy, as identified by patients who have undergone this surgery and by healthcare professionals caring for these patients.

### **Study II**

The aim was to develop and test a version of the Interaktor app adapted for patients who have undergone pancreaticoduodenectomy.

### **Study III**

The aim was to evaluate the impact on health-related quality of life and self-care activity when using the Interaktor app following pancreaticoduodenectomy due to cancer.

### **Study IV**

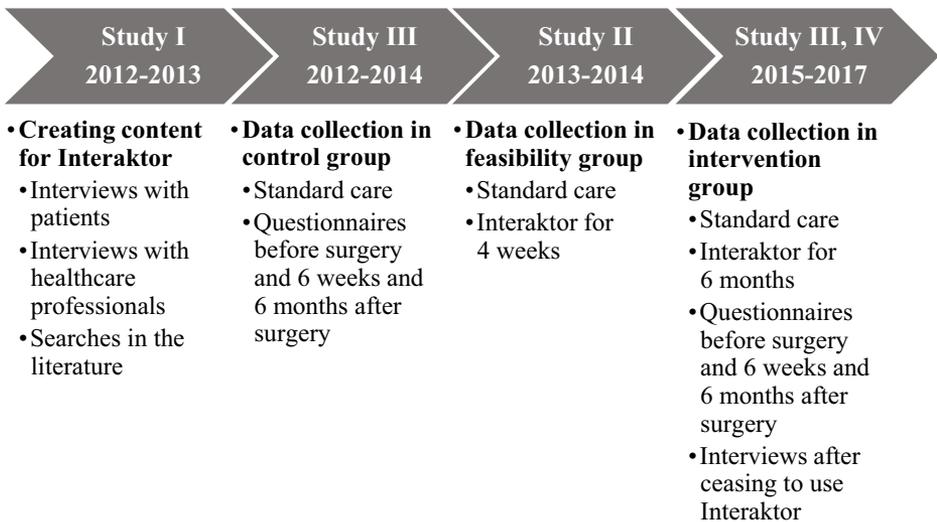
The aim was to describe how patients following pancreaticoduodenectomy due to cancer have used Interaktor and their experiences of using it.

## 5 METHODS

### 5.1 Design

The study design is underpinned by the Medical Research Council's (MRC) complex intervention evaluation framework (Craig et al., 2008). An intervention can be considered to be complex if several interacting components exist, if several and difficult behaviors are required by those involved, if several groups or organizations are involved, if several and variable outcomes are being aimed at, and if the intervention are tailored yet flexible (Craig et al., 2008). The intervention in this thesis can be considered complex as multiple components are involved which require active engagement from patients and healthcare professionals. The components include the technology where patients send reports on symptoms to the hospital while being at home, the automatically triggered alerts to healthcare professionals, the suggestions to view self-care advice and the possibility for healthcare professionals to view patients' reports. The MRC framework initially includes three phases; 1) developing the intervention, 2) assessing feasibility and 3) evaluating the intervention (Craig et al., 2008). The different phases represent the studies included in this thesis (Table 1).

The timeline for the data collection of the studies included in the thesis is presented in Fig. 1.



*Figure 1. Timeline showing the data collection throughout the studies included in the thesis.*

**Table 1. Overview of the phases in the Medical Research Council's framework and the studies in the thesis**

Framework phase	Study	Design	Sample	Data Collection	Data analysis
I	I	Qualitative descriptive	Patients (n=14) Healthcare professionals (n=10)	Semi-structured individual interviews and focus groups	Qualitative content analysis
II	II	Qualitative and quantitative descriptive	Patients (n=6) using Interaktor (feasibility group) Nurse (n=1) monitoring alerts	1) Semi-structured individual interviews 2) Logged data in the app	1) Qualitative content analysis 2) Descriptive statistics
III	III	Quasi-experimental and quantitative descriptive	Patients (n=33) receiving standard care (control group) Patients (n=26) receiving standard care and using Interaktor (intervention group)	1) Descriptive data, SOC-13, EORTC QLQ-C30, EORTC QLQ-PAN26, ASA-A 2) Logged data in the app	1) Descriptive statistics, t-test, Chi-Square-test, Fishers Exact Test, Repeated measures ANOVA, multiple regression 2) Descriptive statistics
	IV	Quantitative and qualitative descriptive	Patients (n=26) receiving standard care and using Interaktor (intervention group)	1) Data logged in the app 2) Semi-structured individual interviews (n=25)	1) Descriptive statistics 2) Qualitative thematic analysis

SOC = Sense of Coherence, EORTC QLQ = European Organization for Research and Treatment on Cancer Quality of Life Questionnaire, ASA = Appraisal of Self-care Agency, ANOVA = Analysis of Variance

## 5.2 Setting and standard care

Pancreatic surgery at Karolinska University Hospital is performed at a highly specialized unit regarded as a high-volume center with more than hundred pancreatic resections annually. At the time of the studies, the patients met a surgeon, a contact nurse, a physiotherapist, an anesthesiologist and a dietician before surgery to gain information about the operation and postoperative care. The patients were given written information regarding pain treatment, physiotherapy and dietary advice including instructions about pancreas enzyme supplements. Following PD, the patients were cared for on a surgical ward for 1-2 weeks. Thereafter, if needed, care at a rehabilitation unit was offered for up to one week. If the patients had questions after discharge, they were encouraged to call their contact nurse at the surgical outpatient unit during working hours (8 a.m. to 4 p.m. on weekdays). If in need of emergency care they were asked to contact the nearest emergency department. Approximately one month after discharge, the patient met with a surgeon and sometimes a nurse and/or a dietician. At this out-patient visit the patients were informed about the microscopic examination of the tumor and a decision were taken whether to offer adjuvant chemotherapy or not. Patients eligible for adjuvant chemotherapy began their treatment within 10 weeks after surgery. Chemotherapy was given at the oncology clinic once a week for 3 of every 4 weeks (1 cycle) for 6 months, i.e. 6 cycles in total. During chemotherapy, the patients regularly met an oncology nurse and, on some occasions, an oncologist and/or a dietician. Between treatments the patients could call either their contact nurse at the oncology department or outside working hours, contact the nearest emergency department if needed.

## 5.3 The Interaktor app

The Interaktor app was developed in co-operation with Health Navigator, a Swedish company specializing in healthcare management and new innovative care solutions. The content of Interaktor is generic and adjustable depending on setting and situation. Simultaneously with the work throughout this thesis, additional versions of Interaktor adapted for patients with prostate cancer undergoing radiotherapy and older people receiving home-based healthcare have been developed and evaluated. Therefore, development of Interaktor has been made throughout the whole project according to results from studies included in this thesis but also from evaluation of versions adapted for other settings and situations (Algilani, Langius-Eklöf, Kihlgren, & Blomberg, 2017; Göransson et al., 2018; Hälleberg Nyman et al., 2017; Langius-Eklöf et al., 2017; Sundberg et al., 2015; Sundberg et al., 2017).

Interaktor can be downloaded onto smartphones or tablets and requires a separate individual log in. The components are 1) regular assessment of self-reported symptoms and problems, 2) a risk assessment model for alerts on frequent or distressing symptoms 3) continuous access to evidence-based self-care advice and links to relevant websites for more information, and 4) graphs for the patients to view a history of their symptom reporting (Fig. 2).

## 1. Reporting

Back Reporting

Difficult to eat

Have you found it difficult to eat since your previous report?

YES

NO

Back Reporting

Difficult to eat

How OFTEN?

Almost always

Often

Sometimes

Almost never

Back Reporting

Difficult to eat

How DISTRESSFUL is this for you?

Very much

Pretty much

A little

Not at all

## 2. Alert

Back Reporting

Your symptom report has caused an alarm.

Red alarm:  
High fever / chills

Yellow alarm:  
Difficult to eat

Do you wish to be contacted by a nurse?

YES

NO

## 3. Self-care

Back Self-care

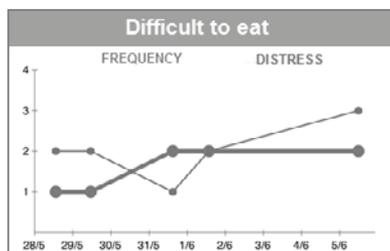
Dietary advice

It is very common with eating difficulties the first period after surgery and it often taken up to 8 weeks before this improves. Since a part of your stomach has been removed during surgery you will feel full faster than before the surgery.

Eat slowly, chew well and swallow small bites. If you chew well enzymes will be released helping to digest the food.

Eat less amount of food more frequently  
In the beginning start with eating approximately half of you earlier portion size to reduce the risk of discomfort after food intake. As long as the portion sizes are

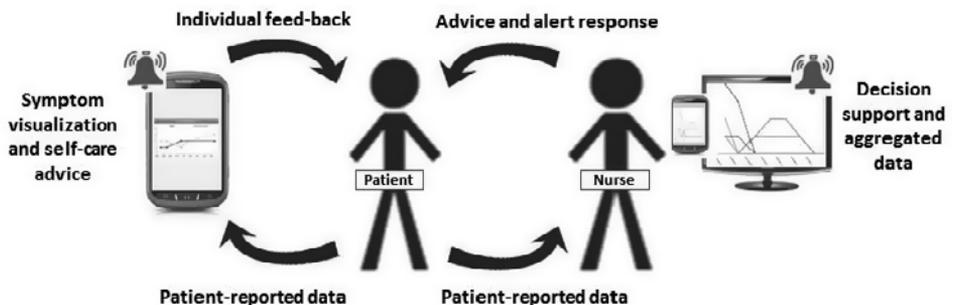
## 4. Visualization



**Figure 2.** Screenshots from the Interaktor app adapted for patients following pancreaticoduodenectomy showing the main components 1) symptom reporting, 2) alerts, 3) self-care advice to read and 4) graph over a symptoms change during the last week.

The structure of the symptom assessment is inspired by a standardized symptom questionnaire, and patients are first asked about the occurrence of the symptom, and then they are asked to rate the frequency and the distress level of the symptom (Browall et al., 2013; Portenoy et al., 1994). For example, if the answer to the question “Have you had trouble eating in the past day?” is “yes”, the patient would be asked how often it occurs (almost never, sometimes, often, or almost always) followed by how distressing the symptom is (not at all, a little, rather much, or very much). After completing the symptom assessment, the report is immediately sent to a secure server that is linked to a web-interface. The server is approved by The Swedish Data Protection Authority. In Interaktor, the patient can view the reports over time in graphs, and through the web-interface healthcare professionals can

monitor the reports. The patients have continuous access to self-care advice related to the assessed symptoms. Through the self-care advice, the patients, if in need for more information, also have access to hyperlinks to websites considered by the research group to be evidence-based. If the risk assessment model triggers an alert the patients gets suggestions about suitable self-care advice to read. If an alert is triggered, a text message (SMS) is sent to a mobile phone at the clinic where the alerted symptoms are viewed in the web-interface. Actions taken after alerts can be documented in the web-interface. There were two kinds of alerts included in the app – yellow and red. A yellow alert indicates that the patient should be contacted the same day. In case of a red alert, the priority is higher, and contact should be initiated by the healthcare professional (in this thesis a nurse) within an hour. Results from evaluating a version of Interaktor for use during radiotherapy for prostate cancer showed that the patients sometimes actively adjusted their symptom reporting to avoid an alert and a call from the nurse (Langius-Eklöf et al., 2017). Therefore, in the first version of Interaktor adapted for patients who have undergone PD (Study II) the SMS-component was changed whereby in case of an alert the patients receive a question asking whether they wanted to be contacted by a nurse. If choosing “yes”, an automatic SMS would be sent to a nurse. If choosing “no”, an SMS was not sent to the nurse, but the alert would still be visible to the nurse in the web-interface. An illustration of the idea with the Interaktor app and the connected web-interface are shown in Fig. 3.



**Figure 3.** Illustration of the idea with the Interaktor app and the connected web-interface.

## 5.4 Phase I – Development of Interaktor pancreas version (Study I)

### 5.4.1 Sample

Over a period of six months in 2012 and 2013, all patients who had undergone PD at Karolinska University Hospital due to suspected cancer were screened for eligibility. Inclusion criteria involved having been discharged from surgery within the last six months, being Swedish-speaking, having no cognitive impairment and living in the Stockholm area. Previous conclusions have been made that a sample of 12 participants are enough to gain knowledge of common experiences in a relatively homogeneous sample (Guest, Bunce, & Johnson, 2006). After stratification for equal sex distribution, 14 patients were invited and all consented to participate in the study. Further descriptive data are shown in Table 2.

**Table 2. Descriptive data of participating patients (n=14) in Study I**

Descriptive data	
Age in years, mean (median, range)	65 (63, 49-69)
Months since surgery, median (range)	6 (1-7)
Histopathology of tumor, n (%)	
Ductal adenocarcinoma	6 (43)
Periampullary adenocarcinoma	6 (43)
Invasive IMPN	2 (14)
Ongoing or completed adjuvant chemotherapy, n (%)	5 (36)

IPMN = intraductal papillary mucinous neoplasm

A purposeful sample of 12 healthcare professionals was invited to participate in two focus groups. The inclusion criterion was that they should represent all professions in contact with the current patient group in connection to the surgery. For all professions, the persons at the site with the longest experience in caring for the patient group were invited. At the time of the focus group interviews, three of the participants who had been invited were unavailable, and one of them agreed to be interviewed individually instead, which resulted in a final sample of 10; registered nurse (n=4) including one contact nurse, enrolled nurse (n=2), physiotherapist (n=2), surgeon (n=1) and dietician (n=1). Their experience of caring for the patient group ranged 2-20 years. No medical social worker could participate either in the focus groups or in an individual interview.

### **5.4.2 Data collection**

Interviews were chosen as a data collection method to get insight on patients perspectives, feelings and thoughts (Patton, 2015). To get a wide view of experiences patients were interviewed at different time points. The interviews followed an interview guide to cover relevant areas (Kvale & Brinkmann, 2009). Questions in the guide were: Which symptoms have you experienced at home after surgery? How do you deal with these symptoms? What advice have you received from healthcare professionals? Do you wish to receive advice about self-care, or do you prefer to receive help from someone else? Probing questions were used when needed to get a deeper understanding (Patton, 2015). Seven patients were interviewed in connection with a follow-up appointment at the outpatient unit, six at home, and one over the phone. The interviews with patients were performed by the author of this thesis (n=11) or a researcher with experience of interviewing people with cancer (n=3). The interviews lasted on average 40 minutes (range 19-60 minutes), and were audio recorded and transcribed verbatim by the author of the thesis (n=9) or an external transcriber (n=5). All transcripts were checked against the audio recording.

The focus group interviews with healthcare professionals were conducted at the hospital where they worked and were facilitated by a moderator and an observer not known to the healthcare professionals. Focus group interviews were chosen as they take advantage of group dynamics in order to access rich information in an efficient manner (Kitzinger, 1994). The individual interview was conducted by telephone with the surgeon who could not participate in either focus group. All interviews followed an interview guide which contained the following questions: What is your impression of how patients experience their life situation after pancreaticoduodenectomy? Which symptoms follow pancreaticoduodenectomy? Which self-care advice do you give regarding the different symptoms? Probing questions were used when needed. The focus group interviews lasted 52 and 40 minutes respectively, and the individual interview for 25 minutes. The interviews were audio recorded and transcribed verbatim by the author of the thesis. The transcripts were checked against the audio recording.

### **5.4.3 Data analysis**

Data were analyzed using inductive qualitative content analysis (Elo & Kyngäs, 2008). Initially, the interview transcripts were read through several times to make sense of the data and get a sense of the whole. Text related to symptoms or self-care was coded using open coding where notes and headings were written in the text while reading it. Two authors coded the text and the codes were then transferred to a coding sheet in Microsoft Excel 2010 where similar codes were grouped together to create categories. The codes and categories were discussed by

the researchers and revised until agreement was reached. Trustworthiness (Lincoln & Guba, 1985) for the analysis was ensured by involving several researchers with different experiences within the field and by having verbatim transcripts to check when needed. Further, quotes were presented to confirm the findings.

## **5.5 Phase II – Assessing feasibility of Interaktor pancreas version (Study II)**

### **5.5.1 Sample**

During a period of 4 months in 2013-2014, all patients (n=33) who were scheduled to undergo PD at Karolinska University Hospital due to a suspected tumor in the pancreatic or periampullary region were screened for eligibility. Exclusion criteria were follow-up care out-side of Stockholm county (n=12), unable to read and understand Swedish (n=1) and logistic reasons (n=3). Logistic reasons were if a patient was estimated to be discharged when the outpatient unit was closed over Christmas or if three other patients already were reporting at the same time since only one nurse was responsible for monitoring reports. After the screening process, 17 patients were eligible before surgery. All, except one who could not be reached, were asked to use the app for 4 weeks starting the first day at home after discharge following surgery. Four patients declined, five patients could not be included after surgery for different reasons, and one started to use the app but dropped out after being readmitted to the hospital after 3 days at home. Thus, six patients were included in the study. The included patients ranged in age from 57 to 74 years (mean 65 years), and there were three men and three women. Three patients were diagnosed with ductal adenocarcinoma and three of periampullary cancer.

One nurse at the surgical outpatient unit was asked to respond to alerts from all participating patients.

### **5.5.2 Procedure**

At the time of Study II, the Interaktor app was not yet downloadable to every smartphone or tablet. Therefore, the patients were supplied with a smartphone with the app installed. The researcher instructed the patient about the different components and thereafter the patient practiced sending a report under the researcher's supervision. The report was then shown in the graphs and discussed together. The self-care advice, including hyperlinks to websites, was introduced. Furthermore, a written manual for using the app was given to the patients to take home. The manual contained illustrations and instructions and was created by Health Navigator and checked by the author of the thesis. The patients were instructed to report symptoms daily for 4 weeks starting the first day after discharge from the surgical or rehabilitation clinic. If the patients received chemotherapy during these weeks, they

were instructed to continue to use the app in the same way. A reminder to report was sent through the app every day. The patients were thoroughly informed both orally and in writing that in case of an alert they would only be contacted during working hours (8 a.m. to 4 p.m. on weekdays) because the report could only be monitored by a nurse during this time. In case an alert had been triggered during weekends, an interaction was initiated on Monday morning. The allocated nurse was employed at the surgical clinic but was not primarily involved in the patients care. The nurse was instructed to call the patients if she received an alert-SMS and to document the actions taken in the web-interface. The patients were also asked to write down comments and thoughts about the app if they appeared on a predesigned note sheet, which was to be collected at the end of the reporting period. The patients got a telephone number and e-mail address to a researcher in case of technical difficulties and the same researcher weekly monitored the patient reports and that alerts were submitted and responded to as intended.

### **5.5.3 Data collection**

Data was collected from three sources 1) logged data, 2) individual interviews with the patients and 3) an interview with the nurse assigned to the study. None of the patients had used the predesigned note sheet to write down comments.

- 1) Logged data concerning the number of reports, the number of reported symptoms, alerts, and documented interactions were extracted as an encrypted Microsoft Excel 2010 file from the database hosted on the secure server. Data regarding the use of the self-care advice could not be logged in this version.
- 2) The patients were interviewed about their experiences of using the app after their final report. Interviews were chosen to get an understanding of the patients experiences (Patton, 2015). A semi-structured interview guide was used to cover relevant areas. The same initial question was used for all interviews but the following questions could come in different order depending on the patients responses (Kvale & Brinkmann, 2009). The initial question was: “What was it like to use the app?” Then followed questions regarding experiences of the content of included questions and self-care advice, viewing graphs of previous reports, being contacted after an alert (if applicable), technical issues, and how long it would be relevant to report symptoms. The interview ended with the question “What has the app meant for you during this time?” Depending on the extent of the patients’ answers, probing questions like “can you elaborate or give an example” were used (Patton, 2015). The interviews lasted for a median time of 34 min (range 22 to 54 min) and were audio recorded. All patients were interviewed in their homes.
- 3) The nurse was interviewed over the phone about her experiences in receiving and managing the alerts and using the web-interface. Notes were taken during the interview.

#### **5.5.4 Data analysis**

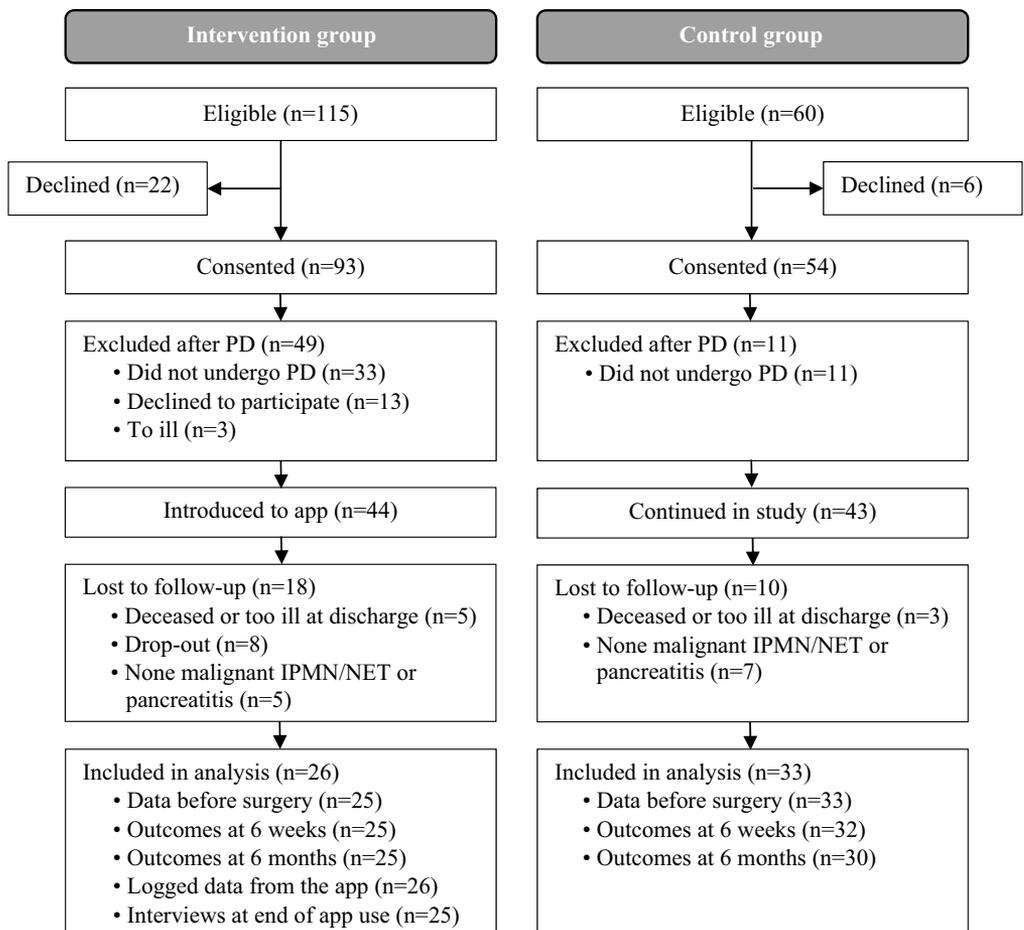
- 1) The extracted logged data were analyzed using descriptive statistics.
- 2) The patients' interviews were transcribed verbatim and were analyzed using qualitative content analysis as described by Elo and Kyngäs (2008). The texts from all the patients' interviews were put together to create one unit of analysis. The text was read through to get a sense of the whole. After that, an open coding was performed by noting codes in the margins of the text. The codes were then transferred to a coding sheet where similar codes were put together to create categories. Trustworthiness was insured in several ways (Elo & Kyngäs, 2008; Graneheim, Lindgren, & Lundman, 2017). All the researchers had different experiences in cancer care and research and thereby preunderstandings could be identified and discussed. Data from all participants were analyzed and characteristics of patients are described as detailed as possible without compromising integrity. Categories were created after discussions among all of the authors and returning to the text when divergences arose.
- 3) The notes from the interview with the nurse were coded and analyzed without creating categories.

### **5.6 Phase III – Evaluation of Interaktor pancreas version (Study III and IV)**

#### **5.6.1 Sample**

Inclusion criteria for Study III were patients scheduled to undergo PD due to a suspected malignancy whose follow-up care was planned to Karolinska University Hospital and who were able to read Swedish. The patients were invited consecutively before surgery to participate in the study. Inclusion and data collection of the control group were made before the intervention group. During a period of 14 months, in 2012-2013, 60 patients were found to be eligible for the control group of which 42% were women. During a period of 16 months, in 2015-2016, 115 patients were found to be eligible for the intervention group of which 50% were women. Six patients declined to participate in the control group, their median age was 71 years (range 56-81 years) and three (50%) were women. A total of 35 patients, declined to participate in the intervention group, their median age was 72 years (range 58-85 years) and 21 (60%) were women. Only patients whose microscopic examination showed a malignant tumor were included in the analysis. Patients who dropped out of the study before the first follow-up six weeks after surgery were not included in the analysis. Reasons for dropping out were not always stated but some patients explained that they felt well and had no symptoms to report and others that they lacked the energy to continue. Further exclusion criterions

after surgery are shown in Fig. 4. A final sample of 33 patients in the control group and a final sample of 26 patients in the intervention group were included in the analysis. The control group received standard care, as described under “Setting and standard care” on page 13, and the intervention group received standard care and the intervention. The sample in Study IV consists of the patients from Study III who were included in the intervention group (n=26).



**Figure 4.** Flowchart over the inclusion process in Phase III. IPMN = intraductal papillary mucinous neoplasm, NET = neuroendocrine tumors.

## 5.6.2 Procedure for the intervention group

Within a few days of discharge, the researcher met the patients (n=44) in the intervention group individually to inform the patients on how to use Interaktor. At the time of this study the Interaktor app could be downloaded to any smartphone or tablet and therefore patients with own access to a smartphone or tablet got help to download the app on that device. Patients who did not have access to a device could borrow a smartphone to use during the study period. The patients got an individual user name and pin code to use when logging in to the app and practiced submitting a report under the researcher's supervision. Further, the graphs over previous reports and the self-care advice components were showed. An updated manual with illustrations and instructions of how to use the app were given to the patients to take home. At six occasions the researcher could not meet the patients before discharge; instead the patients were visited in their homes or got instructions over the phone. The patients were instructed to submit a report once a day starting on the first day at home after discharge and until six months after surgery. The patients were thoroughly informed that reports were only monitored during working hours (8 a.m. to 4 p.m. on weekdays) and that in case of an alert they would only be contacted during these hours. In case an alert had been triggered during weekends, an interaction was initiated on Monday morning. If in need of contact outside of working hours they were instructed to contact healthcare according to standard care procedure described on page 13. Also, the patients got contact information to the researcher in case of technical problems with the app. The researcher monitored the patients' reports during the first days to identify if there were any problems. If no reports had been submitted the researcher called the patients to give further instructions. One patient, who borrowed a smartphone, required two additional training sessions over the first weeks of reporting and the researcher then visited the patient at home. Patients undergoing adjuvant chemotherapy were asked to continue to use the app until one week after their final chemotherapy cycle which could be up to 9 months after surgery depending on the start of the first cycle and any pauses in cycles.

## 5.6.3 Data collection

### 5.6.3.1 *Descriptive data and questionnaires (Study III)*

Four sets of data were collected; 1) descriptive data, 2) Sense of coherence (independent variable), 3) Health-related quality of life (outcome variable) and 4) Self-care activity (outcome variable).

- 1) A number of descriptive data were collected. Data concerning age, sex, histopathology of tumour, and oncological therapy were collected from the patients' medical records. Data concerning living situation and educational level were collected via questionnaires to patients before surgery, or if patients' responses were missing at that time data were collected after surgery.

- 2) Sense of coherence (SOC) were collected before surgery, six weeks after surgery and 6 months after surgery using the scale developed by Antonovsky (1987) which reflect a person's inner resource for coping with stressful life events and is built on how *comprehensive*, *manageable*, and *meaningful* life appears. The SOC scale has been used in a wide range of samples including people of different countries, ages and health status and found to have high validity and reliability (Eriksson & Lindström, 2005). The scale is a self-assessment questionnaire that consists of 13 items that measure SOC (SOC-13). The questionnaire utilizes a 7-point scale with two anchoring responses. The total score range from 13-91 points where a higher score indicates a higher degree of SOC. Levels of SOC were collected to be used as an independent variable since level of SOC are normally stable over time (Eriksson & Lindström, 2005; Lindblad, Sandelin, Petersson, Rohani, & Langius-Eklof, 2016) and since a high SOC has shown predictive validity for a good HRQoL (Pillay et al., 2015; Rohani, Abedi, Omranipour, & Langius-Eklöf, 2015) and higher self-care activity level (Fex, Flensner, Ek, & Söderhamn, 2012). Further, SOC has shown predictive value for survival, argued to depend on that patients with high SOC can understand the need, handle side-effects and have enough motivation to go through difficult cancer treatments (Lindblad et al., 2018). Internal consistency of SOC-13 in Study III showed Cronbach's  $\alpha \geq 0.87$ .
- 3) Data on health-related quality of life were collected before surgery, six weeks after surgery, and six months after surgery as an outcome variable using the Swedish versions of EORTC QLQ-C30 (version 3) and the pancreas module QLQ-PAN26. The EORTC QLQ-C30 has shown high validity and reliability for assessing the HRQoL of patients with cancer (Aaronson et al., 1993; Björdal et al., 2000) and has been widely used. It is a self-assessment questionnaire consisting of 28 questions with a 4-point rating scale; not at all, a little, quite a bit, very much and two questions with a 7-point scale from very poor to excellent. The questions are scaled in one global health status domain, five functional domains exploring physical, role, emotional, cognitive and social functioning, as well as eight symptom scales/items namely fatigue, nausea/vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea and one item concerning financial difficulties. All of the scales and single-item measures range in score from 0 to 100 where a high score for the global and functional scale represents a high level of HRQoL/functioning, whereas a high score for symptom scales/items represent high levels of symptoms or problems (Aaronson et al., 1993). The disease-specific pancreatic cancer module QLQ-PAN26 is not yet fully validated but is one of the most used instruments for patients with pancreatic cancer and is currently undergoing phase III testing. It comprises 26 questions, with the same 4-point rating scale, and is divided in seven multi-item scales assessing pancreatic pain, digestive symptoms, altered bowel habit, hepatic symptoms, body image,

satisfaction with healthcare, and sexuality, as well as 10 single items assessing bloating, taste/smell alterations, indigestion, flatulence, worry about low weight, muscle weakness, xerostomia, side-effects, worry about future health, and planning social activities. Higher scores in symptoms and satisfaction scales/items represent high level of symptoms or satisfaction, whereas a high score for sexuality represents worse sexual function (Fitzsimmons et al., 1999). To ensure reliability internal consistency was measured for all subscales by Cronbach's reliability coefficient  $\alpha$ . All showed an acceptable Cronbach's alpha of  $> 0.70$  (Pallant, 2016) except for cognitive function at six months ( $\alpha=0.62$ ), nausea/vomiting before surgery ( $\alpha=0.62$ ) and at six months ( $\alpha=0.32$ ), pancreatic pain at six months ( $\alpha=0.62$ ), digestive symptoms at six weeks ( $\alpha=0.63$ ), altered bowel habits at all time points ( $\alpha=0.62-0.65$ ) and hepatic symptoms at six weeks ( $\alpha=0.06$ ) and at six months ( $\alpha=0.60$ ). Cronbach's alpha are dependent on the number of items within the scale and it is not uncommon that scales with few items can have small alphas (Pallant, 2016). Therefore, the mean inter-item correlation was measured for scales with two items and a Cronbach's alpha that did not reach  $> 0.70$ . Then, only the subscale hepatic symptoms six weeks after PD showed correlation outside the reference range of 0.15-0.50, namely 0.03.

- 4) Data on self-care activity levels were collected before surgery, six weeks after surgery, and six months after surgery as an outcome variable using the Swedish version of the Appraisal of Self-Care Agency scale (ASA-A). The ASA-A scale is a self-assessment questionnaire that measures the activation of power and engagement in self-care activities, based on Orem's self-care deficit theory of nursing (Söderhamn, Evers, & Hamrin, 1996a). The ASA-A have been validated in Swedish in a sample of older lucid people and showed high reliability and validity (Söderhamn, Lindencrona, & Ek, 1996b). It is a Likert-type scale including 24 items for self-appraisal, each item having five response categories ranging from 1 ('totally disagree') to 5 ('totally agree'). The total score range from 24-120 points, where higher scores reflect a higher degree of self-care activity. Internal consistency of ASA-A in Study III showed Cronbach's alpha  $\geq 0.86$ .

#### *5.6.3.2 Logged data from the app (Study III and IV)*

Data concerning number of submitted reports, reported symptoms, triggered alerts, free text comments and viewed self-care advice by the intervention group were extracted in an encrypted Microsoft Excel 2010 file.

#### *5.6.3.3 Interviews (Study IV)*

The patients in the intervention group were interviewed, after their final report, about their experiences of using the app. A semi-structured interview guide was used to cover relevant areas (Kvale & Brinkmann, 2009) and to ensure trust-

worthiness (Lincoln & Guba, 1985). Questions were “What was it like to use the app?”, “In which way have you been in contact with healthcare?” and “In which way have you been able to be involved in your care?” Probing questions were used to deepen the patients’ responses (Patton, 2015). All interviews were conducted by the author of the thesis. The interviews lasted for a median time of 31 min (range 16 to 71 min) and were audio recorded. To ensure that the patients were comfortable they were interviewed either in their own home (n=21) or at the hospital (n=4) according to their own choosing.

## **5.6.4 Data analysis**

### *5.6.4.1 Questionnaires (Study III)*

One patient in the intervention group had incomplete data before surgery but completed all the other measurements and was therefore included in the analysis.

The items in the SOC-13 were processed according to the manual (Antonovsky, 1987) where five items are reversed, and the scores were then aggregated to a total SOC-score. Randomly distributed missing values (0.2% in total) were imputed according to the manual. Missing questionnaires were excluded (7.8% in total).

The items in EORTC QLQ-C30 were processed according to the EORTC scoring manual (Fayers et al., 2001) and the items in EORTC QLQ-PAN26 according to CD Johnson, responsible for the pancreas module (personal communication). Raw scores were linearly transformed into 0-100 scales. Randomly distributed missing values in multi-item scales (0.4% in total) were imputed according to the scoring manual while missing values for single-items (0.7% in total) were not imputed. Missing questionnaires (4% in total) were not imputed.

The items in the ASA-A scale were processed according to Fex and colleagues (2012). Nine items, negatively stated, were reversed in the summation of the scores. Randomly distributed missing values (0.2% in total) were given a neutral score of 3 (‘neither disagree nor agree’). If the patients had more than three missing values the whole questionnaire was excluded (Fex et al., 2012). These excluded questionnaires together with non-returned questionnaires represented 9.6%.

Effect size was calculated by subtracting the group means and dividing the result with the pooled standard deviation giving Cohen’s *d*. Cohen’s *d* was interpreted as small if  $d = 0.2$ , medium if  $d = 0.5$  and large if  $d = 0.8$  (Cohen, 1988). Further analyses were performed using IBM SPSS Statistics 24 where a 2-tailed statistical significance level of  $p < 0.05$  was applied. Between-group analyses were performed using chi-square or Fisher’s exact test for categorical variables and independent sample *t*-test for continuous variables. Variables showing significant mean differences at six weeks and six months were run in multiple linear regression models as dependent variables with group affiliation (coded as control

group=0, intervention group=1), chemotherapy (coded as No=0, Yes=1) and SOC scores collected 6 weeks after surgery as independent variables using the standard method. Chemotherapy was used as an independent variable since decisions on chemotherapy may be based on patients' general condition at that time. To evaluate changes over time an ANOVA for repeated measures was analyzed separately for the intervention group and the control group.

#### *5.6.4.2 Logged data from the app (Study III and IV)*

Logged data from the app were analyzed with descriptive statistics using Microsoft Excel 2010. Adherence to report was calculated as the number of days a patient submitted a report divided by the number of days a patient was intended to report, and presented as a mean percentage in the whole group. Data was analyzed as one data set throughout the whole reporting period (Study IV) but also separated as two data sets, one with data from the first four weeks and one with data for the rest of the reporting period (Study III). This time point approximately corresponds to the measurements at six weeks after surgery and also to when patients normally begin chemotherapy.

#### *5.6.4.3 Interviews (Study IV)*

The patients' interviews were analyzed using thematic analysis as described by Braun and Clark (2006). First, all interviews were transcribed verbatim and read through several times. Statements regarding the app were systematically coded throughout the entire dataset with an inductive approach. A code could consist of a few words or a whole sentence. Similar codes were then put together and created themes. All data in one theme were then reviewed to see if the theme worked in relation to the codes. This reviewing process was made by all authors. If a theme did not work the process to collate codes started from the beginning until all themes corresponded in relation to the codes and the entire dataset. During the whole process themes were defined, named and re-named. Final analysis and adjustments were made during the manuscript-writing. Trustworthiness was ensured by following Braun and Clarks (2006) 15-points checklist.

## 6 ETICAL CONSIDERATIONS

All work comprised in this thesis was made according to the ethical principles stated by the Declaration of Helsinki (World Medical Association, 2013) and the regulations by the Swedish Act concerning Ethical Review of research Involving Humans (The Swedish Riksdag, 2003). The principles involve informed consent of participants, that information must be easy to understand, and that participants can choose not to continue to participate at any time. Further, the consequences of the research should be good for society, the research should mean minimal risks and the participants' integrity and interest must come before the research. The law also stipulates how sensitive information regarding participants should be handled. The studies in the thesis have undergone ethical examination and were approved by the Regional Ethical Review Board in Stockholm, Sweden (Reg.no: 2011/1780-13/2). When implementing mHealth several ethical considerations exist (Botrugno, 2019). mHealth enables healthcare professionals to have access to a great portion of patients' daily lives and consequently a large portion of sensitive data. These sensitive data need to be protected against unauthorized access and healthcare professionals are obliged to monitor all of the data regardless of its relevance to the patient's conditions. This could lead to the exposure of unforeseen liability issues for healthcare professionals. Also, to ensure effectiveness of the mHealth intervention substantial engagement is required by patients, who need to contribute to the management of their own diseases through an active approach. While this could be positive in the sense that it improves patients' awareness of their own health conditions, the balance between patient's autonomy and the healthcare professionals responsibilities can be problematic (Botrugno, 2019).

The patients in Study I-IV received written information about the study in connection to a clinical visit prior to surgery. After 1-2 weeks a researcher called the patient to answer questions about the study and ask if the patient wanted to participate. Patients who accepted to participate signed a written consent but were informed that they could withdraw from the study at any time without specifying a reason. When the app was introduced to the patients upon discharge information about the study was given once again. In Study III-IV a researcher called patients using the app after approximately one month to ask if they wanted to continue to use the app. All patients in Study I-IV were given a specific code which was stored separately from clinical and sociodemographic data and answers to questionnaires. Personal data on participating healthcare professionals in Study II were not collected. In the connected web interface patients name and personal number are logged to ensure easy access for the participating nurses to the patients' medical records. All logged data from the app and the web interface were logged on a secure server hosted by the participating company Health Navigator. The server was approved by The Swedish Data Protection Authority. Log-in number and

password to the web interface was given to nurses responsible to monitor patients, to researchers involved in the project and to appointed staff at Health Navigator for technical support. The app required a user name and password unique for each patient. A researcher monitored the web interface weekly to ensure that alerts were being responded to. Completing a daily electronic symptom questionnaire may cause patients to focus more on their symptom experiences than if they were not asked to complete these symptom questionnaires. However, the patients were encouraged to raise this with their contact nurse who followed them throughout the study. Also, the patients were given the phone number and e-mail address to a researcher in case they experienced difficulties with the app or felt unsure about usage. Being interviewed about personal experiences can bring forth unpleasant emotions. Therefore, all interviews were conducted by a nurse with years of experience of cancer and critical care.

## 7 RESULTS

### 7.1 Phase I – Development of Interaktor pancreas version (Study I)

#### 7.1.1 Foundation for the content

##### 7.1.1.1 Symptoms to assess

In Study I, five areas of symptoms were identified through the data analysis of interviews with patients and healthcare professionals, namely eating, fatigue, bowel function, emotional wellbeing and pain. Eating difficulties included descriptions of appetite loss, taste- and smell alterations, rapid satiety and nausea, sometimes with vomiting. Several of the symptoms, especially fatigue and loose stool, were described to lead to reduced ability to engage in social activities. Pain in the surgical area was described to be mostly present in the first weeks after discharge and dependent on activity level, amount of oral intake, flatulence or that the opioids had been reduced too quickly. There was a consistency in descriptions of symptoms between the patients and the healthcare professionals except for emotional wellbeing. The healthcare professional experienced that patients struggled with anxiety and sadness after surgery and a few of the interviewed patients mentioned it. Examples of quotes from the patients and the abstraction to symptoms to assess in Interaktor pancreas version are shown in Table 3.

**Table 3. Examples of quotes from patients following pancreaticoduodenectomy and the abstraction to symptoms to assess in Interaktor pancreas version.**

Quote	Symptom to assess
"Sometimes I want food but my stomach is crammed full."	Eating difficulties
"I can't manage to watch TV. I can't manage to read /.../. I can barely manage to remove the plate from the table."	Fatigue
"I need to go to the toilet as soon as I have eaten something and it just runs straight through me."	Loose stool
"I became a completely different person when I came home, and that's also difficult to accept, and then this depression comes. I fall apart and it's tough, it's really tough."	Depression
"At first I couldn't do anything because I had such pain. Not able to lift anything and such."	Pain

### 7.1.1.2 Self-care advice to include

Self-care advice and strategies to manage the experienced symptoms were described by both the patients and the healthcare professionals but to a varying degree. Most patients had at discharge lacked advice on how to manage symptoms, especially regarding the dosage and function of enzyme supplement to reduce loose stool and weight loss and how to manage pain and reduce pain medications. On the other hand, the healthcare professionals expressed that patients repeatedly get advice but also pointed out that the patients often forget or cannot absorb all the advice they were given while at the hospital. In the interviews several self-care advice and strategies were brought up like forcing oneself to eat at predetermined time points, eat smaller amounts of food but more often, letting someone else cook the meals, distraction by doing something fun and stimulating and exercise. Examples of quotes from the interviews with the patients and the abstraction to important areas of self-care advice to include in Interaktor pancreas version are shown in Table 4.

**Table 4. Examples of quotes from the interviews with patients following pancreaticoduodenectomy and the abstraction to important areas of self-care advice to include in Interaktor pancreas version.**

Quote	Self-care advice to include
"Mostly my wife has been cooking. It wouldn't have worked out for me if I'd had to cook the meals, feel nauseous and then eat the food."	Advice on eating
"I still haven't quite learnt about Creon a hundred percent. Sometimes I forget to take them (...). If you could only get some help on how much to eat. Someone said you could eat as much as you liked and someone said one pill was enough. There have been conflicting messages about it."	Advice on pancreatic enzyme supplements
"I didn't get any information about the pain medication before I went home. I stopped taking them when I got home because I thought I had recovered. But I had a lot of pain. I had been too optimistic. So I called and they said I had to continue taking them."	Advice on pain management
"I have been careful to be as mobile as possible and tried from the beginning to go out for short walks /.../. If I lay down I only get more and more tired."	Advice on fatigue

## 7.1.2 Development

### 7.1.2.1 Symptom assessment

The pancreas version of Interaktor was determined to contain twelve common symptoms and concerns important to assess in the target population based on the results in Study I. The included symptoms and concerns were: fever, eating difficulties, nausea, vomiting, loose stool, constipation, pain, dizziness, fatigue, sadness and worry, and problems with daily activities at home and outside the home.

### 7.1.2.2 The risk assessment model

The risk assessment model for alerts was created by the research group consisting of healthcare professionals with expertise in cancer and pancreatic surgery. The alerts were triggered in different ways depending on how the symptom was reported; either on level of occurrence, frequency or distress. Some alerts were triggered after one report and some after multiple consecutive reports (Table 5).

**Table 5. The risk assessment model for alerts in the version of Interaktor adapted for patients who have undergone pancreaticoduodenectomy.**

Symptom	Lowest rated as	Alert Triggered after...	Type of Alert
Fever/Chills	Occurrence "Yes"	One report	Red
Pain in abdomen and/or back	Frequency "Almost always"	One report	Red
Vomiting	Frequency "Almost always"	One report	Red
Dizziness	Frequency Almost always	One report	Red
Vomiting	Frequency "Sometimes"	2 consecutive days	Yellow
Dizziness	Frequency "Sometimes"	2 consecutive days	Yellow
Pain in abdomen and/or back	Frequency "Often"	2 consecutive days	Yellow
Loose stool	Frequency "Often"	3 consecutive days	Yellow
Constipation	Occurrence "Yes"	3 consecutive days	Yellow
Eating difficulties	Frequency "Often"	7 consecutive days	Yellow
Nausea	Frequency "Often"	7 consecutive days	Yellow
Fatigue	Distress "Rather much"	7 consecutive days	Yellow
Sadness/ depression/worry	Distress "Rather much"	7 consecutive days	Yellow
Problems performing daily activities at home	Distress "Rather much"	7 consecutive days	Yellow
Problems performing daily activities outside home	Distress "Rather much"	7 consecutive days	Yellow

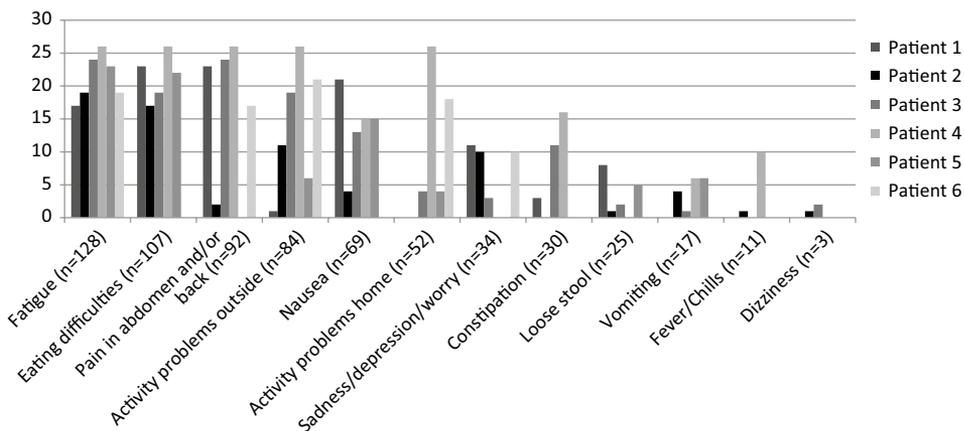
### 7.1.2.3 Self-care advice

Twenty-two areas of different self-care advice were included in the pancreas version. These were identified in Study I and through additional searches in the literature and guidelines. The advice was based on the latest evidence and refers to the reported symptoms, for example, advice on nutrition and physical activity, but also to other areas of importance such as advice on how to manage the surgical wound and recommendations on alcohol consumption.

## 7.2 Phase II – Assessing Feasibility of Interaktor pancreas version (Study II)

### 7.2.1 Logged data

Among the patients (n=6) who consented to test Interaktor pancreas version for four weeks, adherence to report symptoms daily was on average 84% (median 84%, range 68-93%). In total, the patients submitted 141 reports which included 652 symptoms, namely in mean 5 symptoms per day. In total, all symptoms included in the app were reported. Fatigue was reported by all patients and was the most commonly occurring symptom whereas dizziness was reported by two patients and the least occurring symptom (Fig. 5).

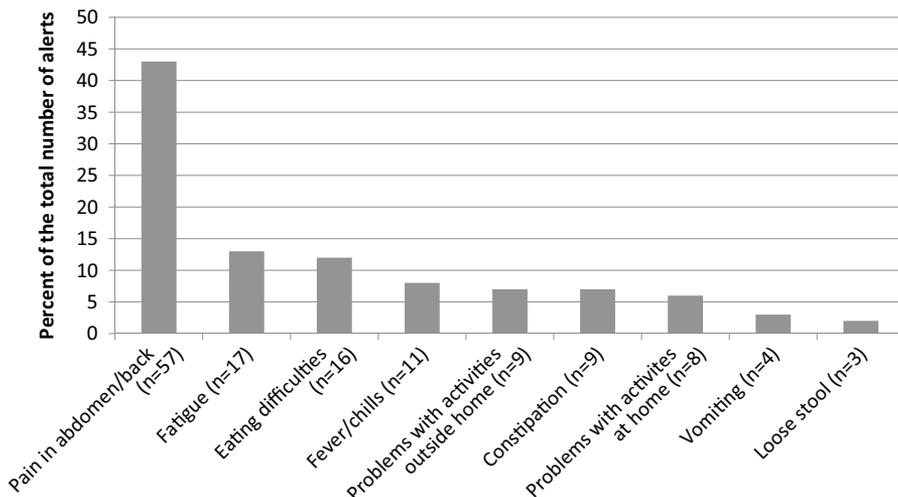


**Figure 5.** Number of symptoms reported by patients during the first four weeks after discharge following pancreaticoduodenectomy.

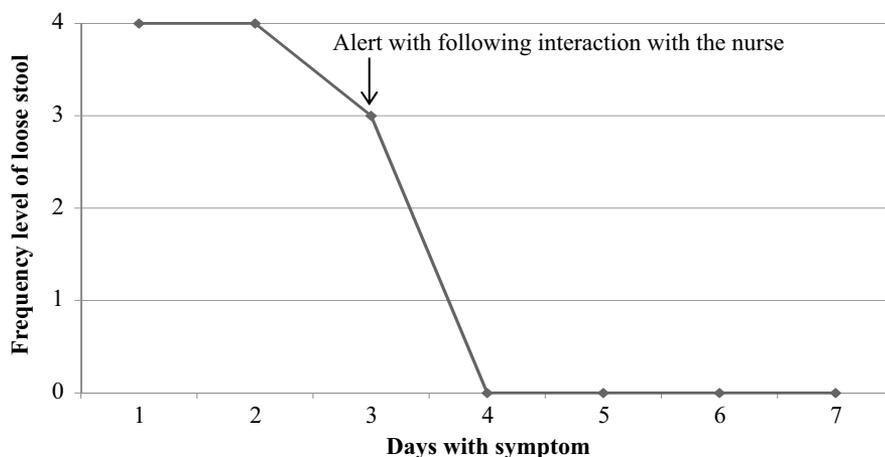
Of the 141 reports, 58 (41%) generated alerts and the total number of alerts was 134 and the range per patient was 0-78. The distribution between red and yellow alerts was 54% red and 46% yellow. The most common alert was related to pain in the abdomen and/or back (Fig. 6). Two of the patients generated alerts almost daily, mostly connected to the question about pain in the abdomen and/or back.

Of the 58 reports generating alerts, 35 (60%) resulted in no interaction with the nurse. The non-interactions were due to the fact that patients had chosen not to send an SMS (n = 30), because an SMS was not sent by mistake (n = 2), due to a system error (n = 1), or because the SMS was missed by the nurse (n = 2). The choice not to send an SMS was made by the two patients who triggered most of the alerts and were mostly in connection to alerts regarding pain. Interactions with patients were documented by the nurse in the web-interface and consisted of advice

and discussions about different symptoms or a re-direction to another healthcare professional. An example of the change of a patients reporting of a symptom's frequency after an interaction with a nurse following an alert is shown in Fig. 7.



**Figure 6.** Percentile distribution the number of alerts (n=134) triggered by patients during the first four weeks after discharge following pancreaticoduodenectomy.



**Figure 7.** Example of a patients report on the frequency of symptom loose stool. 0 = not occurring, 1 = occurs almost never, 2 = occurs sometimes, 3 = occurs often, 4 = occurs almost always. An alert was triggered after occurring often or almost always for three consecutive days. After being advised to increase the pancreatic enzyme supplements the symptom does not occur during the following days.

### **7.2.2 Experiences from patients**

The patients perceived the symptom questions as relevant and that they comprised all experienced symptoms. The structure of the questions regarding frequency and distress were mostly found to be sufficient but sometimes to include too few nuances. The app was described to be easy to use and navigate through. Some misunderstandings arose regarding the patient's choice not to be contacted by a nurse following an alert. For instance, one patient was unaware that he had chosen not to be contacted and therefore expected a call that did not happen. There were discrepancies in opinion about this component where some patients felt that there was not always need for contact while other patients felt that it was hard to decide by themselves when contact was needed. The patients felt reassured and cared for at home and thought that the app enable an easy way to come in contact with healthcare. Further, they had gotten support for symptom management either by reading the self-care advice or by getting support from the nurse or other health-care professionals following an alert.

### **7.2.3 Experience of the nurse**

The nurse expressed that Interaktor was valuable for the patients but found it difficult to support patients during the time they underwent chemotherapy because a nurse working at a surgical clinic is not normally an expert on the symptoms of oncological treatment. Also, the nurse felt insecure whether or not to call a patient if no SMS was received but the alert was visible in the web-interface.

### **7.2.4 Changes made before start of Phase III**

Based on the results that several of the alerts did not lead to an interaction with the nurse and that patients continued to report the alerting symptoms the component where patients could choose whether or not to send an alert was removed. Instead a free text section for patients to write messages was added. Further, the consecutive alert on pain was modified to be triggered after seven days instead of two and some of the questions were rephrased according to the patients' suggestions. Three additional questions were added for patients undergoing adjuvant chemotherapy and some advice was added and some was modified as to relate to chemotherapy. During chemotherapy all alerts were programmed to be triggered after one report, and none after several consecutive days, since patients have weekly contact with healthcare professionals during that time (see manuscript for Study IV for details).

## 7.3 Phase III – Evaluation of Interaktor pancreas version (Study III and IV)

### 7.3.1 Descriptive data including sense of coherence

The analysis of descriptive data and sense of coherence showed no statistically significant differences between the intervention group and the control group (Table 6).

**Table 6. Descriptive data and sense of coherence of study participants (n=59) in Phase III.**

Descriptive data	IG (n=26)	CG (n=33)	p
<b>Age, years</b>			
Mean (SD)	67 (8,7)	66 (8,8)	0.78 <sup>†</sup>
Median (range)	67 (51-82)	66 (47-82)	
<b>Sex, No. (%)</b>			
Female	9 (35)	13 (39)	0.79 <sup>‡</sup>
Male	17 (65)	20 (61)	
<b>Living situation, No. (%)</b>			
Married/living with partner	21 (81)	25 (76)	0.76 <sup>‡</sup>
Living alone	5 (19)	8 (24)	
<b>Highest education level, No. (%)</b>			
Junior compulsory	1 (4)	5 (15)	0.18 <sup>§</sup>
Senior high school	9 (35)	15 (45)	
Postgraduate or university	15 (58)	12 (36)	
Missing data	1 (4)	1 (3)	
<b>Histopathology, No. (%)</b>			
Pancreatic ductal adenocarcinoma	12 (46)	18 (55)	0.55 <sup>§</sup>
Periampullary cancer	12 (46)	12 (36)	
Invasive IPMN-cancer	2 (8)	1 (3)	
Invasive neuroendocrine carcinoma	0 (0)	2 (6)	
<b>Chemotherapy, No. (%)</b>			
Yes	22 (85)	22 (67)	0.14 <sup>§</sup>
No	4 (15)	11 (33)	
<b>Sense of coherence, mean (SD)</b>			
Before surgery	74.7 (8.5)	72.3 (12.5)	0.45 <sup>†</sup>
6 weeks after surgery	73.3 (12.5)	73.3 (11.8)	>0.99 <sup>†</sup>
6 months after surgery	75.3 (12.4)	73.2 (12.3)	0.54 <sup>†</sup>

IG = Intervention group, CG = Control group, IPMN = intraductal papillary mucinous neoplasm

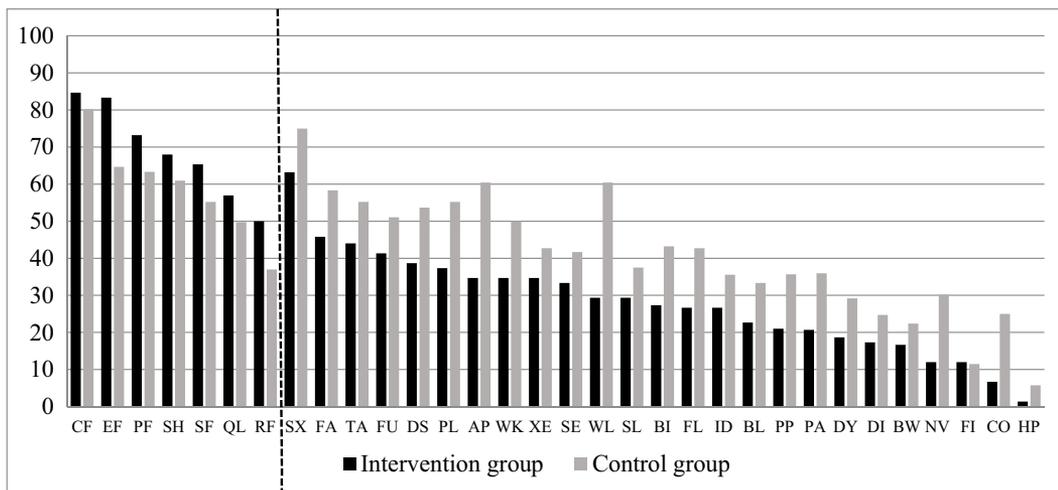
<sup>†</sup> 2-tailed *t*-test

<sup>‡</sup> Chi-square

<sup>§</sup> Fisher's exact test

### 7.3.2 Impact on health-related quality of life and self-care activity (Study III)

Before surgery, the intervention group rated significantly less worry about low weight with moderate effect size ( $p=0.039$ ,  $d=0.6$ ). At six weeks after surgery the intervention group overall rated higher levels of functioning and satisfaction and fewer symptoms than the control group when comparing mean values (Fig. 8).



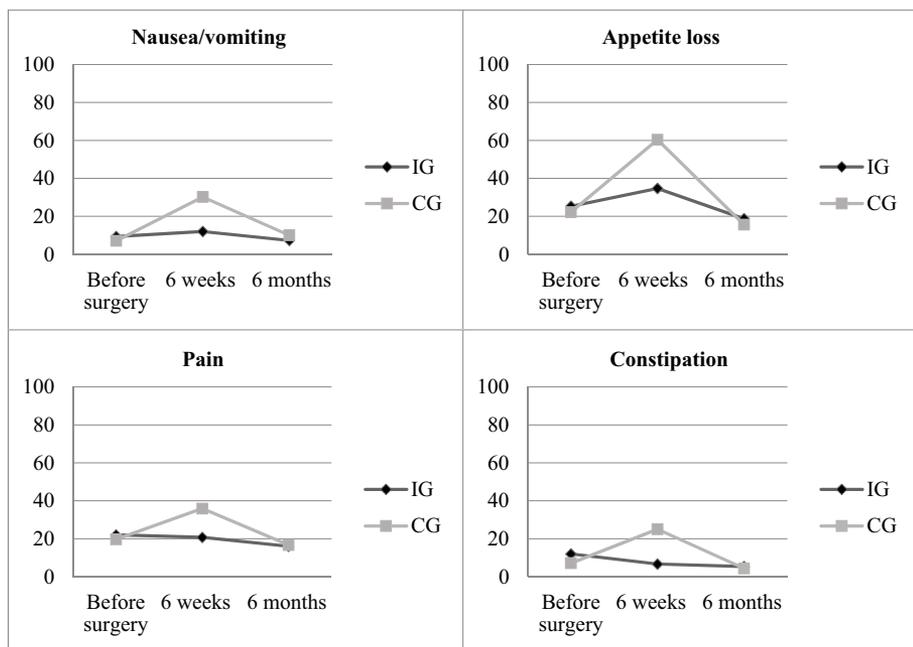
**Figure 8.** Mean values of EORTC QLQ-C30 and EORTC QLQ-PAN26 as reported by patients six weeks following pancreaticoduodenectomy. For outcomes left of the dotted line higher values represent better quality of life/functioning or more satisfaction. For outcomes right of the dotted line higher values represent more symptoms or worse functioning.

Cognitive functioning (CF), Emotional functioning (EF), Physical functioning (PF), Satisfaction with healthcare (SH), Social functioning (SF), Global health status (QL), Role functioning (RF), Sexuality (SX), Fatigue (FA), Taste/smell alterations (TA), Worry about future health (FU), Digestive symptoms (DS), Planning social activities (PL), Appetite loss (AP), Muscle weakness (WK), Xerostomia (XE), Side-effects (SE), Worry about low weight (WL), Insomnia (SL), Body image (BI), Flatulence (FL), Indigestion (ID), Bloating (BL), Pancreatic pain (PP), Pain (PA), Dyspnea (DY), Diarrhea (DI), Altered bowel habits (BW), Nausea/vomiting (NV), Financial difficulties (FI), Constipation (CO), Hepatic symptoms (HP).

Statistically significant differences also with moderate or high effect sizes were shown for emotional functioning ( $p=0.001$ ,  $d=0.9$ ), worry about low weight ( $p=0.001$ ,  $d=1.0$ ), constipation ( $p=0.003$ ,  $d=0.9$ ), nausea/vomiting ( $p=0.004$ ,  $d=0.9$ ), appetite loss ( $p=0.005$ ,  $d=0.8$ ), pancreatic pain ( $p=0.007$ ,  $d=0.8$ ), flatulence ( $p=0.035$ ,  $d=0.6$ ) and pain ( $p=0.047$ ,  $d=0.5$ ). Moderate effect size was shown for physical functioning ( $d=0.5$ ), fatigue ( $d=0.5$ ), digestive symptoms ( $d=0.5$ ), hepatic symptoms ( $d=0.5$ ), body image ( $d=0.5$ ), muscles weakness ( $d=0.5$ ) and planning social activities ( $d=0.5$ ).

At six months after surgery the intervention group rated significantly fewer hepatic symptoms ( $p=0.035$ ), less worry about low weight ( $p=0.037$ ) and a higher self-care activity rate ( $p=0.033$ ) all with a moderate effect size ( $d=0.6$ ).

Over time, the intervention group reported non-significant changes in 21 of the EORTC scales as compared to 8 for the control group. Examples of within-group changes over time are presented in Fig. 9. There were no statistically significant changes in ASA-A in any of the groups over time.



**Figure 9.** Within-group changes over time for symptoms in EORTC QLQ-C30 showing significant differences between groups at 6 weeks after surgery. Higher value reflects more symptoms and range 0-100. IG = Intervention group. CG = Control group.

In the multiple regression models, controlling for received chemotherapy and level of SOC six weeks after surgery, the intervention group still rated significantly higher level of emotional functioning ( $p < 0.001$ ) and less constipation ( $p = 0.001$ ), worry about low weight ( $p = 0.003$ ), nausea/vomiting ( $p = 0.008$ ), appetite loss ( $p = 0.009$ ), pancreatic pain ( $p = 0.009$ ), pain ( $p = 0.024$ ) and flatulence ( $p = 0.040$ ) six weeks after PD and fewer hepatic symptoms ( $p = 0.029$ ) and higher self-care activity level ( $p = 0.040$ ) six months after surgery.

### **7.3.3 Logged data from the app (Study III and IV)**

#### *7.3.3.1 Adherence to report as intended*

Patients who used the app adhered to report symptoms for in median 82% of the intended days (24-100%). Highest adherence was seen during the first four weeks after discharge when adherence was 95% in median (range 32-100%). Patients used the app for a median of 190 days (range 35-245 days). Reasons to cease reporting in advance were; own choice ( $n=1$ ), follow-up care transferred to a clinic not included in the study ( $n=3$ ) or death ( $n=1$ ).

#### *7.3.3.2 Reported symptoms*

During the first four weeks the patients reported occurrence of a total of 70.5 symptoms in median (range 8-157) and during that time fatigue, eating difficulties, pain and loose stool were the symptoms reported by most patients. During the whole study period the patients reported a total of 6320 symptoms (median 170 per patient, range 9-994) and on group level all symptoms were reported but not by each patient (Table 7). The follow-up questions four-point rating values were all used. Levels of frequency and distress of a symptom were mostly concordant except for nausea, vomiting and dizziness, where patients reported a higher distress level than frequency and the opposite for numbness in hands or feet (Table 7). Fatigue and pain were the most occurring symptoms and also reported by most patients (Table 7).

**Table 7. Occurrences, frequency, and distress of the symptoms as reported in the app by patients (n=26) following pancreaticoduodenectomy due to cancer.**

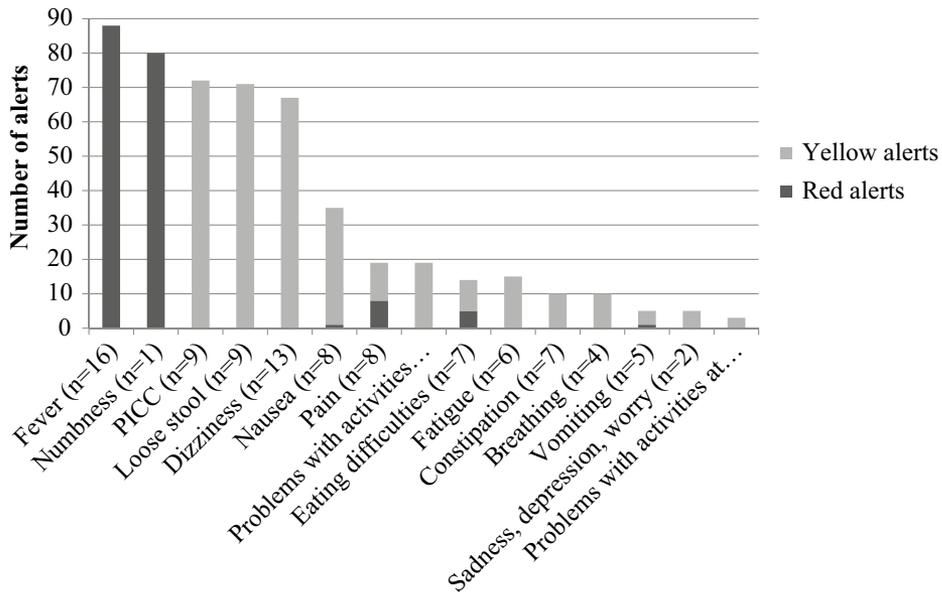
Symptoms (reported by number of patients)	Occurrence n=6320			Frequency Mean	Distress Mean
	n (%)	Median	Range		
Fatigue (n=24)	1445 (23)	35.5	3-198	2.4	2.3
Pain (n=23)	863 (14)	19	1-169	2.1	2.3
Problems performing activities outside home (n=21)	605 (9.6)	21	1-161	2.4	2.3
Nausea (n=21)	572 (9.1)	11	1-158	1.9	2.3
Eating difficulties (n=22)	535 (8.4)	13.5	2-160	2.4	2.5
Loose stool (n=24)	526 (8.3)	6	1-133	2.1	2.1
Problems performing activities at home (n=20)	518 (8.2)	12.5	1-127	N/A	2.3
Sadness, depression, worry (n=12)	386 (6.1)	14	3-169	2.3	2.3
Dizziness (n=15)	267 (4.2)	10	1-91	1.9	2.3
Numbness in hands or feet <sup>†</sup> (n=9)	204 (3.3)	2	1-85	2.2	1.8
Constipation (n=23)	132 (2.1)	4	1-28	N/A	2.2
Fever (n=16)	87 (1.4)	3	1-18	N/A	N/A
Swelling/pain/redness from SVP/PICC <sup>†</sup> (n=9)	69 (1.1)	3	1-49	N/A	N/A
Breathing difficulties <sup>†</sup> (n=7)	61 (1.0)	3	1-41	2.2	2.0
Vomiting (n=14)	50 (0.8)	2.5	1-11	1.4	2.5

N/A = not applicable, SVP = Subcutaneous vein port, PICC = peripheral induced central catheter

<sup>†</sup>Symptoms only reported during adjuvant chemotherapy

### 7.3.3.3 Alerts

During the first four weeks alerts were triggered 3 times in median per patient (range 0-16). The total number of alerts for the whole study period was 513 (median 9, range 0-87) and almost all patients (n=24) reported an alert. Of these alerts 36% were severe (red). The most common alert was fever which was also triggered by most patients (Fig. 10).



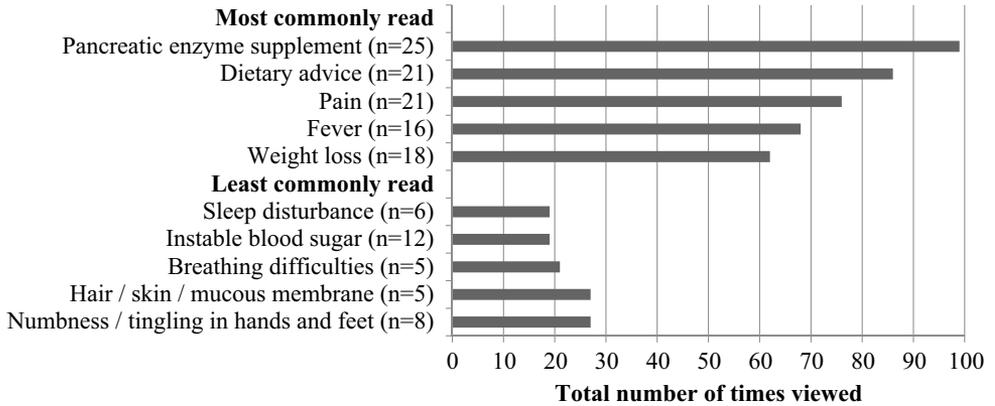
**Figure 10.** Distribution of the number of alerts (n=513) triggered in the app by patients (n=24) after discharge following pancreaticoduodenectomy due to cancer. n=number of patients who triggered the specific alert.

#### 7.3.3.4 Free text comments

The free text comment section to communicate with healthcare was used in total 302 times (median 7.5, range 0-90) and comments were written by most patients (n=24). Most comments were a description about a symptom which sometimes was followed by a wish for counselling or the text “You do not need to call me”. The patients also used the free text to document values for weight, blood glucose, blood pressure, and temperature or to inform on admission to hospital, going away on holiday, or need for prescriptions.

#### 7.3.3.5 Self-care advice

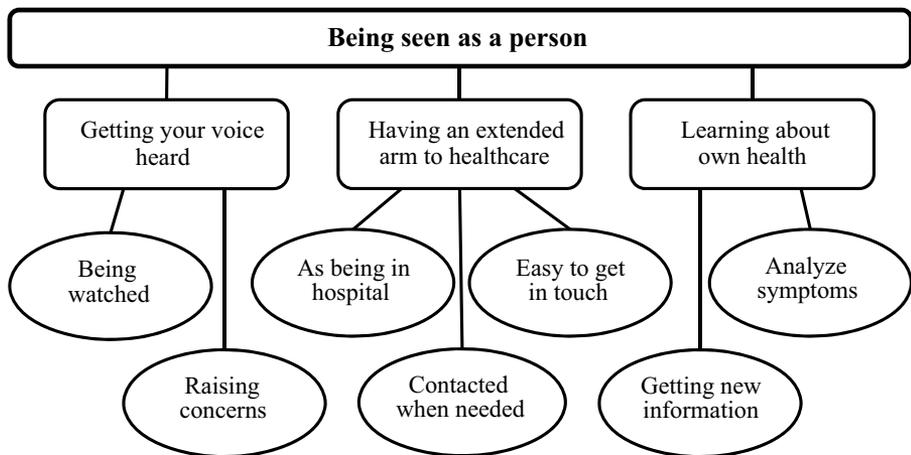
During the first four weeks self-care advice was viewed 13.5 times in median per patient (range 1-93) mostly regarding pancreatic enzyme supplements, dietary advice and pain. During the whole study period the patients had viewed self-care advice in total 1231 times (median 30.5, range 3-181). The most commonly and least commonly viewed self-care advice during the whole period is shown in Fig. 11.



**Figure 11.** The five most and least commonly viewed self-care advice and number of times viewed by patients using Interaktor after discharge following pancreaticoduodenectomy. *n* = number of patients viewing the specific advice.

### 7.3.4 Experiences of using the app (Study IV)

The overarching theme “Being seen as a person” with subthemes; “Getting your voice heard”, “Having an extended arm to healthcare” and “Learning about own health” were identified (Fig. 12).



**Figure 12.** Thematic map with overarching theme, subthemes and examples of codes from the transcribed interview text with patients (*n*=25) who used Interaktor following pancreaticoduodenectomy.

The patients expressed that since someone was watching how they were feeling they felt taken care of at home. In the dialogue with the nurse following an alert they could get individually adjusted advice and raise concerns important to them.

The patients described the app as a reassuring link to healthcare after discharge and using the app was a sort of follow-up that was otherwise lacking. Through the app they had a faster and easier way to get in touch with healthcare than they were used to. A wish that contact should always be initiated when needed was raised, even in nights and weekends. Some patients wanted to decide for themselves if a nurse should contact them following an alert since they sometimes had been contacted when they did not have any need of a contact. Other patients found it reassuring that someone else was responsible to make the decision when contact was needed and knowing that if someone did not call everything was satisfactory.

Being asked about symptoms daily or watch symptoms change over time supported the patients to reflect and analyze how they felt. Having access to self-care advice provided new knowledge on symptoms and how to manage them. The patients expressed that having easy access to the advice was important, because information is easy to forget or that they had not been given sufficient information before discharge or had not been able to absorb information at that time. Some patients expressed a need for individualized advice as a complement to the app.

## **8 DISCUSSION**

### **8.1 Discussion of results**

The main findings in this thesis are that the Interaktor app decreased symptoms after PD for patients with pancreatic or periampullary cancer. Patients using the app had high adherence to report symptoms daily. The patients described the app to have relevant content and being valuable in order to have their voices heard, to have an extended arm to healthcare and to learn about their own health.

#### **8.1.1 Clinical importance of the app for patients with pancreatic cancer**

Clinically important decreases in symptoms for the patients who used the app were seen for a majority of the evaluated symptoms. Previous conclusions have been drawn that 10-points EORTC-QLQ-C30 score changes represent changes in supportive care needs for patients with cancer (Snyder et al., 2015). These conclusions can be used when comparing the values of patients using the app to patients not using the app. For most values six weeks after surgery, patients using the app reported > 10-points higher scores in mean on the function scales and < 10-points lower scores in mean on the symptom scales compared to the control group. Further, thresholds for clinical importance of the EORTC QLQ-C30 scale have been determined to be; >83 for physical functioning, >70 for emotional functioning, <39 for fatigue and <25 for pain (Giesinger et al., 2016). Patients not using the app did not reach any of the thresholds six weeks after surgery while patients using the app did so for emotional functioning and pain. Interestingly, the patients using the app also reported values on emotional functioning, cognitive functioning, pain, dyspnea and constipation that are comparable to reports from age and sex matched persons from the Swedish population (Derogar, van der Schaaf, & Lagergren, 2012). This shows the app's high clinical relevance and that the app can respond to supportive care needs for patients with pancreatic cancer.

There was a statistically significant difference between the groups six months after surgery where patients using the app reported higher level of self-care activity. This can be a result of the long-term easy access to self-care advice and the possibility to discuss alerting symptoms with a nurse and also reflect patients' descriptions of how they had learned about own health. Cut points for a clinical important level of ASA-A have previously been determined to be 95 points on the 24-120 point scale (Söderhamn et al., 1996b). The intervention group reached that cut point on all time points, while the control group did not. However, it is questionable how clinical important the difference is. Previously a value of > 92 have been described as a high level of self-care activity (Dale, Söderhamn, & Söderhamn, 2012), indicating that both the intervention group and the control group had high

levels of self-care activity. Further, using conclusions for quality of life scores where a change in 10 % is considered clinically relevant (Osoba et al., 2005), the difference between the groups is not clinically important.

The app's impact on symptoms was greatest six weeks after surgery. This coincides with the time when symptoms are most likely to be focused on, since previous research has shown the first weeks after surgery to be the time when patients with pancreatic or periampullary cancer experience most symptoms (Rees et al., 2013). This was confirmed by the amount of symptoms reported in the app during the first month compared to the following months. Statistically significant decrease in symptoms for the patients who used the app was shown for symptoms of pain and for gastrointestinal symptoms such as low weight, nausea/vomiting, appetite loss, constipation, and flatulence. One of the explanations for this is that advices on pain, weight loss and diet were among the most read self-care advice by the patients. Surprisingly, there were no statistically significant differences between the groups in the symptom diarrhea, known to be dependent of the amount of pancreatic enzymes, even though the advice on pancreatic enzyme supplements was the mostly read by the patients using the app. This may reflect that the control group in this study was well informed about management of diarrhea. Also, diarrhea was one of the least experienced symptoms six weeks after surgery in both groups. Patients who used the app also reported higher emotional functioning six weeks after surgery, which includes questions on feeling tense, worried, irritable and depressed. This is consistent with patients using Interaktor during radiotherapy for prostate cancer (Sundberg et al., 2017). The impact on these concerns can be explained since the patients felt reassured and taken care of at home and could get in contact with healthcare when needed. Having symptoms monitored while at home and having an easy way to contact nurses have been reported to reduce anxiety for patients with cancer (Maguire et al., 2015) and for patients following surgery (Dahlberg, Jaensson, Nilsson, Eriksson, & Odencrants, 2018).

Interestingly the level of SOC reported by the patients did not influence how they rated their symptoms which indicate a strong support for the app's effect in this group of patients with pancreatic cancer. This is slightly different from what Sundberg et al. (2017) found in patients with prostate cancer using the Interaktor app, where patients with higher level of SOC mostly rated fewer symptoms, regardless if they had used the app or not.

To reduce symptoms the first weeks after surgery, as done for patients with pancreatic cancer using the app, may play an important role to make patients be in as good as possible physical and mental condition for adjuvant chemotherapy. Receiving and staying on adjuvant chemotherapy is vital for patients with pancreatic cancer for increasing survival (Neoptolemos et al., 2004). Hence, it is important to continue offering patients the use of the Interaktor app during adjuvant

chemotherapy. Previous findings have shown that clinical use of patient-reported symptoms makes patients with cancer stay longer on chemotherapy (Basch et al., 2016). Data on compliance to adjuvant chemotherapy were not collected in this thesis. However, previous data from patients at the same hospital undergoing chemotherapy showed that patients' deterioration in many cases caused late cancellations (Fuentes & Frödin, 2015). The authors suggested that the routine monitoring patients' statuses can be helpful for reducing such late cancellations. Further, patients with colorectal cancer have described that to regularly report side-effects of chemotherapy, as a source to decision-making of further treatment, is a way to participate in care (Drott, Vilhelmsson, Kjellgren, & Berterö, 2016).

### **8.1.2 Patients' interest in using the app**

For interventions to be meaningful and relevant in clinical care they need to be co-created with patients and healthcare professionals (Rose & Bezjak, 2009). The involvement of patients and healthcare professionals in Phase I was successful since the app later on was perceived to have relevant content with few modification suggestions later on. Also, the logged data showed that all symptoms included in the app were reported and all self-care advice was viewed.

The patients high adherence to report symptoms daily as intended are comparable to results from patients undergoing radiotherapy for prostate cancer using Interaktor (Langius-Eklöf et al., 2017). Notable is that some patients using the app following PD had 100% adherence, meaning that they used the app to report symptoms every day for six months. This confirms that the app was valuable for patients to use. In general, high adherence has been reported for patients using different kinds of mHealth to support needs related to cancer, independently of the length of the reporting period (Richards et al., 2018). The high adherence to using the app, even by unexperienced smartphone users, demonstrates that there are no reasons not to implement ICT tools based on the argument that patients can have difficulties managing technology. On the contrary, smartphone use is increasing and now 90 % of Swedish households have access to a smartphone (The Swedish Internet Foundation, 2018). During this thesis project, patients have been able to borrow a smartphone and in Phase III only two patients needed to do so. It has been reported to be essential to allow several training opportunities for patients with less technical knowledge, so they can be comfortable in using new systems (Seto et al., 2012). However, patients using Interaktor only got demonstrations of the app and practiced reporting at one supervised occasion. This is a strength, since it reflects the reality. When implementing new systems in clinical care, there is seldom time for multiple supervised training sessions. Still, only practicing once could have affected the drop-out rate and how patients used different components in the app.

In a Swedish sample of patients with cancer, people who were younger, had a partner, and had a higher level of education were more likely to use the Internet to search for health information (Mattsson, Olsson, Johansson, & Carlsson, 2017). Age-wise this is comparable to patients interested in using the Interaktor app, since patients who consented were younger than those who declined. Further, the level of education reported by patients using the app are higher than the Swedish population with the same age range (Statistics Sweden, 2018). However, these differences were seen in the control group as well. The only conclusion drawn from patients who declined to participate is that more women than men declined to use the app. This is in contrast to previous findings where gender of patients with cancer had no association with attitudes towards using eHealth (Jansen et al., 2015). Further, amongst the public several studies have found that women are more likely to use the Internet for health purposes than men (Andreassen et al., 2007; Carroll et al., 2017; Nölke, Mensing, Krämer, & Hornberg, 2015).

Some barriers of using mHealth to enhance recovery after surgery have been reported by the public, such as concerns of the security and protection of personal information along with failure of technology (Abelson et al., 2017). Such barriers were not brought up by the patients using Interaktor or by patients who declined to do so.

### **8.1.3 The app as an enabler to person-centered care**

The findings in this thesis show that the Interaktor app can enable person-centered care, supported by Leplege and colleges (2007) views that person-centered care means to involve patients as active partners in care who interacts with healthcare professionals. Letting patients report occurrence, frequency, and distress of their symptoms to a nurse was a way to lay the ground for the patients' narrative. A narrative described by Ekman and colleges (2011) as the starting point for the partnership between patients and healthcare professionals. By being called following an alert or by sending a message to the nurse through the free-text component, the patients could describe and discuss their concerns further. To what extent the following conversation between the patient and the nurse was person-centered are not known. However, the patients described how the app enabled them to get their voices heard and to raise concerns important to them.

The findings in this thesis shows that patients monitored at a distance can feel safe and cared for, regardless if they were called by a nurse rarely or often, meaning that the reporting and monitoring itself was valuable. This contributes to new knowledge on person-centered care since most person-centered care interventions have been targeting patients in primary care or hospital setting, and the patients narrative have mostly been sought through patient interviews (Olsson, Jakobsson

Ung, Swedberg, & Ekman, 2013). Also, previous empirical studies have found that for patients to be able to participate in own care the relationship with the nurse is fundamental (Angel & Frederiksen, 2015). In contrast, the relationship with the nurse did not come up as essential in the interviews with patients using the app. Instead, the app itself and that “someone” was monitoring them was described as a way to have an extended arm to healthcare. This is useful knowledge in times where continuity among nurses, and time to build relationships, is not always achieved.

That the patients using the app felt that they had an extended arm to healthcare can be one of the explanations for the impact on symptoms six weeks after surgery. During the first weeks patients in the control group did not have continuous contact with healthcare except for having a name and number to a contact nurse. The patients using the app had, above that, timely interactions with their nurse in case of alerting symptoms. This could also explain why there were few differences in symptoms between the groups six months after surgery. During that time, most patients in both groups had weekly contact with nurses since they underwent adjuvant chemotherapy. During those sessions, concerns and symptom management could be discussed. However, in a sample of patients with prostate cancer who daily meet nurses the findings still showed that the app was effective to reduce symptoms at the end of treatment (Sundberg et al., 2017). Also, when analyzing symptom changes over time in this thesis, the patients who used the app were more stable in symptoms compared to patients who did not use the app. This indicates that using the app is valuable also for patients with regular visits to hospital and contact with nurses.

For patients to participate in care, shared knowledge and information between patients and healthcare professionals have been found to be essential (Angel & Frederiksen, 2015; Ekman et al., 2011; Larnebratt et al., 2019). Owing to those conclusions the app enables patients to participate in care since they expressed that they had learned about own health by conversations with nurses, analyzing their own reports and from reading the self-care advice. When interviewing patients in the development phases, about self-care advice to manage symptoms, many experienced a lack of advice from healthcare at discharge from the hospital. This confirms previous finding for this patient group (Andersson et al., 2012; Carey et al., 2013) and shows the need to support symptom management. By including self-care advice in the Interaktor app, patients had continuous access to advice to manage their symptoms. Having this continuous access to self-care advice was described as important since information is easy to forget or cannot always be absorbed while at hospital. However, the logged data showed large variety of how often self-care advice was read, showing that this was not equally important for patients.

Many of the descriptions from the interviews with patients using the pancreas version of Interaktor are consistent with findings in evaluations of other versions of Interaktor (Göransson et al., 2018; Hälleberg Nyman et al., 2017) and of similar ICT tools where patients report symptoms, are contacted after alerting of symptoms and where they can read self-care advice (Maguire et al., 2015; Weaver et al., 2014). Patients interviewed in the aforementioned studies described how they participated in their own care by being able to discuss symptoms with nurses, felt in control of the situation, learned about their own health, and expressed that it was reassuring to have a link to healthcare and not being alone (Göransson et al., 2018; Hälleberg Nyman et al., 2017; Maguire et al., 2015; Weaver et al., 2014). Feeling reassured by the link to healthcare and being more in control over the recovery process was also described by patients who reported symptoms at home after day surgery and could choose if they wanted to be contacted by a nurse (Dahlberg et al., 2018).

It is important to consider the prominent differences in opinions between the patients who used the app regarding who should be responsible for initiating contact. Two different approaches have been tried in the studies included in this thesis, with conflicting findings. While some patients wanted to be the ones initiating contact, others felt reassured in knowing that the decision was someone else's. However, one of the important findings is that these patients with pancreatic cancer got help with their symptoms when the nurse contacted them following an alert. Patients using a similar app have expressed that when the nurse contacted them, and not vice versa, they felt less "bothersome" (Weaver et al., 2007). Further, patients with different cancer diagnosis have described that they find it hard to by themselves estimate the seriousness of their symptoms (Jansen et al., 2015). Considering these results, it does not seem responsible to put the responsibility for contacting healthcare on patients with such severe symptoms and poor prognosis as patients with pancreatic cancer are known to have. Therefore, in future development of Interaktor and similar tools, we suggest that the risk assessment model should continue to trigger alerts to nurses which they respond to. This could be extended to include an easy way for patients to communicate if they do not wish to be contacted and why.

The findings show that the patients used the app's components in different ways, which reflect the app's intent to offer a support system that address patients' different supportive care needs. This was also evident since patients made personal adjustments when they made arrangements with their nurse over symptoms which did not require a call, adjusted their reports when they felt no need for a call, or used the free text to leave a comment that a call was not necessary. The reports can lay the ground for the care after discharge making it person-centered according to the patients' wishes and needs. Care can then be given in a more timely manner instead of solemnly follow a disease-specific schedule.

## **8.2 Discussion of methods**

### **8.2.1 Design and sample**

Using a quasi-experimental design with a historical control group when evaluating the intervention has disadvantages since treatment and clinical care can change over time. Further, non-randomization can create samples not equal in baseline data (Polit & Beck, 2012). However, throughout the whole study period neither standard treatment regime nor clinical care routines, such as access to healthcare professionals, were changed. This was assured by close contact with the participating clinics. Further, the two groups did not differ in descriptive data before surgery. However, the decline and dropout rate was not comparable between the groups (10 % for the control group and 37 % for the intervention group) and more women than men declined to use the app. While this affects the generalization of the findings, it also gives insight on which patients were interested in using mHealth following PD. There were a small number of patients included in the evaluation phase. However, the descriptive data shows a variety representative for the patient group, and in terms of age the sample is comparable to previous descriptions of patients at the same clinic (Noorani, Rangelova, Del Chiaro, Lundell, & Ansorge, 2016). Despite the small sample, a moderate to high effect size was seen for most outcome variables. The limitation with the design and sample size is important to consider and affects the possibility to draw general conclusions of the app's favorable outcomes for patients undergoing pancreaticoduodenectomy. Still, for several results in this thesis, other studies report similar findings which strengthen our conclusions.

It has been advantageous to use the MRC framework (Craig et al., 2008) for achieving the positive results. Involving patients and healthcare professionals when creating the content for Interaktor resulted in an app that was perceived as relevant and sufficient by the patients who later on used it. By performing a small-scale feasibility test we gained insights on who should monitor reports, which necessary adjustment of questions and alerts that needed to be made, and an estimated inclusion time could be calculated. However, it is important to keep in mind that this thesis does not include all phases of the framework and evaluation of costs, healthcare visits, and implementation is yet to be completed.

### **8.2.2 Questionnaires**

One advantage when evaluating the app's impact on symptoms is the use of well-validated and reliable instruments. The only EORTC subscale showing low internal consistency and low inter-item correlation were hepatic symptoms measured six weeks after PD. Similar results have been found in a recent psychometric analysis of EORTC QLQ-PAN26, concluding that the hepatic subscale has poor internal consistency in postoperative patients (Eaton et al., 2017). Looking at the

data in the sample included in the thesis, the low internal consistency was due to little variation between patients' values and overall low reported values by patients, meaning that most patients did not experience the symptoms included in the subscale. Therefore, the low internal consistency of the scale did not affect the interpretation of the data.

The ASA-A instrument has not been used previously in a sample of patients with pancreatic or periampullary cancer. However, sum scores and analysis of internal consistency is comparable to previous validation of the instrument in adult patients with chronic diseases managing self-care at home (Fex et al., 2012; Sousa, Zauszniewski, Zeller, & Neese, 2008). Owing to the comparable results, the ASA-A instrument is a suitable measurement to evaluate self-care activity in patients following PD due to cancer.

The SOC-13 scale has not been used previously in a sample of patients with pancreatic or periampullary cancer. Consistent with previous findings, the levels of SOC was stable over time (Eriksson & Lindström, 2005; Lindblad et al., 2016). Further, the mean levels of SOC are comparable to means of patients with prostate cancer using Interaktor during radiotherapy (Sundberg et al., 2017). This shows that the SOC-13 scale is a suitable measurement of sense of coherence in this patient group.

Missing data from the questionnaires were handled according to the instruments recommendations. The amount of missing data within a questionnaire was small and considered to be missing at random. Therefore, they were not believed to affect the results of the between-group analysis at the different time points (Jakobsen, Gluud, Wetterslev, & Winkel, 2017). The only answers considered not to be missing at random were for questions included in the subscale sexual function, since patients often left comments instead of values as a response on those questions. Left out values for sexual function have been reported previously (Eaton et al., 2017) showing that this is not fully valid questions for this patient group. There were some missing questionnaires which are not believed to affect the between-group analysis at the different time point. However, the amount of missing ASA-A questionnaires can affect the within-group analysis since the missing values for the ANOVA exceeded 5% (Jakobsen et al., 2017). Therefore, findings of the Interaktor app's impact on especially self-care activity over time should be confirmed in another study.

### **8.2.3 Logged data**

A weakness in the feasibility test is that data on how often patients had viewed self-care advice were not logged. However, this was logged in the following evaluation. A consistent weakness is that data on how often patients viewed the

historical graphs was not logged, which would have been interesting to analyze. However, conclusion regarding use of self-care advice and historical graphs can be made from the interviews with patients.

#### **8.2.4 Interviews**

To establish trustworthiness, the well-known and classic criterion *credibility*, *dependability*, *confirmability* and *transferability* originated by Lincoln and Guba (1985) were considered. To further ensure trustworthiness for the thematic analysis Braun and Clarke (2006) 15-point checklist of criteria was followed.

A potential weakness when creating the content for the app is that no medical social worker was interviewed, which might have affected the results especially self-care advice concerning emotional well-being to be included in the app. Healthcare professionals in contact with the patient group during adjuvant chemotherapy were not interviewed either. However, five of the interviewed patients had completed or were undergoing chemotherapy treatment at the time of the interview and could give their views on symptoms and self-care strategies during that time. Further, when modifying questions and self-care advice in the app for patients undergoing chemotherapy before start of Phase III, care programs and patient information were scrutinized.

All participating patients chose the location of the interview. Some preferred to be interviewed at the hospital but most were interviewed in their own homes. This can affect dependability since the interview situations were not the same. However, dependability was ensured by using study specific interview guides.

The interview with the nurse who participated during the feasibility test was not audio recorded and the analyses were made according to the notes taken during the interview. This is a weakness, since it affects confirmability of the findings. Also, the data was not rich enough for creating categories or getting a deep understanding of the nurse's experiences of caring for patients using an interactive app. However, for the purpose of feasibility testing, the findings were considered to be enough to make necessary adjustments of the app before start of Phase III.

Not all interviews in Phase III reached the rich descriptions hoped for, despite the use of probing questions (Patton, 2015). This can be due to lacks in the interview guide and to a somewhat inexperienced interviewer. However, as many as 25 patients were interviewed and several patients are considered to have given descriptions rich enough to provide valuable findings.

## 9 FUTURE RESEARCH

This thesis does not include all phases in the MRC framework. Full evaluation of effects and cost-effectiveness using an RCT and subsequent implementation studies are yet to be completed. The findings in Study III can be used to calculate sample size for such a RCT. However, to perform a full scale RCT would be time consuming or require a multicenter design. Meanwhile, the high adherence to report symptoms and the findings from the interviews shows that an interactive app like Interaktor is something that patients are interested in, and the question is how much more evidence is needed before implementation? It may not be ethical to randomize patients who are interested in using mHealth to be involved in care to a control group, with the current standard clinical care regime, when we know from the results in this study that using the app was highly appreciated and valuable.

Instead of further evaluation of the pancreas version of Interaktor in an RCT, efforts should be made to study the implementation of the app in clinical practice. For instance by letting the reported symptoms form the basis of follow-up visits, both in terms of when in time visits are best held and what they should concern. Also, the reported symptoms could advice on further adjuvant chemotherapy treatment. For this to be feasible, the reports would ideally be transmitted directly to the patients' medical records so that all involved healthcare professionals have access to the data.

Further, it would be interesting to find out more about how patients who are not interested in using mHealth would like to participate in own care when they are discharged. The ideal would be to offer patients different solutions based on their own wishes and then study the effects of these interventions.

## 10 CONCLUSIONS

- Patients can experience fewer symptoms after discharge following pancreaticoduodenectomy if they regularly reports relevant symptoms and concerns via an app to their contact nurse and get support to manage these symptoms.
- The impact on symptoms was highly clinically relevant, indicating that the app responds to supportive care needs for patients with pancreatic cancer.
- To let patients report symptoms or write messages to nurses can be a way to enable the patients narrative, and thereby form a partnership necessary to create care planned according to patients' wishes and needs, and not only by predefined disease-specific standard care schedules.
- Monitoring patients at a distance and offering them an extended arm to healthcare can make them feel reassured and taken cared of at home.
- To offer a system where the nurse is responsible to contact the patient for alerting symptoms, and not vice versa, is effective to achieve timely symptom management.
- Patients can learn about their own health by having easy access to self-care advice and by analyzing their daily symptoms.
- To offer an app with multiple components enables patients to use the app according to their individual needs.
- To co-create the content in interventions together with patients and health-care professionals is advantageously to get a relevant and valuable content.
- Not all patients are interested in using an app like Interaktor. However, patients who are interested have high adherence and find it valuable and easy to use.

# 11 SVENSK SAMMANFATTNING (SUMMERY IN SWEDISH)

## Bakgrund

Patienter med pankreas- eller periampullär cancer har dålig prognos även efter kurativt syftande kirurgi. Den vanligaste operationen är pankreatikoduodenektomi som ofta resulterar i svåra symtom och försämrad livskvalitet under lång tid efteråt. Patienterna har ofta otillräcklig kunskap och stöd för att kunna hantera sina symtom. För att möta patienters behov behövs en mer personcentrerad vård som utgår från varje patients behov och för detta krävs ett partnerskap mellan patienter och vårdpersonal. Rutinmässig insamling och hantering av symtom med stöd av mHälso-verktyg har visat sig kunna förbättra hälsorelaterad livskvalitet och minska symtom för patienter med cancer.

## Syfte

Att utvärdera om insamling och hantering av patientrapporterade utfallsmått i klinisk vård, med stöd av en interaktiv app (Interaktor), kan främja personcentrerad vård och förbättra utfall för patienter som genomgått pankreatikoduodenektomi p.g.a. cancer.

## Interaktor

Genom Interaktor rapporterar patienten symptom till sin kontaktsjuksköterska genom att svara på frågor om olika symptoms förekomst, frekvens och besvärsgard. Vid alarmerande symptom ringer kontaktsjuksköterskan upp patienten för att ge råd eller annat stöd. I appen kan patienten även se grafer över sina rapporterade symptom samt läsa egenvårdsråd för symptomhantering.

## Metod

Ett ramverk för komplexa interventioner, utarbetat av Medicinska Forskningsrådet i Storbritannien, användes för att utveckla och utvärdera appen. Detta gjordes genom tre faser. I **Fas I** utvecklades innehållet i appen genom intervjuer med patienter (n=14) och vårdpersonal (n= 10). I **Fas II** gjordes ett genomförbarhetstest då patienter (n=6) använde appen under en månad. I **Fas III** utvärderades appen genom att analysera dess påverkan på symptom och egenvårdsaktivitet hos patienter (n=26) som använt appen under sex månader jämfört med en historisk kontrollgrupp av patienter (n=33) som inte använt appen, genom analys av patienters (n=26) loggad data i appen och genom intervjuer med patienter (n=25) som använt appen.

## Resultat

Resultaten i **Fas I** visade att patienter efter operationen ofta upplevde ätsvårigheter, tarmbesvär, trötthet, smärta samt oro. Patienterna upplevde brister i informationen och råd om framför allt hantering av läkemedel med konstgjort bukspott samt nedtrappning av smärtlindring. Vårdpersonalen beskrev att de ofta gav patienterna råd men att patienterna ofta hade svårt att ta till sig all information som gavs. Resultaten bidrog till kunskap om vilka symtom som är viktiga att bedöma närmsta månaderna efter pankreatikoduodenektomi och några egenvårdsråd och strategier för att hantera dessa symtom. Detta formade sedan innehållet i appen.

Resultaten i **Fas II** visade god genomförbarhet och att appen hade relevant innehåll. Patienterna kände sig trygga och omhändertagna i hemmet och fick stöd att hantera sina symtom. Efter att några frågor och larm i appen justerats startades nästa fas.

Resultaten i **Fas III** visade att patienter som använde appen upplevde färre symtom och hade högre egenvårdsaktivitet efter pankreatikoduodenektomi jämfört med kontrollgruppen som inte använt appen. Patienterna som använde appen hade hög följsamhet till att rapportera symtom och kände att de genom appen fick sin röst hörd, att de hade en förlängd arm till sjukvården och att de lärde sig om sin egen hälsa.

## Slutsats

Avhandlingen visar en interaktiv app som Interaktor kan stödja patienter med svåra symtom och dålig prognos. Att monitorera patienter när de befinner sig i hemmet kan få dem att känna sig trygga och omhändertagna. Patienter kan lära sig om sin egen hälsa genom att ha enkel tillgång till egenvårdsråd och genom att analysera sina dagliga symtom. Personcentrerad vård kan främjas genom att göra patienter till aktiva partners i vården och genom att i rätt tid identifiera symtom som är viktiga för dem. Interaktor kan bidra till att utveckla vården till att vara anpassad till patienters individuella behov och inte enbart följa ett förutbestämt sjukdomsspecifikt vårdprogram. Alla patienter är inte intresserade av att använda mHälsa men de som är det har hög följsamhet och tycker det är värdefullt och enkelt att använda.

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