Aspects of uptake, use and effectiveness of eHealth interventions for self-management support and patient-provider communication

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Summary

Background

The prevalence and burden of chronic diseases, including cancer, are escalating worldwide. New models of care are needed to combat this rising challenge. A growing body of evidence supports the effectiveness of eHealth interventions in providing self-management support and enabling online patient-provider communication. However, a number of barriers to achieve the full benefits of what eHealth can offer have been reported.

Aims

The main objective of this doctoral dissertation was to address gaps identified in the literature related to the uptake, use and effectiveness of eHealth interventions, especially: 1) the benefits and barriers to maintaining the use of eHealth interventions in clinical practice, as experienced by health care providers, 2) the need to better understand user characteristics and use patterns of patients who are offered eHealth interventions, and 3) the need to better understand which components can contribute to the effect of eHealth interventions. These gaps were addressed from different perspectives through three different studies. Study I (related to eHealth *uptake*) explored nurses' experiences of benefits of and barriers to maintaining the use of an interactive tailored patient assessment tool, called Choice, in cancer care one year after implementation. Study II (related to eHealth *use*) explored user characteristics and use patterns associated with the use of different components of a web-based self-management support system, called WebChoice, for patients with cancer. Study III (related to eHealth *effectiveness*) tested and compared in a randomized controlled trial (RCT) the effects of (a) a stand-alone secure e-mail service, (b) the secure e-mail service with additional features of WebChoice, a multi component system, and (c) usual care on: symptom distress, anxiety, depression, (primary outcomes), and self-efficacy (secondary outcome) after six month of system access.

Methods

This dissertation used a multi-method approach, employing both qualitative and quantitative methods that included interviews, secondary analyses of longitudinal data and a RCT. Study I had a qualitative design, in which 20 nurses participated in focus group

discussions about their experiences of using Choice in regular care. Analyses were performed using content analysis. Study II used secondary analysis of user characteristics and use patterns of 162 patients with breast or prostate cancer who had 12 months access to WebChoice in a previous RCT. Analyses were performed using logistic regression and latent class analysis. Finally, study III entailed a three-group randomized controlled trial in which 167 breast cancer patients recruited from three hospitals in Norway were randomized to a nurse-administered secure e-mail service, or to the Web-based self-management support system WebChoice (which included the secure e-mail service) or to usual care. Analyses of primary and secondary study outcomes were performed using linear mixed models.

Results

In study I, which addressed the nurses' perspectives about barriers and benefits related to the *uptake* of the interactive tailored patient assessment and communication tool Choice in regular care, three major themes important to maintaining use of Choice, were identified from transcripts of interviews with nurses. Choice was perceived as (1) facilitating shared understanding between patients and clinicians and facilitating patients' engagement in their own care; 2) enhancing the patient's own strengths; 3) yet also presenting new challenges for the nurses, such as organizational challenges, the need for communication training and ethical challenges (paper I).

In study II, designed to improve the understanding of user characteristics and factors associated with the *use* of different eHealth components, high level of computer experience and no additional illnesses besides cancer increased the overall probability for patients with breast or prostate cancer to use the WebChoice intervention. Men with prostate cancer and women with breast cancer who had low scores on social support, accompanied by high levels of symptom distress and high levels of depression, were more likely to use the e-mail component. For men, these characteristics were also associated with high use of the self-management advice component (paper II).

Finally, in the randomized clinical trial in study III, focusing on *effectiveness*, the group who had access to all features in WebChoice reported significantly lower scores of symptom distress, anxiety and depression than the usual care group. About 40% of those with access to sending secure e-mails used this opportunity. The group with access to the secure e-mail only

reported significantly lower depression scores than the usual care group; no differences were observed in symptom distress or anxiety.

Conclusion

The results from this dissertation suggest that, from nurses' perspectives, integration of an interactive tailored assessment tool such as Choice in clinical practice offers many benefits for communication and enhancement of patient-centered care that contribute to maintenance of use. However, to reap these benefits, use of such tools must receive equal priority to other routines and require sufficient time and competence.

Further, this dissertation provides emerging evidence that different user characteristics are associated with different use patterns of Web-based self-management support. Such information is important in order to target Web-based support systems to different patient groups. In study II, secure e-mail and self-management advice were particularly used by patients who had low levels of social support and a high illness burden, suggesting that patients with these characteristics may find such tools particularly useful.

Finally, this dissertation shows that a Web-based self-management system can be an important contributor in providing health care for breast cancer patients in terms of reduction of symptom distress, anxiety and depression scores. The secure e-mail component alone contributed to reduced depression scores, which indicates that secure e-mail is an important part of multi-component systems and can also effectively be offered as a stand-alone service. This is promising, as depression is highly prevalent and debilitating among cancer patients. An e-mail service is much easier to develop and to implement widely than more complex multi-component solutions. Despite the concerns identified in the literature regarding health care providers being flooded by messages, only modest use was observed in these studies, indicating e-mail as manageable to integrate in routine care.

In summary, through materials from three different studies and use of multiple methods, this dissertation adds to the knowledge about the *uptake, use* and *effectiveness* of eHealth interventions in real life settings. The results and knowledge gained are important to the design of support systems that are better tailored to the individual and the context of use.

Abbreviations

CBI	Cancer Behavior Inventory
CES-D	Center for Epidemiological Studies Depression Scale
CI	Confidence Interval
CMIS	The Comprehensive Model of Information Seeking
ESAS	Edmonton Symptom Assessment System
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health Related Quality of Life
ITPA	Interactive Tailored Patient Assessment
LCA	Latent Class Analyses
LMM	Linear Mixed Models
MOS-SS	Medical Outcomes Study Social Support Survey
MSAS	Memorial Symptom Assessment Scale
MSAS-SF	Memorial Symptom Assessment Scale – Short Form
OR	Odds Ratio
RE-AIM	Reach, Adoption, Effectiveness, Implementation and Maintenance
RCT	Randomized Controlled Trial
SCQ-19	Self-Administered Comorbidity Questionnaire
SPSS	Statistical Package for Social Science
15D	15D Health-Related Quality of Life Instrument

List of papers

Paper I

Børøsund E, Ruland CM, Moore S, Ekstedt M. Nurses' Experiences of Using an Interactive Tailored Patient Assessment Tool One Year Past Implementation. Int. J. Med. Inform. 2014 Jul;83(7):e23-e34

Paper II

Børøsund E, Cvancarova M, Ekstedt M, Moore SM, Ruland CM. How User Characteristics Affect Use Patterns in Web-Based Illness Management Support for Patients with Breast and Prostate Cancer. J Med Internet Res. 2013 Mar;15(3):e34

Paper III

Børøsund E, Cvancarova M, Moore SM, Ekstedt M, Ruland CM. Comparing Effects in Regular Practice of E-communication and Web-Based Self-management Support on Symptom Distress, Anxiety, Depression and Self-Efficacy among Breast Cancer Patients. Preliminary Results from a Randomized Controlled Trial. *Submitted*

The publications and manuscript will be referred to in the text by their Roman numerals (I-III).

1. Introduction

The burden of chronic diseases is expected to escalate worldwide [1,2] and the incidence of one of the leading chronic diseases, cancer, is rising dramatically [3]. In order to meet this challenge, new models for care are required. eHealth has become increasingly important in the delivery of self-management tools and health communication systems. A growing body of evidence supports the effectiveness of web-based self-management support interventions [4-8] and electronic interventions to support patient-provider communication [9-11].

Barriers to realizing the benefits offered through eHealth interventions nevertheless still exist [12]. There is a large gap between research on eHealth interventions that have shown to be effective in clinical trials and eHealth implementation in regular clinical practice [13-15]. This dissertation seeks to address this issue through examining aspects of the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework [16], a widely used framework to improve translation of health promotion interventions into practice. In particular, this dissertation, using multiple methods, addresses aspects related to uptake, use and effectiveness of eHealth interventions in real-life settings in the hospital and in patients' homes, from the perspectives of patient and health care provider.

The first aspect we addressed relates to the challenges associated with sustainable use and maintenance (i.e. uptake) of eHealth interventions in clinical practice (Study I) [17-19], the maintenance dimension in the RE-AIM framework. While a number of studies have addressed aspects of system implementation, few have examined factors related to sustained use and the challenges that may emerge over time *after* a new intervention has been implemented [20]. This dissertation contributes to knowledge in this area by exploring nurses' experiences of an interactive tailored symptom assessment intervention (i.e. Choice) in routine practice one year after its implementation (Study I).

The second aspect addressed in this dissertation is the need to better understand user characteristics and user patterns related to the use of eHealth interventions (Study II), the implementation dimension of the RE-AIM framework. Although many studies have shown eHealth interventions to be effective, users appear to use these interventions differently than intended [21,22]. Furthermore, while perceptions of a system's perceived usefulness have been investigated in a number of studies, the systems have primarily been evaluated as a

whole on a set of general criteria. The usefulness of specific components that the system offers is seldom addressed. In order to design Web-based systems that can better target different user groups, more research is needed to examine which user characteristics are associated with use of different components of support [8]. This dissertation therefore adds to this knowledge through exploring the characteristics of different users and their use-patterns of a multi-component web-based self-management support system (WebChoice) in study II.

Finally, study III addresses the effectiveness dimension of the RE-AIM framework. While eHealth interventions are often complex systems, consisting of several components, little is known about which components contribute to the observed effects [23,24]. We know little about how many components are needed to create an effect, or which components are particularly effective. In addition, little is known about the effects in clinical trials if parts of an intervention were offered as an integrated part of regular care. Testing of interventions in diverse settings increases external validity, an important factor in implementing complex interventions [25]. This dissertation contributes important information to the area through comparing, in three different settings, the effect on patients' outcomes of the multi-component self-management support system WebChoice and a single secure e-mail component to usual care, when the interventions were integrated as a part of regular care (Study III).

1.1 Specific aims

The main objective of this dissertation was to address gaps identified in the literature related to uptake, use and effectiveness of eHealth interventions into practice from different perspectives. The specific aims were:

I. To explore nurses' experiences of benefits of and barriers to maintaining use of an interactive tailored patient assessment tool called Choice in cancer care, one year after its implementation (study I).
II. To describe user characteristics and user patterns associated with the use of different components of a web-based illness management support system for cancer patients called WebChoice (study II).
III. To test and compare the effects of (1) a secure e-mail service, (2) the multi-component WebChoice intervention (including the e-mail service), and (3) usual care on: symptom distress, anxiety, depression, (primary outcomes), and self-efficacy (secondary outcome) after 6 month of access (study III).

The RE-AIM framework, consisting of Reach, Effectiveness, Adoption, Implementation and Maintenance dimensions, was used as the conceptual framework to guide this dissertation [16]. RE-AIM is designed to improve the likelihood of translating health promotion interventions into practice [16,26]. It has been argued that to fully embrace the potential offered by eHealth, a continuous systematic evaluation is needed [27]. RE-AIM addresses important elements to consider in such an evaluation. To contribute with new knowledge to the evaluation of eHealth systems, this dissertation address three dimensions of the RE-AIM framework in particular; the maintenance, implementation and effectiveness dimensions. The reach and adoption dimensions are also addressed in the studies, but not to the same extent as the three other dimensions. More details of the RE-AIM framework are provided in *Chaper 2.6 Theoretical framework*. A summary of aspects studied, aims, eHealth interventions, RE-AIM dimension and methods used is displayed in Table 1.

Table 1. Overview of aspects studied, aims, eHealth interventions, methods and RE-AIM dimensions addressed

	Study I	**Study II**	**Study III**
Aspect studied	Uptake	Use	Effectiveness
Aim	Explore nurses' experiences of benefits and barriers of use and maintenance of Choice in regular care	Explore user characteristics and patterns of use of different components	Compare effectiveness of WebChoice and secure e-mail vs usual care on patient outcomes
eHealth intervention	Choice[a]	WebChoice 1.0[b]	WebChoice 2.0[b] Secure e-mail
Method	Qualitative Focus groups	Quantitative Exploratory	Quantitative RCT
RE-AIM dimension	Maintenance[c], Implementation	Reach, Implementation[c]	Reach, Effectiveness[c], Adoption, Implementation

a Interactive tailored patient assessment system.
b Web-based self-management support system, including communication components.
[c]Main RE-AIM dimensions addressed

2. Background

Recent improvements in detection, diagnosis, treatment and recovery allow people with cancer to live longer [28]. As such, cancer is seen as a chronic illness over a longer time. Longer life expectancy poses new challenges for patients and families related to self-management and coping with the consequences of illness. It also challenges the way the health care system is organized in terms of long-term care for patients. Cancer and other chronic conditions are associated with considerable psychosocial burden and extensive costs for the health care system [1]. Increasing pressure to maintain or reduce health care costs leads to demands for more effective ways to provide information and self-management support for patients. Furthermore, patients increasingly want to be involved in their own care and the decisions made [29]. This presents both new opportunities and new demands for patients, their caregivers and the health care system. Society needs to offer ways to improve patients' self-management capability as well as to offer systems that allow patients to take part in their own treatment and care.

New technologies bring new opportunities for delivering health care, for health communication and for supporting self-management [30]. The development and use of eHealth interventions has become an emerging, rapidly evolving field [31]. The concept of eHealth came into use in 2000 [32], and has become one of the most frequently used terms recently [31]. Several definitions have been used to describe this concept and vary depending on the scope and stakeholders involved. A review by Pagliari et al. identified 36 different eHealth definitions [32]. In this dissertation the following definition of eHealth is used: *"the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care" [33, p.1]*. This definition emphasizes eHealth's potential to improve or enable health and health care, and includes both patients and health care providers.

The importance of utilizing opportunities offered by eHealth has been highlighted by governments in different parts of the world in recent years. The World Health Organization strongly recommends implementing self-management support programs to enable persons with chronic illnesses such as cancer to manage their symptoms [34]. The European Commission has developed an action plan for digital solutions in Europe's health care systems

[12], with the goal of improving health care for the benefit of patients, giving patients increased control of their care and reducing health care costs. In this plan the European Commission also addresses barriers to full use of digital solutions, and acknowledges that digital health care has yet to fulfill its potential to improve health care and to generate efficiency savings [12].

Thus, the potential of eHealth to improve health care is still not fully realized, even though there is political willingness to take advantage of new technologies. To increase utilization, there is a need to look at factors beyond effectiveness. This dissertation focuses on aspects related to uptake, use and effectiveness of eHealth interventions. In the following, a short summary of literature related to electronic symptom assessment and communication tools (interventions with similarities to Choice, used in Study I) and Web-based self-management systems (interventions such as WebChoice, used in Study II and III) are provided first. Next, literature specifically related to the aims of the dissertation will be presented, followed by a description of the theoretical framework that guides this dissertation.

2.1 Electronic symptom assessment and communication tools

In recent years a growing number of electronic symptom assessment and communication tools have been introduced in clinical practice [10,35,36]. In addition to helping patients report their symptoms, problems and concerns, such tools can support clinicians' efforts to provide individually tailored support and follow-up [11,37]. Studies report significant effects of such tools on patient care by reducing symptom distress and patients' need for symptom management support [11], reducing anxiety and depression scores [38], improving quality-of-life outcomes [39,40], addressing patients' symptoms [41,42] and disclosing patients' cues and concerns in communication with clinicians [43-46].

Electronic symptom assessment tools are found to be feasible and well accepted by health care providers and patients [47-50], and to be easy for patients to use across a range of user characteristics [51-53]. Health care providers have reported these tools to be helpful in detecting, assessing and managing the patients' symptoms [43,47,54,55]. Access to patients reported symptoms and quality of life issues are also reported to improve patient-provider communication by increasing the number of issues discussed during the intervention consultation [41,42,53].

Despite the recognition of effects and benefits of using electronic symptom assessment tools, concerns have also been noted. Concerns include patient burden resulting from the need to fill in their symptoms and problems, issues with the wording and formatting of the questions, and technical difficulties [55]. Physicians have raised concerns that such tools might increase their workload, and that it is a challenge to change their set of patterns of questioning and behavior during a medical consultation [53]. However, little is known about how these tools are used in regular care and how nurses, who are the providers highly involved in symptom management for patients, perceive the barriers and benefits. In addition, few studies have examined experiences of use over time (maintenance), or challenges that may emerge after implementing these interventions into practice. In study I, this dissertation therefore explored nurses' perception of benefit and barriers of maintained use of Choice one year after implementation.

2.2 Web-based self-management support

Recent years have also seen a growth in Web-based systems to support self-management for people with chronic illness [6,56-59] and specific conditions such as asthma [60], diabetes [61-67], rheumatology [68,69], mental health [70-72], cardiac disease [73,74] and cancer [7,24,75-79] The purpose of such Web-based self management support systems is to contribute to better illness self-management for users.

Self-management, a core concept in chronic care, in brief, refers to the actions individuals take to manage their own illness. Lorig defines self-management as "learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" [80, p.11]. The aim of self-management is described as keeping wellness in the psychological foreground [81]. To be able to do so, as first described by Corbin and Stauss [82], a person has three self-management tasks to perform: 1) managing the medical aspects of the condition; 2) managing life roles, included changes in the roles due to the illness; and 3) managing the emotions brought by the illness, such as anger, fear, frustration and depression. To perform these tasks, the person has to possess a set of self-management skills [81]. Self-management support involves helping patients and caregivers to achieve the necessary skills and confidence to cope and to manage the illness [83-85].

It is not enough just to tell patients what to do, as is often the norm. Patients' central role in their own care has to be acknowledged to enable them to take responsibility for their own

health. eHealth interventions can contribute to increasing self-management capability, strengthening the roles of patients and users roles through their ability to provide and communicate information and knowledge, as well as being a channel for communication with other patients and health care providers [86]. Acknowledging patients' ability to be a partner in their own care and offering systems that target the patients' conditions can enable self-management.

Self-management support interventions delivered through the Internet have the potential to reach a large group of users because Internet access in the population increases worldwide every year [87]. In addition people regularly use the Internet to obtain health information [88-90]. Web-based self-management support systems usually contain several components, such as illness-specific information/education, symptom monitoring, treatment instructions, self-management training, decision support, peer support, communication between patients and health care providers though electronic messages and electronic diaries [8,91,92].

A number of advantages are known in connection with Web-based self-management systems, compared with more traditional ways to provide self-management support [8,31,93]. These include, among others, anonymity, convenience and flexibility for users, equity, increased access to reliable information, tailoring potential and interactivity. On the other hand, concerns have been raised regarding possible adverse effects such as patients receiving incorrect information or advice; patients making inappropriate decisions (as judged by health care providers); exclusion of users because of the digital divide; breakdown of the relationship between the patient and the health care provider; information overload among health care providers and breaches of users' privacy [8,94]. To counterbalance some of these possible adverse effects, a prerequisite is to offer interventions of high quality through secure systems.

Multiple studies have demonstrated the effects of Web-based self-management support interventions in chronic illnesses. A Cochrane review concluded that users tended to become more knowledgeable, feel more socially supported and were likely to have increased self-efficacy [8]. Web-based self-management support interventions for people with chronic illnesses are reported to improve quality of life [66,73,95-98], self-management [73,99] and self-efficacy [56,58,65,66,95,100]. In addition, they have been found to increase patient activation [6,65], acceptance [57], social support [66], and knowledge [63,98], as well as to reduce depression [57,66,71], stress and loneliness [57]. In a review of Web-based interventions designed for cancer patients, Ventura et al [101] concluded that these

interventions are being used and are helpful to individuals regardless of their age, gender, literacy level and disease stage. Web-based interventions for cancer are also reported to reduce symptom distress [7,75,76], cancer-related fatigue [78], anxiety scores [78], and overall negative emotions [102], as well as to increase social support [102-104], quality of life [78,103], emotional processing and health information competence [24] and fighting spirit [77].

Web-based self-management support interventions are also shown to achieve similar improvement in knowledge, self-efficacy and self-care activities compared with face-to-face follow-up [105]. In a review of Web-based interventions for depression and anxiety disorders, the majority of studies demonstrated some evidence of effectiveness [106]. It was concluded that these interventions offer promise for use as self-help interventions or as an adjunct to usual care. However, there are also conflicting reports. In a recent review, Paul et al [23] concluded that although it was possible to achieve positive effects on psychosocial outcomes using web-based approaches, effects were not consistent across conditions. A well powered study of a Web-based diabetes self-management support program showed no significant differences in psychosocial outcomes at 12-month measurement [62]. Similarly, no effects were detected in a study including patients with multiple sclerosis [107]. These inconsistent findings highlight that users may benefit in different ways. Little is known about how specific diagnoses or characteristics among users contribute to impact, and which component combinations contribute to effects. To add to this knowledge, user characteristics, psychosocial outcomes and their relation to user pattern were explored in study II in this dissertation. In addition, effects of one single component and the whole WebChoice intervention were tested in study III to tease out the differences between single and multiple component interventions.

2.3 Uptake of eHealth interventions in routine care

A consistent finding from clinical and health services research is the failure to translate evidence into practice and policy [108]. Similar challenges are also evident in the field of eHealth [14,18,109-111]. While a number of studies have examined initial implementation efforts, little research has examined the maintenance of interventions or programs after they have been implemented [20]. In addition, there is limited evidence on how to effectively promote the maintenance of eHealth interventions by healthcare professionals [112].

Therefore, nurses' experiences of benefits of and barriers to an eHealth intervention that had been used in clinical practice for one year were explored in study I.

2.3.1 Barriers to technology adoption and maintenance

The published literature on factors that promote or inhibit eHealth implementation and maintenance is described focusing mainly on organizational issues and less on the wider social framework important to consider when introducing new technologies [18]. Typical organizational barriers noted are fear of, or experienced, additional workload [113-115], lack of financial reimbursement [110,113], costs [110,116], and lack of support [115]. Concerns regarding privacy, safety and confidentiality of digital information are also reported to influence implementation [116-118]. In addition, a fear that use of technology will dehumanize patient care [119] and concerns about whether the system actually benefits patients have been noted [120]. Issues regarding design and technical challenges of e-Health interventions are reported as barriers [114,119]. For instance, failure to develop interventions that consider patient or staff characteristics and needs in the design phase can inhibit implementation [121].

Regarding the interaction between health care providers, differences in adoption of innovations between nurses and physicians are reported to create challenges in the implementation phase [54,118]. Resistance from one group may limit realization of an innovation's full potential. If the system lacks functionality to encompass the perceived roles of all multidisciplinary team members, including physicians, this may also limit use [54]; attitudes within the clinical community, negative attitudes and resistance to change can also be barriers to use and implementation [19,121]. Introduction of technology into health care settings can be challenging for the existing culture because these organizations are often hierarchical and have a tradition of adopting evidence-based approaches based on lengthy trial periods [122]. This carries the risk of slow adoption of new technology, based on the fear of the consequences of failure. More research is however needed to address this issue.

Among patients, lack of interest and concerns about privacy [117], technical difficulties such as login procedures as well as the time required to learn how to use the system [123,124] and staff resistance to using technology [125], are reported as barriers to implementation of eHealth interventions.

2.3.2 Facilitators and incentives for technology adoption and maintenance

The interaction between the innovation, the intended adopter(s), a particular context and the manner in which the implementation process is carried out determines the adoption rate [25,126]. Most translation models suggest that planned knowledge translation for healthcare professionals and consumers is more likely to be successful if the choice of knowledge translation strategy is informed by an assessment of the likely barriers and facilitators [108].

One of the key elements to successfully implementing and maintaining change is to have an effective strategy for communicating the intent, design, testing and implementation of the technology involved. When key people feel informed, they are much more likely to support the change [126]. However, until eHealth interventions are ‘‘fit for purpose’’, health care professionals are unlikely to adopt them, which may create a risk of implementation failure [27].

Perception of the benefits of an innovation (system usefulness, ability to solve problems) is described as the most common facilitating factor influencing the adoption of information and communication technologies by healthcare professionals [114,127], followed by ease of use [114]. Benefits include both patient outcome [119] and workload improvements [128,129]. These factors are addressed in study I. Patients are also more likely to make use of beneficial and easy-to-use resources [122,125,130].

Key factors to make the systems useful are the involvement of users (both patients and providers) in development and implementation phases, support from leaders, use of project champions or other key staff, providing adequate training and support, and monitoring system use in the early stages of implementation [114,116,119].

Interventions that fit into the existing workflow, routines and culture are more likely to be adopted [127,128,131,132]. To facilitate implementation of new interventions, one may require a redesign of internal processes [110,127,133]. In addition, significant resources and expertise, as well as user training among patients and providers, are required to implement eHealth interventions [36,134].For secure e-mail communication, integration with reimbursement systems, triage, and initial uptake by larger health-care organizations are expected to speed up the adoption into routine health care [135].

Initial concerns about integration of eHealth interventions can sometimes be overcome by simply exposing providers to this process [136]. In a service offering e-mail as a method of communication between nurses and patients with lung cancer, nurses expressed concerns prior to the study but were extremely positive about e-mail service after the study [137], and e-mail was found to be useful and convenient, with advantages outweighing any disadvantages. A similar observation was made in a survey to determine the methods of remote symptom assessment that cancer outpatients would be comfortable using; most patients reported that they did not feel comfortable using technology such as a secure website, email, or mobile phone text message [138]. However, studies examining the acceptability of these new methods after patients have used them report greater acceptability [49,52]. Therefore, studying maintenance of eHealth interventions used in regular care is essential, such as in study I, in order to increase knowledge about these factors.

Implementing and maintaining eHealth interventions is more than simply putting technologies in place. It requires new resources and considerable effort [139] and it creates culture change [128]. This takes time, active engagement and patience. To better understand why a given technology is successful or not is in itself a topic for further research [140]. There is increasing recognition that the extent to which new programs are maintained is influenced by many different factors [20].

2.4 User characteristics and use pattern of eHealth interventions

Although eHealth interventions are shown to be effective, varying levels of user adherence, non-usage attrition and high rates of dropout have been seen in many studies [21,22,141,142]. Further insight into who the users and non-users are and whether use patterns can be used to inform the best type and best way to deliver Web-based interventions can be beneficial in targeting content to different groups of people with chronic illness [8,143,144]. The role of socio-demographic characteristics in relation to outcomes or issues of reach and adoption of eHealth interventions are only explored in a few studies [23]. This dissertation therefore explored user characteristics and use patterns of different components of a Web-based self-management support system in study II.

2.4.1 User characteristics and use patterns of Web-based self-management support

Several demographic factors are reported to influence use of Web-based self-management support systems. Higher age [145-147], female gender, higher education [148-150] and higher income [149] have all been associated with higher use. Some studies suggest that higher use is associated with younger age [149] or lower income [102], while other studies show no connection between user characteristics and system use [21,151,152]. In addition, how users' health relates to usage is not clear. For some systems, higher levels of functional well-being [153] and not having a chronic condition [145] have been associated with higher use. In contrast, patients with a greater need for care were found to be more engaged in long-term use and in seeking out information in other studies [21,153]. These divergent findings indicate that further exploration of user characteristics in eHealth studies is needed. In this dissertation both demographic and disease-related variables are therefore included in study II and III to explore these relationships.

Psychosocial factors are also described as having an impact on use. Lower levels of social support and symptoms of depression or negative mood have been associated with higher use [150,153,154]. In addition, prior Internet/computer experience has been identified as a factor linked with increased use and acceptance of eHealth interventions in some studies [146,155], but not others [152]. The limited evidence available on how psychosocial factors impacts use pattern motivated the aim in study II.

Patients' compliance with the intervention is not clearly described in many Web-based interventions [156]. The variability in usage is large [157], and some interventions are not used very often [158,159]. For example, website use has been described as relatively high initially and declining thereafter [71,152,160]. Studies often indicate the number of logins, but few examine the utilization of different program elements [161]. In a summary of 10 years' experience with a Web-based support system called CHESS, Gustafson et al observed that different populations used CHESS in different ways [162]. For example, underserved populations used discussion groups less frequently, and used informational services and analyzing services more. In a study of a diabetes tool functionalities and self-management features were used by less than half of the participants even though user evaluation showed high satisfaction with the tool's content, credibility and user-friendliness [63]. Baker et al. noted that participants now use Web-based support less often than they did before [163]. To

add to the sparse knowledge about usage of different program elements and about how user characteristics affect use of different components, we explored these aspects in study II through examining user characteristics associated with use of different components of WebChoice.

It can be a challenge to compare results between studies, as the duration of the interventions varies widely. In the studies described in chapter 2.2, interventions are reported to last from four weeks [77] to 25 months [76]. In addition, recommended use varies widely. Some interventions are participant driven, where the participants chose the functions they want to use and how much they want to use them [7,76]. Other interventions are more prescriptive and offer a set of modules that the participants are meant to attend to or perform [56,77]. To ensure transparency in reporting eHealth interventions, descriptions of duration, recommended usage and how the intervention was actually used are strongly recommended [164], and this is therefore described in study III and III.

Another known challenge in eHealth research is the large proportion of users who drop out before completion, or stop using the intervention [22]. Mean dropout rates of Web-based interventions are reported to be 21-23% [156,157]. Several studies report higher attrition rates in the intervention group than in the control group [6,57,62]. Dropout rates from RCTs of Web-based interventions are however low compared to dropout from open access websites [165]. Reasons given for dropout include deteriorating health, time constraints, technical or computer-access problems [57,165,166], family problems [57], nonparticipation in study activities [166], lack of motivation, burden of the program, lack of face-to-face contact, and perceived lack of treatment effectiveness or of improvement in condition [165]. Predictors reported for dropout are divorce [57], being single, low levels of computer skills [166] and being male [59]. To add to the knowledge on how user characteristics affect dropout, we also compared those who dropped out and those who stayed in study III.

2.5 Contributors to effectiveness of Web-based self-management support

2.5.1 Components and relations to effectiveness

As described in chapter 2.2, a number of Web-based self-management interventions have demonstrated positive effect on patient outcomes [6-8,24,56,57,63,65,66,71,73,75-79,95-100].

However, as mentioned before, these interventions often consist of several components, making it difficult to determine each component's degree of contribution and benefit to patients [24,167]. Knowledge of the use and effects of single components on patient outcomes is important in identifying component candidates for inclusion in Web-based support systems [24,79,168], and in determining which components are effective as stand-alone services.

In a study examining a Web-based support system for cancer patients, different features of the system were tested and compared [24]. Results suggested that the benefit of the system was connected to the information and support services. The complex services such as coaching and tailoring of content did not produce benefits beyond simple access to the Internet. Some of the same patterns could be seen in a study examining an intervention targeting fibromyalgia patients [158], where the presence of interactivity elements, such as a Web-forum and chat room, failed to improve knowledge, empowerment or health outcome.

A review of diabetes interventions found that the most effective systems were those that linked medical management and self-management [110]. Patient satisfaction was highest when the Web-based system gave them the ability to track blood glucose, receive electronic reminders, schedule physician visits, e-mail their health care team and interact with other diabetic patients. To add to the knowledge about effective components, in this dissertation the effect of one component (secure e-mail) was compared with the multi component support system, WebChoice.

2.5.1.1 Secure e-mail

There is growing interest among patients in using secure e-mail services [123,169,170], and several studies report positive effects of using secure e-mail alone in terms of assisting patients in managing illness, improving health outcomes, increasing satisfaction [171], reducing depression scores [172] and improving quality of care [173,174]. Patient access to secure e-mail is also associated with fewer visits to primary care offices [175-177] and telephone contacts [176,178]. In a review of interventions targeting chronically ill patients, communication with health care providers and/or website moderators was reported to be particularly useful for self-management support [5]. Similarly, in an earlier study of WebChoice, patients rated the nurse-administered secure e-mail service as the most valuable component [179], even though this service was managed by cancer nurses with no treatment responsibilities for the patients. Cornwall et al. also reported high levels of satisfaction with

nurse administered e-mail [137]. This suggests that secure e-mail can be important both as a stand-alone service and in multi-component Web-based support systems. However, little is known about the effect of stand-alone nurse-administered e-mail services and patient outcomes because previous studies have to a large extent focused on services between patients and physicians [134], and have not explored how they compare to more comprehensive Web-based support systems where e-mail is one of several components. In addition, little is known about nurse-administered secure e-mail services integrated as part of routine care. Study III therefore tested the effects of nurse-administered secure e-mail services integrated in routine care, as well as the e-mail service with the additional features of WebChoice.

2.5.2 Dose of use and relations to effectiveness

A research topic within the eHealth field is the relationship between the amount of use and improvement in outcomes to explain the effectiveness of a program. An assumption behind this reasoning may be that more use will contribute to better health outcomes [180]. Little is known about the mechanisms or components of the interventions that have the greatest impact, however, and few formal evaluations consider user engagement or adherence to the Web-based interventions when addressing the overall impact on health outcomes [143].

There are many challenges in determining the role of intervention adherence on outcomes in eHealth interventions. A review of the impact of adherence on the effectiveness of eHealth interventions concluded that the number of logins, as a measure of adherence, correlated best with physical outcomes, while module completion correlated with psychological outcomes [141]. However, the studies included in this review examined very heterogeneous populations, interventions, length of follow-up and outcomes measured, and the authors therefore recommended further exploration of the relationship between adherence and outcomes.

Several studies report no relation between Web-site use and outcomes [158,160,181]. Other studies, however, have detected positive associations. For example, higher use of Web-based diabetes interventions is associated with improved outcomes [61,105]. In a study of an eHealth intervention supporting palliative care among cancer patients, exploratory analysis of survival curves indicated no significant differences between the study groups [76]. However, a survival difference was detected in favor of the users, compared to the non users. Active users of an Internet peer support group for cancer reported a significant increase in fighting

spirit whereas non-users reported a decrease [182], and higher use of a support system for cancer patients was related to positive changes in patients' psychosocial outcomes [180]. These findings of positive association between use and outcomes must however be interpreted with caution. Analysis of adherence and its relationship with outcomes often requires additional explorative analysis, which makes this evidence less robust. In addition, low usage or dropouts do not necessarily indicate failure, because dropouts may well be "e-attainers" who have accomplished what they needed from the eHealth intervention [183]. As such, there is no clear consensus on whether dose of use of Web-based self-management support and patient outcomes are connected. In study III, we therefore explored whether being a user or not was associated with differences in outcomes, seeking to further contribute to this knowledge.

2.6 Theoretical framework

2.61 The RE-AIM framework

This dissertation addresses gaps identified in the literature related to uptake, use and effectiveness of eHealth interventions for self-management support and patient-provider communication. A framework widely used to plan, implement, evaluate and report health promotion and disease management interventions is the RE-AIM framework [16,184,185]. It was developed to improve the likelihood of translating health promotion interventions research into practice and focuses on factors facilitating intervention planning and evaluation, while balancing internal and external validity [16,26]. In addition, RE-AIM provides a set of outcomes that can aid in understanding the context of intervention development and testing, with a goal to speed up research-practice translation. RE-AIM is congruent with, and not opposed to, efficacy research, as it asks for transparency of procedures used, and details of inclusion and exclusion at the contextual levels of settings and staff, as well as patients [186]. RE-AIM has earlier been adopted into eHealth evaluations [15,187], and was used as the theoretical framework in this dissertation.

This dissertation mainly focuses on three of the RE-AIM dimensions; *Maintenance, Implementation* and *Efficacy/Effectiveness*. However, the *Reach* and *Adoption* dimensions are also addressed, especially in study III.

The *Reach* dimension focuses on the characteristics of the participants. It highlights the importance of collecting information from both participants and non-participants to address

representativeness [16,188]. This can be an ethical challenge because non-participants have not consented to study inclusion [16]. In this dissertation, information on the Reach dimension is available in study III through description of individuals approached, eligible and consenting to participate in the study, and in study II where representativeness of participants is discussed.

Efficacy or *effectiveness* is measured at the individual level and reflects the success of the intervention when implemented as guidelines prescribed under optimal conditions or in real-world situations [16,188]. It is important to document both positive and possible negative or unintended consequences of the intervention. In this dissertation the effectiveness dimension is addressed in study III through outcome measures of symptom distress, anxiety, depression and self-efficacy.

Adoption refers to the proportion and representativeness of the settings that adopt the intervention [16,188]. Different settings (e.g., hospitals) and agents (e.g., physicians, nurses) may vary based on resources, level of expertise and commitment to intervention programs. Understanding how adoption varies among settings and intervention agents is critical to the potential impact of an intervention. The framework also encourages examination of barriers to adoption when nonparticipating sites are assessed. In this dissertation, adoption is addressed by description of the number of hospitals that agreed to participate in study III, including reasons for not participating among those that declined.

Implementation refers to the intervention agents' fidelity to the elements of an intervention's protocol [16,188]. This includes consistency of delivery as intended as well as the time and cost of the intervention. For the individual, implementation considers how the individual makes use of the intervention. This dimension is addressed in study II, focusing on user characteristics among users and non-users as well as user pattern. In addition, study III gives a broad description of user characteristics and of how WebChoice was used.

Maintenance refers to the extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies [16,188]. At the setting level, the extent to which a program or policy is sustained, modified, or discontinued following initial trial or study period is addressed. In this dissertation the maintenance dimension is addressed in study I, where nurses' experiences of the use of Choice in regular care were explored one year after implementation.

At the individual level, maintenance has been defined as the long-term effects of a program on outcomes after 6 or more months after the most recent intervention contact. This is not addressed in this dissertation.

Table 2. RE-AIM framework dimensions, definitions and operationalization in the dissertation

RE-AIM dimension	Definition	Variables measured in the thesis
Reach	The number and proportion of those invited and eligible who participate and their representativeness	Study II: Representativeness of participants Study III: Number and percent of invited and eligible who participated and their representativeness
Effectiveness/ Efficacy	The amount of change in temporally appropriate outcomes and impact on quality of life or any adverse effects	Study III: Effectiveness on symptom distress, anxiety, depression and self-efficacy
Adoption	The number, percent, and representativeness of settings and staff invited who participate	Study III: Hospital participation
Implementation	The extent to which a program or policy is delivered consistently, and the time and costs of the program	Study I: Nurses experiences of use Study II: User characteristics, use pattern Study III: User characteristics and use
Maintenance	The extent to which a program or policy is sustained, modified, or discontinued following initial trial or study period	Study I: Nurses' experiences of benefits and barriers to using Choice in regular care

(Adapted from Bennett & Glasgow 2009)

2.6.2 Additional theories and models

In addition to the overall framework for the dissertation (RE-AIM framework), other theories and models informed the studies as well. Roger's theory of diffusion of innovations states that users' willingness to implement an innovation depends on five attributes of the innovation [189]. In study I, the findings were discussed in light of these attributes. In study II, the Comprehensive Model of Information Seeking (CMIS) was used to inspire disease-related, demographic, and psychosocial variables included in the analyses [190]. Rogers' theory of diffusion of innovations and CMIS are described in more detail in paper I and II.

2.7 Summary

In summary, eHealth interventions for chronically ill patients hold promise in enhancing patient-provider communication and self-management, improving self-efficacy, knowledge, patient activation and health outcomes. However, there is a gap between eHealth interventions shown to be effective in clinical trials and interventions that are actually implemented and

maintained in regular practice. This indicates that barriers to benefiting from the possibilities of eHealth still exist. In order to improve the likelihood of translation of eHealth interventions into practice, there is a need to study several factors. This dissertation aspires to address aspects important for uptake, use and effectiveness of eHealth interventions. First, we focus on the challenge of maintenance of eHealth interventions in regular care by exploring nurses' experience of using the electronic symptom assessment tool Choice, one year after implementation. Next, through exploring user characteristics and user patterns of the Web-based self-management system WebChoice, we address the need to better understand how such systems are used and by whom. Finally, because eHealth interventions are often complex systems with multiple components, we compared a practice-integrated secure e-mail service and a multi-component self-management system (including the e-mail service) to disentangle effective components. The RE-AIM framework was used as a theoretical framework for this dissertation.

3. Methods

This dissertation is based on scientific, practical and feasibility considerations. Originally, all data were to be obtained from study III. However, the initial collaborating hospital withdrew from the study just before patient recruitment was about to start. This delayed start-up of study III and resulted in change of plans. New hospitals were invited for collaboration; the process of setting up the necessary contracts and training health care providers in answering e-mails and in recruitment procedures, and eventually initiating and undertaking recruitment took a year longer than initially anticipated. A decision was therefore made to include data from two additional studies (study I and II) to make it possible to examine factors important for translation of eHealth interventions into practice. This allowed completion of the dissertation within the assigned time and with the available funding. Although this process was not as originally planned, the approach is scientifically meaningful because it provides data on all aspects intended for study in this dissertation.

Consistent with RE-AIM, it is recommended that eHealth interventions should be evaluated as complex interventions and make use of more pragmatic designs rather than RCTs only [191-193]. Pragmatic trials are designed to answer the question of whether a program works under usual conditions, compared to explanatory trials that answer the question of whether an intervention works under ideal conditions [194,195]. Complex interventions are described as interventions containing several interactive components [196]. Several characteristics of these interventions have to be considered, including the number of interacting components, the number and difficulty of behaviors required by those delivering or receiving the interventions, the number of groups or organizational levels targeted, the number and variability of outcomes and the degree of flexibility or targeting offered by the interventions [196]. Within health care, randomized controlled trials (RCTs) are seen as the “gold standard” to test interventions due to their unique ability to control for known or unknown confounding factors. RCTs are of great importance, as uncontrolled evaluations of complex interventions are reported to be twice as likely to yield positive results as controlled studies [197]. Although essential, this experimental design approach does not sufficiently account for and help to understand all contextual factors that play a major role in the success or failure of implementing complex interventions, such as eHealth interventions, into practice [25].

Evaluation of eHealth interventions therefore often requires a multiple-method approach [191,193], which was used in this dissertation.

This dissertation aims to move research on eHealth interventions for self-management and communication forward by addressing gaps identified in the literature related to uptake, use and effectiveness of eHealth interventions. These aspects are addressed using the RE-AIM framework and a multiple-method approach, including both qualitative and quantitative methods [198](p7). Qualitative methods, examining a deeper understanding of human experience are rooted in constructivism, while the quantitative approach comes from a positivistic tradition [199]. A qualitative approach was used to explore experiences of use of the Choice interventions in regular care (Study I). Quantitative methods were used to explore user characteristics and user patterns, and to test the effects of secure e-mail and WebChoice (Study II and III). This dissertation thus combines methods from different paradigms [198]. A combination of these methods within the same project might generate confusion about the ontological bases of the different approaches. However, several researchers within the social sciences are now articulating mixed-methods research as the third research paradigm [200]. Qualitative and quantitative methods could be viewed as complementary rather than conflicting [201], and a combination can thus offer a broader picture of a phenomenon [202,203] and be useful for better understanding the complexities of implementation processes [204]. The use of different materials and methods has been important in this dissertation because uptake, use and effectiveness of eHealth interventions involve several factors and stakeholders.

All interventions included in this dissertation have either previously been tested in RCTs (Study I: [11]; Study II: [7]), or were tested in the present RCT (study III). In this dissertation, we move the research a little further; in addition to effects measured in the RCTs, we look at other aspects important to a deeper understanding of how, for whom and under which conditions such interventions could work. In the next sections, a description of the interventions studied is provided first. Next, an overview of the three studies included in the dissertation is provided, followed by methods for each study. Finally, ethical and security aspects are discussed.

3.1 Interventions studied

This chapter presents an overview of the different interventions studied in this dissertation. The interventions build on each other and experiences regarding development, usefulness and usability are integrated into the development of each new intervention level.

3.1.1 Choice

Choice is the intervention t used by the nurses who participated in study I. It is an interactive tailored patient assessment and communication tool for cancer patients designed to (a) help patients report their experienced symptoms, problems, and priorities for care and (b) support clinicians in providing individually tailored symptom management support [11]. The development of Choice was based on a thorough literature review of symptoms, problems and symptom management in patients with cancer and on oncology expert focus groups as well as interviews with cancer patients [11].

Through Choice, patients report their symptoms and health problems along physical, functional, and psychosocial dimensions, record their degree of distress or affliction and prioritize their need for symptom care. The assessment in Choice is individually tailored to each patient based on his/her initial response, which allows patients to focus on aspects that are personally relevant, while skipping those that are not.

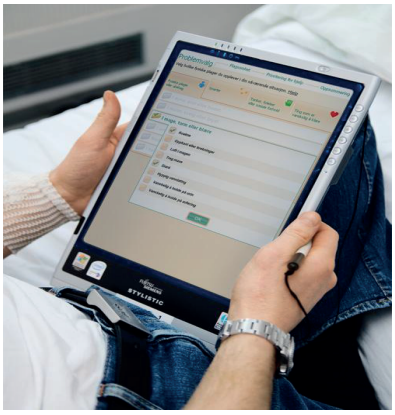

Figure 1. The Choice tablet

When the assessment is completed, the system immediately creates a summary displaying patients' selected symptoms and distress level, ranked by prioritized need for care (Figure 2).

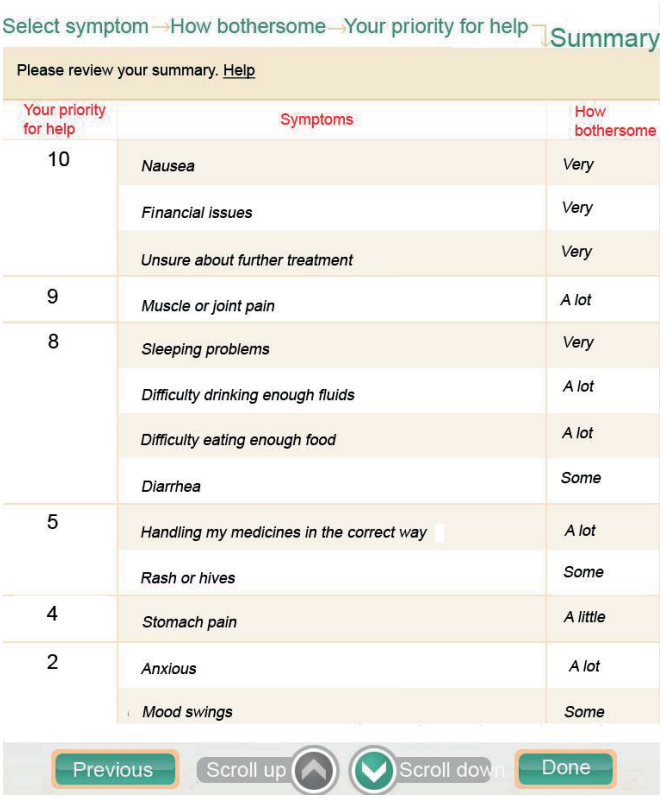

Figure 2. Screenshot showing the Choice summary sheet.

The assessment summary is transferred to the hospital's electronic system, and the patient receives a copy. The assessments themselves do not take up time for health care providers because patients complete these on their own prior to being seen by a clinician. The assessment summary can direct the clinician's attention to the issues most important to the patient, and the results can assist care providers to better tailor symptom management and care for each patient, as well as to support and improve person-centered communication.

When the nurses in study I used Choice, they handed out the touch-screen computer tablet to the patients and explained why and how to use it. The completed assessment summary was then used in patient-provider conversations in admission interviews, in follow-up conversations and in interdisciplinary meetings.

In clinical trials, Choice has been shown to significantly decrease cancer patients' symptom distress over the course of their illness, reduce patients' needs for care, increase disclosure of patients' cues and concerns in communication with clinicians, and increase the number of symptoms and quality-of-life issues addressed in patient consultations [11,41,44,205]. The system has demonstrated satisfactory validity and reliability [206], and has received high ratings on usefulness by patients, nurses and physicians [207].

3.1.2 WebChoice 1.0

WebChoice, the intervention used in study II, is a multi-component Web-based self-management support system based on patient-centered principles. It is designed to assist cancer patients in self-management of their illness while at home [7,208]. It was developed in close cooperation with users and health care providers [209], and aims to enable patients to self-manage their illness and to facilitate patient-provider communication and partnership. WebChoice 1.0, used in study II, was designed for patients with breast or prostate cancer and contained the following components:

1. A symptom assessment component based on the Choice intervention, in which patients can monitor their symptoms, problems, and priorities for support in physical, functional, and psychosocial dimensions. From a predefined list, patients can choose symptoms and problems they experience, and can rate the burden of these and what they need help with. Information from the symptom assessment can be used to monitor changes in the condition and determine when to alert health care providers, to prepare for a hospital/physician consultation, to contribute to improved patient-provider communication or to obtain immediate access to self-management advice components as described below.

2. An advice component that provide illness self-management support. Patients' self-reported symptoms/problems trigger the display of appropriate self-management activities that patients can choose from in order to relieve their symptoms and problems. Each choice contains an explanation of what the activity is; how to perform it; potential risks, side effects, and contraindications; when to contact a physician; levels of evidence; references to the source of the evidence; and links to other reliable websites for related information.

3. An information component in which patients have access to other reliable Web sources in Norwegian and English, such as information about tests, treatments, and potential side effects, lifestyle suggestions, and information about patients' legal rights.

4. A communication component for sharing experiences with other patients or for obtaining help from oncology nurses. Patients can participate in an online forum group discussion that allow them to exchange messages anonymously with other patients, or use secure e-mail communication in which they can ask questions, share experiences, and get advice from oncology nurses. The nurses in study II were employed at the research center and were not involved in the direct care of the patients. They logged onto the communication component each weekday and they monitored and contributed to the discussion group when appropriate.

5. A diary component where patients can keep personal notes.

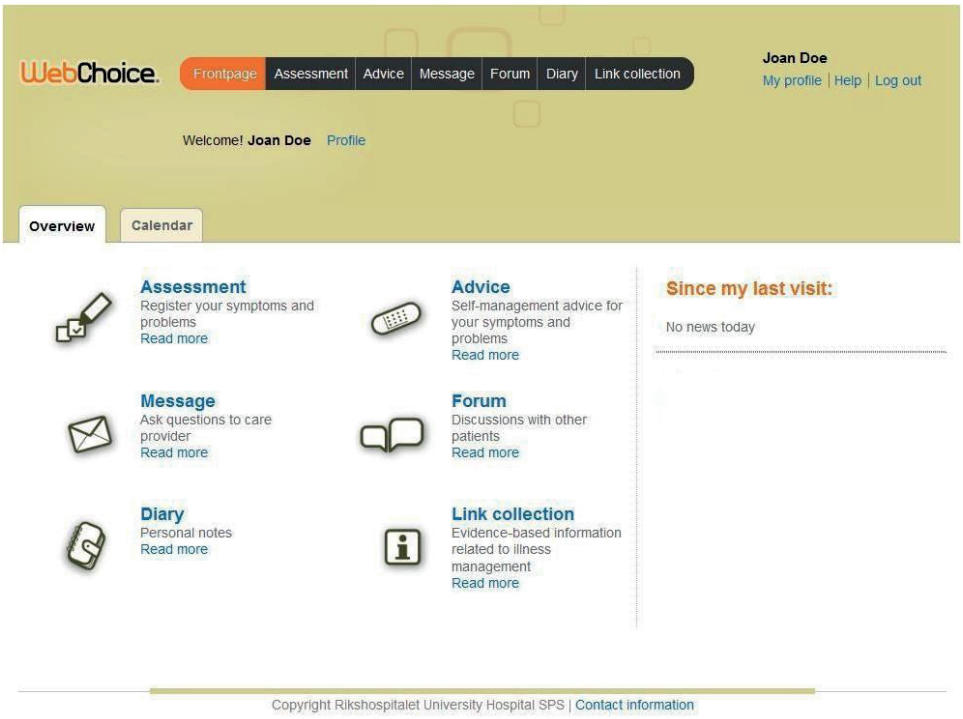

Figure 3. Screenshot of the WebChoice overview page.

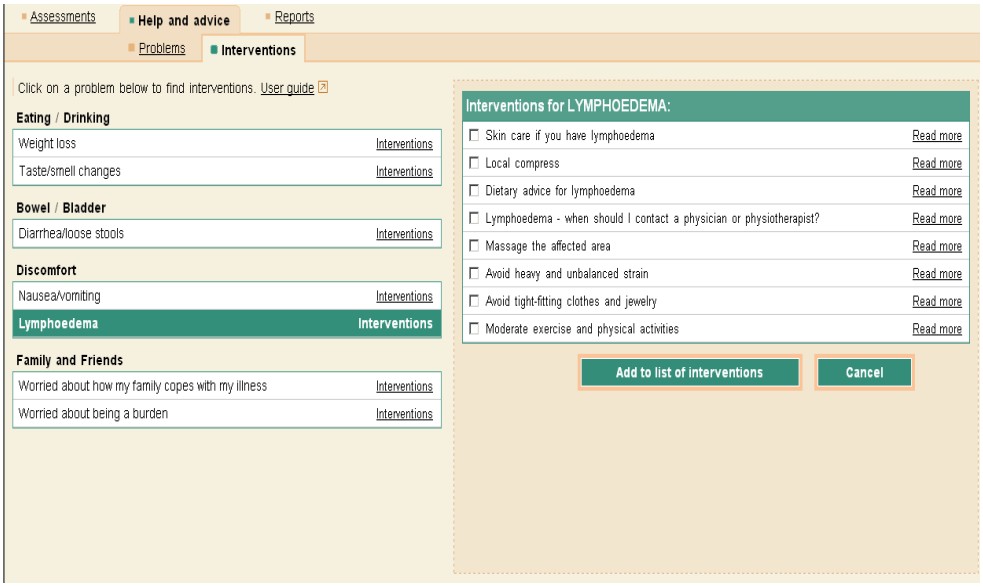

Figure 4. Screenshot of results of an assessment, and the associated advice/interventions

An RCT including 325 patients with breast cancer or prostate cancer, showed that WebChoice significantly reduced symptom distress [7]. During the study period, patients in the WebChoice group also showed significant within-group improvements in depression. This was not the case for the control group, which also experienced significant deterioration in self-efficacy and health-related quality of life during the study period [7]. Secondary analyses on data from this study were performed in Study II.

3.1.3 WebChoice 2.0

Following testing of the first version of WebChoice [7], feedback from patients through focus groups and questionnaires was used to update and refine the intervention [179]. In WebChoice 2.0, used in study III, targeting breast cancer patients, a blog component was added, the advice component could be accessed without finishing a symptom assessment first and the advice and link collection was refined and updated [210]. WebChoice 2.0 was also pilot-tested by cancer patients with different levels of computer experience in order to ensure user-friendliness.

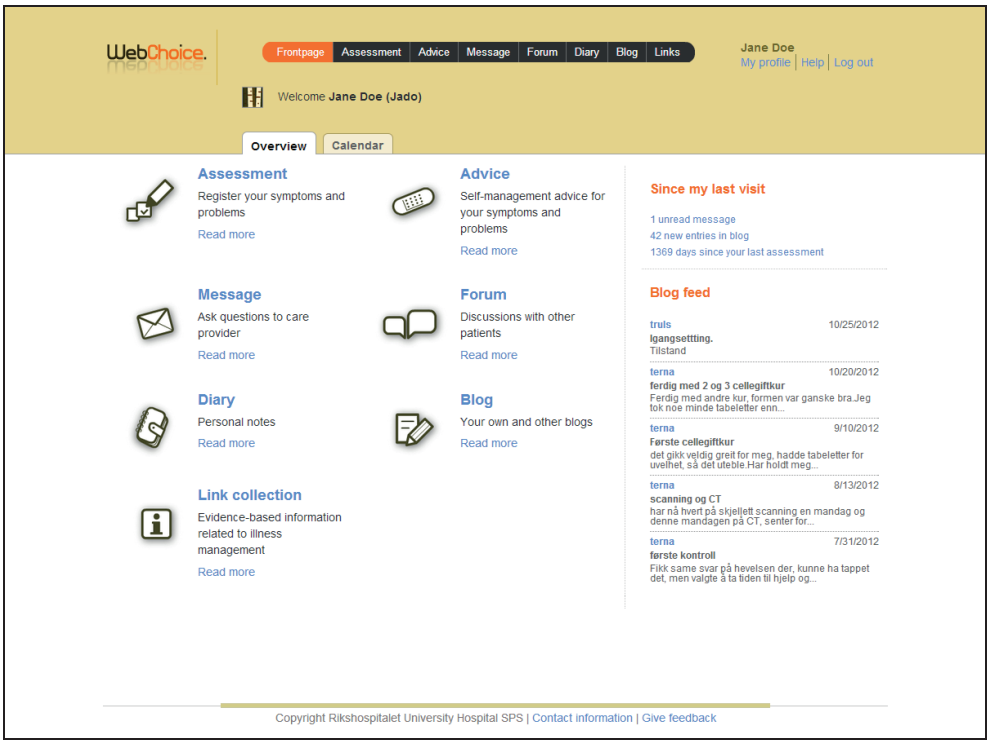

Figure 5. Screenshot of the WebChoice 2.0 overview page

One of the most appreciated components of the first version of WebChoice was the option of secure e-mail [179]. Health-related questions and worries are often the reason why patients schedule a physician appointment, suggesting that an e-mail service alone could, to some extent, help alleviate patients' problems and concerns. Because an e-mail service is easier to develop and implement than more complex multi-component interventions, comparing such interventions is of interest. In order to further test and improve the component, the secure e-mail service was redesigned in WebChoice 2.0 to also enable communication with a team of health care providers (e.g. nurse, physician and social worker) at the hospital of care. Messages from patients were received in an e-mail mailbox by a team of nurses. The nurse could either answer the e-mail directly, or forward the e-mail to the mailbox of physicians or social workers who could answer the patients directly or return comments to the nurse (see Figure 6).

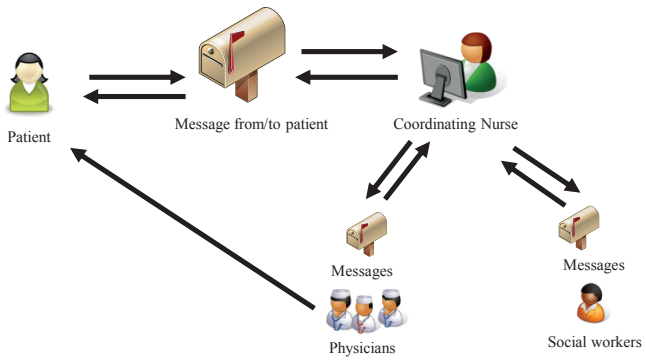

Figure 6. Message flow between patients and health care providers in the secure e-mail service.

As with other components of Choice and WebChoice the e-mail service was developed in close cooperation with patients and health care providers who described the needs and necessary functions and also tested prototypes and the final version of the e-mail service [211].

In this dissertation, "WebChoice" refers to WebChoice version 1.0 in study II and WebChoice version 2.0 in study III.

3.2 Overview of the studies in the thesis

The main objective of this dissertation was to address important challenges identified in the literature related to uptake, use and effectiveness of eHealth interventions into practice from different perspectives: 1) To explore nurses' experiences of benefits of and barriers to maintaining use of Choice in cancer care, one year after its implementation (study I); 2) To describe user characteristics associated with the use of different components of WebChoice (study II); and 3) To test and compare the effects of (a) a secure e-mail service, (b) the e-mail

service with additional features of WebChoice, and (c) usual care on patient outcomes after 6 month of access (study III).

To address these objectives, multiple methods and methodologies were used. Below is a summary of design, participants, methods for data collection and analysis in each of the three studies.

Table 3. Study overview

Study	Study I	Study II	Study III
Design	Qualitative Retrospective descriptive	Quantitative Exploratory secondary analysis	Quantitative Effect study, RCT Group 1: WebChoice Group 2: Secure e-mail Group 3: Usual care
Participants	N=20 Nurses	N=162 Intervention group from a previous RCT Breast and prostate cancer patients	N=167 Breast cancer patients
Data collection	Interviews in groups	Existing data from self-reported instruments and system use	Self-reported instruments and system use
Data analysis	Qualitative content analysis	Descriptive statistics Logistic regression Latent class analysis	Descriptive statistics Linear mixed model

3.3 Study I

3.3.1 Design

In this qualitative study, the aim was *to explore nurses' experiences of benefits of and barriers to maintaining use of Choice in cancer care, one year after its implementation*. Focus groups as described by Brink & Wood (1998)[212] were used to explore their experiences. Focus group discussions have the qualities of interviews as well as discussions [213] and also benefit from group dynamics [214] through stimulating participants to interact and exchange comments and feedback, with the ultimate goal to elicit as wide a range of experiences as possible.

3.3.2 Participants

The focus groups included nurses who had been part of the implementation process and who had used Choice in regular practice for one year. They were recruited from three inpatient and one outpatient cancer ward at two teaching hospitals in Norway. Head nurses identified potential participants, and nurses received information leaflets regarding participation. A total of 20 nurses agreed to participate, two males and 18 females, ranging from 23 to 55 years old (mean 34), with a range of 1 to 25 years (mean 5.9) of nursing experience. Of the participants, eight nurses had a clinical specialist education, such as oncology, mental health, intensive care or a master of nursing science.

3.3.3 Procedure for data collection

To address the maintenance dimension of the RE-AIM framework, an interview guide was developed by the research team to foster consistency in the questions asked across groups [214]. The opening question concerned the participants and their initial thoughts about being in the study. After a brief introduction to the area of interest, participants were asked about their experiences using Choice in their daily work. Thereafter key questions were posed concerning Choice's ability to elicit the patient's symptoms, problems and priorities for help, possibilities and challenges and perceived barriers to using Choice. The interview guide ended with an invitation for participants to comment on the assistant moderator's oral summary of the discussion (see appendix). The interview guide was first tested in a pilot focus group consisting of experienced nurses. No changes were made in the interview guide and the results from the pilot were included in the study.

Four focus group discussions were conducted in hospital meeting rooms with 4-6 respondents in each group. To circumvent the risk that experienced nurses would dominate the discussion in the groups [215], the respondents were divided into two groups of experienced nurses (two or more years at the unit) and two groups of less experienced nurses (less than two years at the unit).

The focus group discussions lasted between 56 minutes and 123 minutes and were audio-taped and transcribed verbatim by the PhD candidate. During all the discussions the PhD candidate and a colleague (both experienced nurses) were present and alternated between being moderator and assistant moderator in the different focus group discussions. The moderator asked questions to encourage participants to elaborate when their statements were

vague. The co-moderator took the role of an observer and recorded field notes during the focus groups. Immediately following the focus groups, the moderator and co-moderator met to discuss and record impressions from the discussions in an observation log.

3.3.4 Analyses

The analytical process of study I was guided by qualitative content analysis, a method of systematically analyzing written or verbal communication [216], as described by Graneheim and Lundman [217]. As little is known about how communication tools such as Choice are received in an organization, an inductive approach was chosen. This means that themes and subthemes were derived from data and not simply structured on the basis of a theory or previous knowledge [218]. The analysis examines both the manifest (i.e. the visible, obvious components) and the latent or underlying content meaning in the text [217]. An approach based on inductive data moves from the specific to the general in several steps, which will be further described below (table 4). The analysis was performed in an interactive process by the PhD candidate and the last author (ME). First, to obtain a "sense of the whole", the interviews were thoroughly read in order to obtain a comprehensive understanding of the nurses' experiences of using Choice. Second, meaning units, i.e. sentences and paragraphs containing aspects related to the same central meaning through content or context [217], were extracted from the text. The meaning units were condensed and summarized and where possible described in terms of the underlying meaning, preserving the core content. The condensed meaning units were compared for similarities and differences and abstracted into sub-themes. By continuously examining parts, as well as the entire text, three main themes and nine sub-themes describing the nurses' experiences were abstracted (see Table 2, Paper I). To ensure trustworthiness, the sub-themes and themes were discussed between the first and last author as well as within the research group until agreement was reached. To increase the transparency of the interpretation, themes and subthemes were illustrated with quotations in paper I.

Table 4. The analytic process of focus group interviews illustrated by extracts of meaning units, condensed meaning units, sub-themes and theme

Meaning units	Condensed meaning units	Sub-themes	Themes
"I'm mentally prepared for the conversation, ... I have time to think things through, both what answers I can provide, what feedback and support I can offer"	Having time to think through, prepares the nurse for communication	Prepares both patient and nurse for communication	Facilitator for shared understanding and engagement in patients' own care
"It's probably a way for them as patients to become more aware, writing thoughts down and being able to organize and better sort things through"	Becoming aware of, and structuring thoughts		
"The patient is well prepared. He knows that he has already checked something off, rather than suddenly being asked about it. Or if they come to us, they are more prepared when they know they have already checked something off"	Knowing what problems they have checked in Choice prepares the patients for communication		
"It's actually easier to prepare treatment plans through the use of Choice. Problems and issues are more evident there, the needs of the patient more clear, and rather than guessing it's easier to determine what needs to be done pointing to Choice and Choice results"	Information revealed in Choice was used as a basis for care planning	Shared engagement in care planning	
"When you use Choice you ask 'what do you think if this could help like this or like that?' That way he participates in the decision making about his own treatment, we create a plan based on our discussions, and he has indirectly participated in making his own treatment plan"	The patient indirectly participates in own care planning through use and communication about Choice results		
"With the quiet ones, we find out about problems we didn't think they had…"	Healthcare professionals get insight into the worries of more quiet patients	Gives the patients a voice	
"And I think there's something in treating people equally but differently. That the tool allows everyone to speak on an equal footing"	Each patient has an equal opportunity to be heard		
"At the same time, it will be up to the patients how much they want to reveal about their thoughts, concerns, and struggles"	The patients decide how much they want to share		

3.4 Study II

3.4.1 Design

In this study the aim was *to describe user characteristics and user patterns associated with the use of different components of WebChoice.* To address this aim, a quantitative exploratory secondary analysis of the RCT in which WebChoice was tested among 325 women with breast cancer and men with prostate cancer [7] was conducted. Secondary analyses involve analyses of data collected for another study, to test new hypotheses or to explore new relationships [219, p.236].

Two research questions guided the study: 1) What demographic-related, illness-related, and psychosocial variables are associated with the use of WebChoice? 2) Among WebChoice users, what are the associations among levels of patients' symptom distress, social support, depression, self-efficacy, health-related quality of life, and their use of different WebChoice components?

3.4.2 Participants

Participants in study II were the 162 respondents from the intervention group (access to WebChoice) in the above-mentioned RCT. In the RCT, patients had been recruited through advertisements in newspapers, in the Norwegian Cancer Society's magazine and on their website, and through pamphlets mailed to potential participants through the Norwegian Cancer Registry. Inclusion criteria were; undergoing active treatment for breast or prostate cancer, above 18 years of age, able to read/speak Norwegian and having access to Internet at home.

3.4.3 Procedure for data collection

All respondents had completed baseline questionnaires before randomization. Baseline data were retrieved from existing files from the RCT. Data on system use, during one year of access to WebChoice, were extracted from user logs on the server. Those who had logged on less than twice were categorized as non-users; those who had logged on twice or more were categorized as users. We specified a minimum of two logins because patients who only logged on once might only have read the welcome message and never actually used the system. Information was collected in the RCT regarding how many times the users logged on,

how much time they spent on the site and on each component and which components of WebChoice they accessed or used actively (e.g. sent e-messages or postings in the forum).

3.4.4 Self-report assessments

In the RCT, participants had completed self-report questionnaires related to demographic and disease-related characteristics as well as psychosocial variables.

Demographic variables (age, gender, marital status, level of education and household income) and *diagnosis-related variables* (diagnosis of breast cancer or prostate cancer, time since the diagnosis, recurrence/metastasis, type of treatment and other illnesses) were recorded with a study–specific questionnaire.

Symptom distress was measured using the 32-item Memorial Symptom Assessment Scale – Short Form (MSAS-SF) [220]. Symptom distress was measured with 5-point Likert scales, where respondents rated the degree from "not at all" (0) to "very much" (4). Higher scores indicated greater symptom distress. Cronbach's α for our sample at baseline was 0.92.

Social support was measured with the 20-item Medical Outcomes Study Social Support Survey (MOS-SS), including five sub-scales addressing emotional, instrumental, tangible and affectionate support and positive social interaction [221]. Responses on 5-point Likert scales ranged from "none of the time" to "all of the time". Higher scores indicated more social support. Cronbach's α for our sample at baseline was 0.96.

Depression was measured with the 20-item Center for Epidemiological Studies Depression Scale (CES-D) [222] with responses on 5-point Likert scales ranging from "rarely or none of the time" to "most or all of the time". Higher scores indicated greater depression. Cronbach's α for our sample at baseline was 0.88.

Self-efficacy was measured with the 33-item Cancer Behavior Inventory (CBI) version 2.0 [223], measuring coping self-efficacy with cancer-related stress on seven dimensions: maintenance of activity and independence; seeking and understanding medical information; stress management; coping with treatment-related side effects; accepting cancer and maintaining a positive attitude; affective regulation; and seeking support. Responses on 9-point Likert scales ranged from "not at all confident" to "totally confident". Higher scores indicated greater self-efficacy. Cronbach's α for our sample at baseline was 0.95.

Health-related quality of life (HRQoL) was measured using the 15-item 15D preference-based single index [224]. From five ordinal levels on each dimension, respondents chose the one that best described their present health status. Higher scores indicated greater HRQoL. Cronbach's α for our sample at baseline was 0.77.

Computer experience was assessed with a simple question about patients' experience with computer use, ranging from 1 – no computer experience at all; to 5 – a lot of computer experience.

3.4.5 Analyses

In this study, descriptive statistics, logistic regression and Latent Class Analysis (LCA) were used. Data were presented as medians and ranges for continuous variables and as proportions and percentages for categorical data. Associations between categorical variables among users and non-users were analyzed using the χ^2-test for pairs of categorical variables; the Mann-Whitney test was used for continuous data with skewed distributions. A multiple logistic regression model was fitted to compare users and non-users on demographic, disease-related and psychosocial variables. Variables with a *P*-value < 0.2 in the univariate logistic regression analyses were included in the multiple regression model.

To prepare the data for LCA, total scores on symptom distress, social support depression, self-efficacy, HRQoL and the data on system use of the different WebChoice components were divided into tertiles based on the scores for patients with breast or prostate cancer combined, using the whole sample of patients with access to WebChoice (Paper II, Multimedia Appendix 1).

3.4.5.1 Latent Class Analysis (LCA)

To identify characteristics associated with use of different components of WebChoice among users, we used LCA, which is a statistical method designed to identify whether there are underlying types or subgroups of individuals that share specific characteristics [225]. LCA is a pattern recognition technique based on the statistical concept of likelihood and thus based on the same principle as factor analysis. The main difference is that cases are not absolutely assigned to classes, but have a probability of membership for each class. The results are presented with estimated probabilities and formal statistical tests can be performed to evaluate different models (see paper II). The main goal for this LCA was to identify how a set of user-

related variables could be associated with different system use. Utilizing LCA enabled us not only to identify these associations but also to quantify their direction and strength. Due to a limited sample size, we fitted LCA models with at most three classes and at most four explanatory variables to avoid overfitting and multicollinearity.

We expected different user patterns for breast and prostate cancer patients because these patient groups differed with regard to gender, age, treatment and presence of other illnesses. Therefore, all LCA models were stratified by type of diagnosis and adjusted for age at inclusion.

To select variables for inclusion in the final LCA models we first fitted models where one psychosocial variable at a time was tested together with sets of three and three user variables. The psychosocial variables that revealed clear patterns of use were kept and integrated in the final LCA models, where a cluster of psychosocial variables was tested with single user variables.

The descriptive statistics and logistic regression were carried out using SPSS version 16.0 (SPSS Inc, Chicago, IL, USA). LCA was performed with SAS version 9.3, using the PROC LCA procedure for LCA [226]. *P*-values <.05 were considered statistically significant and all tests were two-sided.

3.5 Study III

3.5.1 Design

The aim of this study was *to test and compare the effects of (1) a secure e-mail service, (2) the multi-component WebChoice intervention (including the e-mail service), and (3) usual care (control group) on symptom distress, anxiety, depression (primary outcomes) and self-efficacy (secondary outcome) after 6 month of follow up*. We hypothesized that; the WebChoice group compared with the usual care group, would have better outcomes than the secure e-mail group compared with the usual care group. We also hypothesized that both groups would have better primary and secondary outcomes than the usual care group.
A RCT design with three groups was used to test these effects, as the RCT design is considered the gold standard for efficacy/effect research [227]. Although it provides no guarantee of getting equal groups, this design is the most acceptable to ensure that variables assumed to impact outcome variables (confounding factors) are randomly distributed in the

groups, thus making the groups comparable [212, p.29]. Additional explorative analyses were also performed to detect whether the outcomes were associated with the actual use of the interventions.

3.5.2 Study sites

Initially, a large University Hospital in Oslo agreed to participate in the study by providing access to recruitment of patients, and health care providers to answer e-mail from patients. Unfortunately, when the study was ready for start-up, the hospital withdrew from participation. The reasons given were reorganization of the hospital and lack of resources to answer e-mail from patients. As all preparations had been made with this hospital, with permissions, etc., we had to start all over again, which delayed the study by one year.

Ten hospitals from all over Norway were then contacted via e-mail and invited to participate. Five declined due to ongoing studies or lack of resources to participate. Five sites were interested and were given an in-person presentation of the study and the activities it would entail for them. Two of these hospitals concluded that they were not able to participate. Again, lack of resources was given as the reason.

Three hospitals agreed to participate. Study participants were recruited from one university hospital and two regional hospitals, at breast diagnostic centers or ambulatory chemotherapy, radiation and surgical units. The hospitals/units did not receive any incentives for participating in the study. For more details, see paper III.

3.5.3 Participants and sample

A statistical power of 80% to detect an effect size of 0.25 at the 5% significance level and a sample size of 369 respondents were originally calculated. This sample accounted for an expected 30% dropout rate during the study period and a 70% utilization rate of the intervention, similar to observations in the previous RCT of WebChoice [7]. Due to the withdrawal of the initial collaborating study site and challenges with slower recruitment than anticipated at the three hospitals where the study took place, we had to stop inclusion after 200 consenting participants, before the calculated sample was obtained. Study III reports on 167 patients for whom 6-month follow-up data were available at the time this manuscript was written. These participants were recruited between May 2010 and September 2012.

Inclusion criteria were recent diagnosis of breast cancer treated with surgery, or under treatment with radiation, chemotherapy, hormone therapy, or combinations of those (maximum 12 months after surgery), age over 18 years, able to write/read and speak Norwegian, having access to the Internet at home and with a public key solution for secure system access (PKI).

3.5.4 Study procedures

3.5.4.1 Pilot

A pilot study of the experimental intervention, data collection and associated procedures was conducted with 15 breast cancer patients, five from each site. The interventions and instruments for data collection worked well. Necessary adjustments in relation to recruitment procedures and information to patients were made before the RCT began.

3.5.4.2 Recruitment

Eligible patients scheduled for surgery or coming for check-ups after surgery or treatment were identified by the study nurses at the hospitals. Upon patients' arrival at the clinic, the study nurses met the patients, provided brief information about the study and asked if they were interested in participating. If the patients agreed, the nurse informed them about the study's purpose and procedures, and asked for written informed consent. Consenting patients completed baseline questionnaires before randomization.

3.5.4.3 Randomization

After completion of baseline questionnaires, patients were randomized according to a predefined automated computerized block randomization, with a block size of 42 stratified by site. To avoid selection bias, the randomization was performed by an external research office, independent of both the researchers and clinicians in the study. The block size was not known to the researchers before analysis of the data. Due to the content of the interventions, patients could not be blinded to which arm they were randomized.

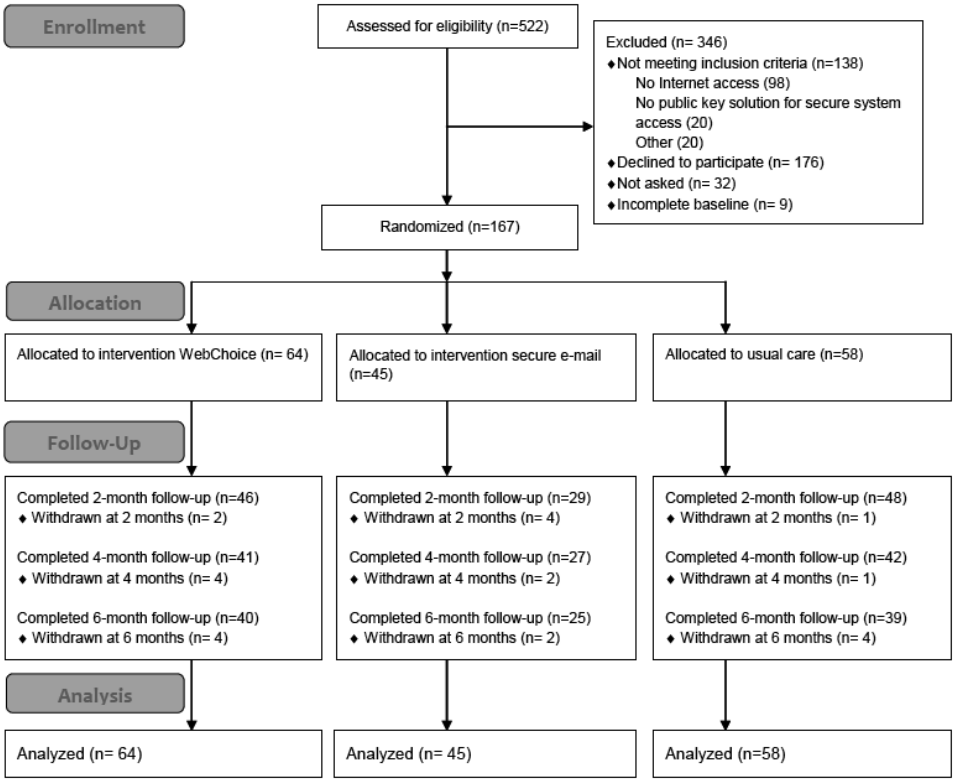

Figure 7. Flow of participants throughout the trial.

3.5.4.4 Interventions

Patient randomized to the usual care group were followed up as usual at the hospitals where they were treated. Patients who were randomized into the secure e-mail or WebChoice groups were informed and instructed in the use of the system. They received a printed user manual with instructions for use, how to log on to the system, contact address and phone number for help if needed. The only in-person information given was instruction on how to access the site and how to connect with the study support service if questions occurred. The study nurses showed them where in the user manual they could find information about how to access the site and how to connect with the study support service if needed. In addition, the participants were informed that they could use the e-mail or any component of WebChoice as much or as little as they liked, and that using the system was entirely voluntary. The e-mail component was the same for both intervention groups.

After being informed about the group assignment, the patients were given access to the interventions the same day. They received an automatic welcome message when the system was ready to use. There was an option to be notified by SMS or regular e-mail when new messages appeared in the system. Most participants wanted this notification.

3.5.4.5 Care providers

Care providers (n=20; 11 nurses, 6 physicians and 3 social workers) who answered questions from patients consisted of a dedicated group of expert nurses and physicians in breast cancer care, and social workers at the hospital where the patients were treated. They were thoroughly trained in administering the secure e-mail service, technically as well as in codes of conduct for online communication with patients and there was a clear schedule for who was responsible for answering patients' messages. The nurses were first-line responders, and received all messages first. If necessary, they could forward the message to other care providers. If considered important, information from the e-mails could be copied into the medical record and made available for other health care providers. When new questions arrived in the system, the recipient was notified through the hospital's e-mail system or by SMS. The same providers answered e-messages from both the secure e-mail and WebChoice groups using the same interface. However, they were not entirely blinded to the intervention group assignment because patients sometimes disclosed their group identification in the messages. The health care providers had no access to details about how patients used other components of WebChoice. They did not receive any reimbursement or additional dedicated time for answering secure e-messages from the participants.

3.5.5 Procedure for data collection

All outcomes were measured at baseline and at 2, 4 and 6 months post baseline, through self-report questionnaires sent to participants by postal mail from an external research office. If no response was received within two weeks, a letter with a reminder was sent once, and participants were informed that they could withdraw from the study at any time. The researchers and the clinicians who answered the secure e-mail had no influence on these reminders. Data on system use were extracted from the user logs on the server. As in study II, those who had logged on less than twice were categorized as non-users; those who had logged on twice or more were categorized as users. Information was collected on how many times the

users had logged on as well as the components of WebChoice that were accessed or used actively (e.g. sent e-messages or postings on the forum).

The primary outcomes were symptom distress, anxiety and depression. The secondary outcome was self-efficacy.

3.5.6 Self-report assessments

Demographic variable/characteristics (age, marital status, level of education, employment status, household income and the use of Internet services) were recorded with a study–specific self-report questionnaire.

The time of diagnosis and stage of disease were obtained from the medical record. Based on the patients' tumor (T), node (N), and metastasis (M) classification at the time of diagnosis, the stage of disease was classified into 5 stages (0 = ductal carcinoma in situ, to 4 = advanced-stage disease) using the TNM Classification of Malignant Tumours of the Union for International Cancer Control guidelines [228].

Comorbidity was measured with the Self-Administered Comorbidity Questionnaire (SCQ-19), which evaluates the number of, treatments for, and functional impact of health problems. It includes 16 common comorbidities and 3 optional conditions [229]. The total SCQ-19 score can range from 0 to 57 when the 3 optional items are used. It is a clinical scale, with established validity and reliability [229], for the assessment of comorbidities in patients with chronic medical conditions. A higher total score indicates a more severe comorbidity profile.

Symptom distress was measured in this study by using the full version of the 32-item Memorial Symptom Assessment Scale (MSAS) [220], which lists physical and psychological symptoms that occur due to cancer or its treatment. For each symptom, patients were asked to indicate whether they had had the symptom during the previous week. If they had experienced the symptom, they were asked to rate its frequency, severity, and associated distress. Symptom frequency and severity were rated using a 4-point Likert scale. Symptom distress was rated using a 5-point Likert scale. The validity and reliability of the MSAS are well established [220], and MSAS has previously been used in breast cancer populations [230]. Higher scores indicate greater symptom distress. Cronbach's alpha coefficient for our sample at baseline was .85.

Anxiety and depression were measured with the Hospital Anxiety and Depression Scale (HADS) [231], a 14-item, self-report measure of psychological distress. The HADS is divided into 2 subscales: anxiety (HADS-A) (7 items) and depression (HADS-D) (7 items). Respondents are asked to indicate which of 4 response options (rated from 0 to 3; score range, 0-42) comes closest to describing how they have been feeling in the previous week for each item. Scores from 0-7 on the subscales are regarded as being in the normal range; a score of 11 or higher indicates probable presence of a mood disorder, and a score of 8 to 10 is suggestive of the presence of anxiety or depression [232]. The scale has been found to perform well in assessing the symptom severity of anxiety disorders and depression in hospital settings, in primary health care and in the general population [233]. Cronbach's alpha coefficient is reported to vary from .68 to .93 for HADS-A, and for HADS-D from .67 to .90 [233]. In our sample, Cronbach's alpha coefficient at baseline was .83 for HADS-A and .76 for HADS-D.

Self-efficacy was measured with the 33-item Cancer Behavior Inventory (CBI) version 2.0 [223]. See further description of the instrument in the method section of study II. Cronbach's alpha coefficient for our sample at baseline was 0.96.

3.5.7 Support and surveillance

The project administrator (the PhD candidate) and IT support staff were available by phone during weekdays to answer questions from both patients and health care providers regarding participation in the study as well as how to perform different tasks in the interventions they were assigned to, and to respond to technical questions. All participants were informed that WebChoice/secure e-mail service could not be used for urgent matters requiring immediate medical attention. To provide help in using the different components, a short explanation was available when participants pressed the "read more" button on each component.

For the discussion forum, guidelines for use were created to ensure appropriate conduct. A nurse employed by our research center monitored new postings to ensure proper use and adherence to the guidelines. The project administrator monitored e-mail communication to ensure that requests sent by patients were responded to within the promised two-workday window.

3.5.8 Analyses

Differences between users and non-users were analyzed using the χ^2-test for pairs of categorical variables and the Mann-Whitney-Wilcoxon test was used for continuous data with skewed distributions.

For analysis of between-group differences in symptom distress, anxiety and depression (primary outcomes) and self-efficacy (secondary outcome), linear mixed models (LMM) for repeated measures were fitted. A diagonal covariance structure was used to model dependencies among measurements on the same individual at different time points. Models for each outcome consisted of 3 effects: measurement occasion (time), interventions (WebChoice, IPPC, usual care) and the interaction of time and intervention. All measured time points of the outcome variables were considered and the LMM approach therefore adjusts for baseline differences. To test whether potential confounders impacted the results, LMM adjusted for variables such as site, age, marital status, education, time since diagnosis, stage of disease and comorbidity were fitted. Compared to the unadjusted models, these adjusted models revealed even larger differences in favor of the intervention groups compared to the usual care group. Taking the limited sample size into account and aiming to avoid over-fitting, only the results from the unadjusted models are presented. As no statistically significant differences were observed between the study groups on demographic and disease-related factors at baseline, these models were not adjusted further for the possible confounders. This approach might underestimate the true differences between the groups, but was chosen based on the limited sample size. Analyses of primary and secondary outcomes were conducted on an intention-to-treat basis, including all participants in each group, independently of whether they were users or non-users of the interventions.

The model parameters were estimated using the classical maximum likelihood approach. No imputation of missing data was necessary or performed, as the LMM uses all data available to estimate the covariance matrix and model the dependencies. The results are presented as p-values for the overall effect of the variables when the baseline score and all time points are included. Moreover, overall mean differences are presented, i.e., the difference between groups adjusted for baseline scores and taking all time points into consideration. Reporting of overall mean differences was chosen because we were interested in differences between the groups over the entire six-month period.

In addition, explorative sub-analyses were performed to detect whether the outcomes were associated with the actual use of the interventions. LMM for repeated measures were fitted for each outcome with three factors: measurement occasion (time), intervention (user/non- user of WebChoice and secure e-mail) and the interaction between time and intervention. In addition, age was added as a covariate because age is known to be associated with use of Web-based self-management support systems [145-147,149].

Analyses were carried out using SPSS version 18.0 (SPSS Inc, Chicago, IL, USA). *P*-values <.05 were considered statistically significant and all tests were two-sided.

3.6 Ethical aspects

All three studies in this dissertation were planned and performed in compliance with the principles outlined in the Declaration of Helsinki [234]. They were approved by the Regional Committee for Medical and Health Research Ethics in Norway (Study II: 2.2205.1593; study III: 6.2009.1098), the Privacy Protection Committee at the hospital (*Personvernombudet*) (Study I: 07/8617; study III: 2010/543), and the Data Security Inspectorate of Norway (Study II: 05/01308-2). Study II and III were registered at ClinicalTrials.gov (NCT00710658, NCT00971009).

Written informed consent was obtained from both patients and health care providers. They were informed that participating was entirely voluntary. The patients who participated in study II and study III were informed that they could use the assigned intervention (WebChoice/secure e-mail) as much or little as they wanted. Participants in study I and III received no reimbursement for participation. However, in the previous RCT, patients in study II had received a lottery ticket worth 20 Norwegian kroner upon completion of their last questionnaires.

In the focus groups with nurses as participants, the nurses were informed that data would be coded and treated confidential and no statements could be traced back to the identity of the participants. Analyses were performed on the transcribed material only (i.e., not the tapes or audiotapes) and the transcribed materials were stored on a secure server at the hospital.

Participants in study III were asked to complete questionnaires four times over a six-month period. Because the participants were included within one year after diagnosis, and thus were dealing with symptoms from the disease as well as the ongoing treatment, completing all forms

could be experienced as burdensome for some. However, if completed questionnaires were not received only one reminder was sent to the participants.

3.7 Security

Strong security levels were implemented to protect the information sent by the patients through the WebChoice interventions. All data were submitted to a secure server at the Oslo University Hospital using an encrypted connection. Patients and health care providers were authenticated using a smart-card based public key (BuyPass) in WebChoice 1.0 and hence had to learn a new procedure in order to log on to the system. In the revised version of WebChoice, WebChoice 2.0, a public key solution that is currently used by Norwegian banks as a security platform (BankID) was used for authentication. Using BankID, the log-on procedure is the same for the users whether they log for online bank services or for the secure WebChoice/e-mail service. All procedures complied with the Norwegian Data Protection Authority.

4. Results

A summary of the dissertation results appears below. A more detailed description of the results can be found in each paper separately.

4.1 Study I

Nurses' Experiences of Using an Interactive Tailored Patients Assessment Tool One Year Past Implementation

The objective of this study was to explore nurses' experiences of the benefits and the barriers to maintaining use of Choice in routine cancer care one year after implementation. Transcripts from the focus group discussions were abstracted into three main themes showing that Choice facilitated shared understanding and engagement, enhanced the patient's strengths and imposed new challenges and ethical demands on the health care professionals. The three themes and subthemes are presented in brief below:

Theme 1: *"Choice as facilitator for shared understanding and engagement in own care"*. Choice was considered a facilitator for communication. Nurses reported that Choice enabled patients to express and share their symptoms and priorities for care with the nurses, making both patients and nurses better prepared to communicate and plan care. The subthemes identified under theme 1 were: *"Preparing both patient and nurse for communication"*, *"Shared engagement in care planning"*, and *"Giving the patients a voice"*.

Theme 2: *"Enhancing the patient's strength"*. When using Choice, patients were able to process and think through many of their problems and the nurses perceived that some healing took place as a "side effect" during the process. The subthemes identified were *"Release of internal strengths"* and *"Confirming "'normalcy'"*.

Theme 3: The third theme, *"New challenges for the nurse"*, dealt with challenges that emerged through use of Choice in routine care. These challenges were divided into four sub-themes: *"Organizational challenges"* including, time to perform the new task and the need for routine changes to better fit Choice into the workflow. *"Interactions with technology"* involving lack of compatibility between different computerized systems and impressions of use of technology. The sub-theme *"A need for communication skills training"* raised the issue

of new skills needed to make full use of Choice in communication with patients. Finally, *"New ethical challenges",* included topics such as results from Choice being overwhelming for the nurse, making them feel bad when unable to discuss all topics from the assessment, or feeling as though they were violating the privacy of patients. For details, see paper I.

4.2 Study II

How User Characteristics Affect Use Patterns in Web-Based Illness Management Support for Patients with Breast and Prostate Cancer

The objective of this study was to explore, in a secondary analysis, user characteristics and user patterns associated with the use of different system components of WebChoice. About two thirds (103/162) logged on to WebChoice more than once, and were defined as users. The users had visited WebChoice on average 12 times (median) during the year (range 2-829). Of the patients who had access to WebChoice, 38% (62/162) had sent e-messages to care providers (Table 5, paper 2). Patients with high level of computer experience were almost four times more likely to use WebChoice than those with no or little experience, and having no additional illnesses besides cancer increased the probability of being a user by a factor of two (OR=.3.77, CI 1.20-11.91; OR=2.10, CI 1.02-4.34, respectively). Latent class analyses showed that both men with prostate cancer and women with breast cancer who had low scores on social support, accompanied by high levels of symptom distress and high levels of depression, were more likely to use the e-mail component. For men with prostate cancer, these variables were also associated with high use of the self-management advice component.

Significant differences between men with prostate cancer and women with breast cancer were found in analysis of associations between WebChoice use and user characteristics. High use of all WebChoice components was associated with low levels of social support among women with breast cancer but not among men with prostate cancer. High use of e-mail, advice, and the discussion forum was associated with high levels of depression among women with breast cancer, but not among men with prostate cancer. For men with prostate cancer but not women with breast cancer, high use of symptom assessments, advice and the discussion forum were associated with high levels of symptom distress. For details, see paper II.

4.3. Study III

Comparing Effects in Regular Practice of E-communication and Web-Based Self-management Support on Symptom Distress, Anxiety, Depression and Self-Efficacy among Breast Cancer Patients. Preliminary Results from a Randomized Controlled Trial

The objective of this study was to test and compare the effects of (1) secure e-mail service, (2) WebChoice (including the e-mail service), and (3) usual care; on symptom distress, anxiety, depression, (primary outcomes), and self-efficacy (secondary outcome), among breast cancer patients. Of the 522 breast cancer patients assessed for eligibility, 138 did not meet inclusion criteria, mostly due to lack of Internet access (see figure 7). Thirty-two were not approached for participation, mainly due to busy wards. Of the remaining 352, 176 agreed to participate, leaving a participation rate of 50% (176/352). Non-participants were older (did not meet inclusion criteria: median age 67; said no: median age 59 years), than participants (median 52 years). Frequent reasons given for declining participation were lack of experience with computers/the Internet or that they had too much on their mind related to their illness. Nine patients were excluded due to incomplete baseline data, leaving a final sample of n=167.

Patients were randomly assigned to the WebChoice group (n=64), the secure e-mail only group (n=45), or the usual care group (n=58). There were no statistically significant differences on demographic or psychosocial variables between participants in the three groups at baseline (Table 1, paper III). Among those with access to WebChoice, 64% (41/64) logged on more than once and 39% (25/64) sent e-mails to care providers (Table 3, paper III). In the secure e-mail group, 40% (18/45) sent e-mails. The e-mails were mainly answered by nurses. Of 153 e-mails, 22% (33/153) were passed on to and answered by physicians. Only one e-mail was passed on to social workers.

Both intervention groups were tested compared to the usual care group but not compared to each other. Linear mixed models analyses revealed that the WebChoice group reported significantly lower symptom distress (Mean diff: .16, 95% CI: .06-.25, *P*=.001), anxiety (Mean diff: .79, 95% CI: .09-1.49, *P*=.03) and depression (Mean diff: .79, 95% CI: .09-1.49, *P*=.03) compared with the usual care group (Table 2, paper III). The secure e-mail group reported significantly lower depression scores than the usual care group (Mean diff: .69, 95% CI: .05-.1.32, *P*=.03) but no differences were observed for symptom distress or anxiety. No

significant differences in self-efficacy were found among the study groups. For details, see paper III.

Exploratory analysis comparing users (WebChoice: logged on twice or more; secure e-mail: sent at least one e-mail) and non-users of the interventions revealed no baseline differences on demographic or disease-related variables. There were no outcome differences between users and non-users of WebChoice or secure e-mail on symptom distress, depression or self-efficacy. The users of the secure e-mail service had significantly lower scores on anxiety compared with the non-users (Mean diff: -1.28, 95% CI: -2.54 - -.01, *P*=.047). No such differences between users and non-users were observed in the WebChoice group.

5. Discussion

This dissertation set out to contribute to the translation of evidence into clinical practice, addressing gaps related to uptake, use and effectiveness of eHealth interventions in practice. The discussion focuses on the main findings, but some additional findings are also discussed Strengths and limitations are discussed in methodology considerations, followed by significance for science and clinical practice, and recommendations for future research.

5.1 Main results

Results of this dissertation provide important new information and show how *uptake* of eHealth interventions creates new challenges for health care providers (study I). The dissertation also adds to evidence showing how different user characteristics are associated with different *use* of Web-based self-management support systems. Secure e-mail and advice were found to be much used components among cancer patients with high symptom burden and low social support (Study II). Further, the findings support the *effectiveness* of Web-based self management support, as WebChoice was effective in reduction of symptom distress, anxiety and depression among cancer patients (Study III). The secure e-mail component alone contributed to reduced depression scores, which is promising, as depression is highly prevalent and debilitating among cancer patients. An e-mail service is also much easier to develop and widely implement than more complex multi-component solutions. In summary, eHealth interventions can be an important contributor in provision of care and support for people with chronic illnesses.

The result of the dissertation will be discussed organized by the RE-AIM framework, a framework designed to improve the likelihood of translation interventions into practice [16,26]. The aims of the dissertation mainly correspond to the Effect, Implementation and Maintenance dimensions. Additional results from the three studies are discussed as appropriate and also address the Reach and Adoption dimensions.

5.1.1 Reach

When eHealth interventions are offered, it is important to know who can be reached by these interventions. The Reach dimension in RE-AIM considers the representativeness of

individuals willing to participate in a study [16,188]. In study III, 50% of those eligible were reached (agreed to participate in the study). During the recruitment we were able to collect information about age, unmet inclusion criteria and reason for declining participation if known. Nearly one third did not meet the inclusion criteria, and the most frequent reason given was lack of Internet access (19%, 98/522). This was surprising given the Internet penetration in Norway, ranging from 90% to 94% during the recruitment period (2010-2013) [235]. Non-participants were older, compared to those included. Frequent reasons given for declining participation in study III were lack of experience with computers/the Internet or that they had too much on their mind related to their illness. Participants included in both study II and III had higher education levels than the average in Norway [236]. This corresponds to literature reporting younger age and having a higher education to be factors associated with more frequent health-related Internet use [88,90,237-240], suggesting that some demographic factors are still associated with ability and willingness to participate in eHealth studies.

One way to increase the participation rates, and through this maybe to increase representativeness, might be to offer a demonstration of the interventions at the time of inclusion. In addition, simply to expose users to new interventions can contribute to use. This was experienced by nurses in study I, where some older patients were initially reluctant about the Choice intervention but became more interested when they tried it, and managed to use it.

5.1.2 Effectiveness/efficacy

The effectiveness dimension in the RE-AIM framework refers to the impact on important outcomes, including potential negative effects, and reflects the success of an intervention [16,188]. In study III, both the multi-component WebChoice intervention and the secure e-mail service alone had significant effects on patients' outcomes when they were offered as a part of a real-life situation.

The findings that WebChoice reduced symptom distress as well as levels of anxiety and depression scores (Study III) are in line with previous research showing that Web-based interventions in cancer populations decrease depression and anxiety scores [78] and reduce symptom distress [7,76]. In addition, results showed a tendency towards increased self-efficacy. This is promising given that study III entailed a relatively small sample from three diverse practice settings in regular care. One possible explanation for the significant results might be related to the unmet needs of cancer patients, such as needs within the domains of

communication, information, psychosocial, psychological and supportive care, which are reported to be highest during the treatment phase [241]. WebChoice allows patients to monitor their psychological, psychosocial and physical symptoms as well as to get individually tailored information and support on how to manage their symptoms through the advice component. The information component can offer educational information through access to other reliable Web sources. Through WebChoice, patients are also able to read the information more than once, when it suits them. Offering self-management interventions in this early phase might be especially helpful, as supported by the results from a study of a secure e-mail service similar to the one in study III, where the need for such a service was described as being most prominent during the first phase following hospital discharge [242].

Also noteworthy is the finding that access to the secure e-mail service alone reduced depression scores (study III). This is especially promising, as depression is debilitating and highly prevalent among cancer patients [243,244]. An e-mail service is also much easier to develop and keep up to date than more complex multi-component solutions. The e-mail service's ability to reduce depression scores might relate to indications that patients with higher scores of depression, in addition to higher symptom distress and low social support, are high users of the e-mail service, as seen in WebChoice (Study II). The e-mail service is thus an intervention that is used by those with high illness burden, likely a group with high needs as well as high potential for improvement. The significant impact of access to secure e-mail in study III was detected despite different settings and variations in organization of care, which holds promise for secure e-mail services as interventions for reduction of depression scores among breast cancer patients, across settings. E-mail will hence be an important component to include in Web-based self-management support systems in the future.

New in study III (i.e. compared to study II), was that the e-mail service was administered, and mostly answered, by nurses known to the patients. As most of the identified studies of e-mail communication effects deal with e-mail between patients and physicians [134], this dissertation adds important knowledge about a nurse-administered service. As part of practice, services administered by a group of nurses might be a model for offering e-mail communication between patients and providers. However, we do not know if services administered by a team of nurses, compared to services answered by a single health care provider (e.g. a physician), have a similar or different impact on patient outcomes. Likewise, we do not know whether the type of services has an impact on the number of messages received, topics in the messages, patient and provider satisfaction, or experiences with use. In

addition, how access to known compared to unknown providers may impact the results needs to be further examined.

Whether a patient was a user or non-user of WebChoice (study III) was not connected to the observed effects on symptom distress, anxiety or depression. Similar results were observed in a previous study of WebChoice [7] and other studies of web-based support systems [158,160,181]. The findings of reduced scores on symptom distress, depression and anxiety (study III), despite just 64% of those with access to WebChoice being users, might relate to the psychological effects of the sheer possibility to use the system when needed. The opportunity to get the information needed for self-management of symptoms and problems, independent of time and location, may create a psychological effect that might contribute to the findings. Similarly, the reduction in depression scores among the secure e-mail group was detected although only 40% sent e-mails in this group. Interviews with non-users of a similar secure e-mail system revealed that even if they did not use the system, they liked having the possibility [245]. The assurance that someone is there for you, and can answer the questions important to you, might contribute to the effects observed on depression (study III). However, the mechanisms behind the effects of "possibility to use the system" are not known. For instance, no demographic or disease-related differences were observed between users and non-users in either intervention group, suggesting that other factors might be in play.

Exploratory analyses of effects of the e-mail service, and relation to use/non-use, revealed that e-mail users had borderline significant lower outcome scores on anxiety than non-users. This might indicate that actual use of e-mail has a potential impact on reduction of anxiety symptoms. However, this result is based on a small sample and needs to be studied further.

WebChoice is a system designed to support cancer patients in self-management of their illness. The system offers different components, so participants can use what they prefer without any push to use the entire system. In study II, different users (those who logged on twice or more) utilized different components, and made from two to 892 visits in the system. Users in study III visited WebChoice from two to 41 times. Whether dose of use impacts patients' outcomes remains to be tested. However, this is not a straightforward analysis. Benefit does not necessarily correspond to total volume of use, but rather depends on the importance of the information or support provided. For example, reading advice for a very bothersome symptom just once may be enough to learn how to find relief, while reading postings on the discussion forum many times may help one feel good, but may not be equally

beneficial for managing symptoms. Reading advice once would be registered as low usage, engaging in the forum as high. How use of different components is connected to patients' outcomes and dose of use remains to be tested.

In recent years, several authors have discussed whether RCTs are the appropriate design for eHealth research [163]. The main argument against RCTs is that they take a long time to conduct. This is problematic within technology studies, as the development of technology moves very fast. Because it often takes seven years from submission of the grant proposal until publication of the results of the study [246], the intervention studied risks being out of date when the results are finally available. In study III, some similar challenges were experienced. At the end of the study, some respondents reported that WebChoice was not of interest to them as it could not be operated using tablets, such as IPads. Similarly, the online discussion forum in study III was used less than in study II, possibly a result of other free applications being available, such as Facebook, offering services for social connection. Despite these challenges, positive results on patient outcomes were detected both in the WebChoice and in the secure e-mail group in study III. WebChoice contained components that might be more independent of technological innovations, such as updated advice on how to handle their specific symptoms and collections of links to trustworthy sources. In addition, secure e-mail communication with health care providers was offered, a service that still is not generally available in Norway. The speed of technology development, however, will continue to challenge design and methods to measure effects of eHealth interventions.

5.1.3 Adoption

Adoption concerns the number and representativeness of settings and intervention agents who are willing to participate in a given initiative [16,188]. To identify the potential for an intervention to work in a real-world environment, it is important to include information on the settings that adopt the intervention [16]. As described in the method section (study III), the initial collaborating hospital withdrew from study collaboration. Three of the next 10 hospitals invited to participate agreed to participate, resulting in an adoption rate of 27% (3/11). One of the reasons mentioned for not participating was lack of resources to answer e-mail from patients. This demonstrates some of the complexity of conducting eHealth studies in "real life" settings. Participating in a study is not the same as implementing secure e-mail in routine care, but this reason for declining should be acknowledged. It highlights the need for reimbursement systems, which are described as accelerating the uptake of secure e-mail services in routine

health care [135]. However, we do not know if factors such as resources, expertise, interest and ability to implement the secure e-mail service contributed to willingness to participate for the hospitals that did participate in the study. More research is needed to address these topics. The adoption dimension can be challenging to assess by quantitative methods only and the use of qualitative data as in study III is recommended [26].

5.1.4 Implementation

The implementation dimension in RE-AIM refers to the intervention agents' fidelity to the various elements of an intervention's protocol, and how the individual makes use of the intervention [16,188]. Although eHealth interventions have been shown to be effective, several implementation-related issues, such as varying levels of user adherence, non-usage attrition and high rates of dropout have been seen in many studies [21,22,141,142].

Consistent with previous research [146,155], prior computer experience made patients more likely to be users of WebChoice (Study II). In addition, individuals without other illnesses were more likely to use WebChoice than those with multiple illnesses. This is also consistent with previous studies suggesting that users of Internet interventions are healthier than non-users [145,247]. Chronically ill people are also reported to be less eHealth literate [237] and may not regard web-based interventions as a suitable alternative for them, or they may be too ill to benefit. However, in study III, no differences could be found between users and non-users in either the WebChoice group or the secure e-mail group on demographic or disease-related variables at baseline. The influence of these factors may be less evident as Internet penetration are increasing in society [87,235]. Whereas demographic factors still play a role in who is available for web-based interventions (Study III), these factors might not impact who uses or does not use the system after agreeing to participate in a study/initiative. To make it possible to follow how demographic factors impact use of Web-based interventions, these variables should be included in future studies.

About two-thirds of participants used the WebChoice intervention in study II and III. Consistent with findings from other studies [76,77], the usage was reported to be modest; 12 visits (median) (study II) and seven visits (median) (study III). Even though website use is described as high initially and declining thereafter [62,71,160], we cannot compare the user frequencies for study II and III directly, as use was reported for 12 months in study II and for six months in study III. However, less use of web-based self-management support systems by

cancer patients in more recent studies was also noticed by Baker et al. [163]. The reasons for this are not known, but the availability of other channels for social interactions, such as Facebook and personal blogs, may play a role. Among users of WebChoice, results suggest that demographic and disease-related factors did not play a role in their user pattern, but several psychosocial variables did (study II). Participants with high levels of symptom distress and depression, indicating high illness burden, who also had low social support utilized the e-mail service and advice component the most. This is consistent with studies reporting an association between lower levels of social support and symptoms of depression or negative mood with higher system use [150,153,154]. High illness burden accompanied by low social support might indicate a higher need for support compared to those who do relatively well, and these patients might have more to gain from e-mail communication. One way to tailor support to this group might be to screen for symptom distress, depression and social support to identify the need for support. More research is needed to explore how user characteristics and user patterns can provide guidance on the best ways to target interventions to groups of people.

The e-mail service in study II was evaluated by patients in previous studies as a supportive and useful component [179,248]. Similar findings were revealed in a study of a Web-based diabetes support system showing e-mail communication with a nurse as an important reason for using the system [21]. Patients felt they received personal feedback and that the nurse looked after them. The possibility to communicate directly with a health care provider seems to be an important and highly valued feature across different patient populations. Study II suggests that this component may particularly appeal to people with high illness burden and a low level of social support, potentially due to a high wish or need for support, here provided through secure e-mail. User characteristics were not associated with high use of the forum, even though the forum was the component in which patients spent most time. It seems that a discussion forum may not be the place to turn to if one has little social support in addition to a high illness burden. This corresponds with the question of whether dose of system use is related to effects, as also discussed in 5.1.2.

Men and women used WebChoice differently (study II), and this might indicate different needs for support and information. Low levels of social support were associated with high use of all components of WebChoice for women with breast cancer, but not for men with prostate cancer. In addition, high levels of depression were associated with high use of several components in WebChoice among women with breast cancer whereas high levels of symptom

distress were associated with high use among men with prostate cancer. Both gender and diagnosis may play a role in these differences, and differences in symptoms could also indicate variations in needs for support. For example, men with prostate cancer have been reported to use online support sites for information while women with breast cancer use them for emotional support [249,250]. To make it possible to test how gender affects use of such systems, studies that include men and women with similar diagnoses in the same studies are needed. As high illness burden and low social support are associated with high use of several components, this indicates that these characteristics are not barriers to use but rather may function as motivators for use. The same pattern has previously been seen in a study testing an interactive cancer communication system [154], and further insight into user characteristics and user patterns can provide guidance for targeting interventions to different groups of people.

5.1.5 Maintenance

The maintenance dimension of the RE-AIM framework refers to the extent to which an intervention is sustained, modified or discontinued after a trial period [16]. In the focus groups with nurses who had used Choice one year after a trial period (Study I), Choice was acknowledged as having several benefits for patients as well as nurses in terms of preparing both parties for communication, providing a shared engagement in care planning and giving the patient a voice. It also was reported to enhance the patients' strengths, in line with findings reported by patients who had used Choice in another study [49]. Similar findings were reported in a study of the Edmonton Symptom Assessment System (ESAS), an assessment tool with some similarities to Choice [54], where most of the nurses found that ESAS enhanced patient care, helped patients to articulate their symptom issues, and facilitated follow-up of patients. Similarly, in a study of an electronic version of ESAS, clinicians reported it as useful [43]. This corresponds to one of the most important facilitating factors for maintenance of interventions; system usefulness/relative advantage [114,189]. According to Loscalzo et al [128], eHealth interventions are ready for implementation only if key professionals and administration understand the value of the interventions. The decision to use Choice in routine patient care was based on the perceived usefulness experienced by the health care providers at the units participating in the earlier trial [207], and the evidence of Choice's effectiveness in reduction of symptom distress and reduction of the need for symptom management support [11]. The decision was supported by the nursing and medical

leadership at the units. The nurses in the study were thus familiar with the potential benefits and experienced several benefits after use in daily work.

Some of the nurses noted, however, that even though they knew the advantages and possibilities Choice could offer, they still did not have their own "good experiences" using it. This impacted how often they used and followed up Choice assessment among their patients, and consistent with Rogers' theory of "Diffusion of innovations"; that it is the individuals' perception of the relative advantage of an innovation (in this case, what the users believe the relative advantage to be) that matters, not the experts' objective evidence [189]. The greater the innovation's perceived advantage to the user, the easier it is to adopt and sustain [189]. Workload benefits are described as facilitating factors in addition to benefits for patients' outcomes [128,129].It became evident that Choice sometimes challenged rather than reduced the workload for some of the nurses, because several challenges were reported, such as fitting the Choice assessment and the follow-up conversation into the daily routines, as well as lack of time and space (Study I).

Introduction of electronic communication tools may also require new ways to work and new competencies to perform new tasks. Through the use of Choice, the nurses described how patients were able to participate more in their own care and could thus contribute to "setting the agenda" when communicating their problems and preferences for care. Earlier, the nurse was more in charge of the conversation at patients' admittance and if little time was available, the nurses sought less information. Likewise, the nurses addressed topics they were comfortable talking about and avoided challenging topics, e.g. being afraid to die or issues related to sexuality. A challenge that arose through use of Choice was nurses' feelings of being overwhelmed by patients' problems, without being able to help. Being unable to live up to expectations and demands at work is likely to foster feelings of powerlessness and threaten a professional's self-image as a competent and responsible nurse. Incompatible demands, stress of conscience and lack of support from managers and colleagues are strongly associated with burnout and job turnover [251]. This highlights the complexity of introducing a new technical tool into practice, as it alters forms of interaction between people [252]. Leaders have to be prepared for unexpected changes, such as needs for user support that may arise after the introduction of a new tool like Choice. In addition, nurses need to be aware that it may not be possible to help patients with all their symptoms and concerns. It could be argued that some problems are and should remain outside the hospital's sphere of responsibility [253], or could be handed over to other professionals (e.g. social workers) or caregivers.

Nurses are however trained to intervene, and nursing interventions are seen as a key function in the nursing process. Furthermore, nurses are not necessarily aware of their facilitator role, such as helping patients mobilize their own strengths. Educating nurses in these important issues may help foster professional confidence, even if they are not always able to solve the problem for the patient.

Findings from study I clearly underscore that, to successfully implement and maintain eHealth interventions in daily practice, the users must recognize that eHealth interventions are beneficial in their daily work and for the patients [119,254]. Understanding a tool's utility affects the motivation to use the system as well as to encourage participation [19]. Further, the focus group discussions with the nurses underscored that this understanding of user usability is important for maintenance of a program until it is fully integrated into daily routines. Choice promoted a shift towards more patient-centered care by inviting the patients to participate actively in their own care by assessing their own symptoms, preferences and needs. Since it is natural to return to old routines during periods of time pressure, one must establish routines that initiate, integrate and protect patient-centered care in daily practice [255]. An unexpected finding in study I was that Choice challenged ethical and knowledge-related skills more than technical ones. When introducing new eHealth interventions in clinical practice, leaders have to be prepared for unexpected changes, such as needs for user support. Needs for new competencies may also arise.

5.1.6 eHealth in regular care?

Providing new ways for self-management support and communication is essential as society faces increasing incidence of chronically ill patients [1]. This dissertation adds to the growing body of evidence supporting Web-based self-management support interventions as effective for patient outcomes in cancer populations (Study III) [7,76-79]. However, the impact of such interventions depend not only on effectiveness, but also on the extent to which interventions reach the targeted group, and the extent to which they are implemented and maintained in clinical practice. This dissertation illustrates the feasibility of offering parts of Web-based interventions in regular care, as the secure e-mail component was answered during regular working hours, by nurses and physicians at the hospital where the patients were treated (Study III). This provided patients with easy access to the expertise without a face-to-face appointment. There still might be factors such as age and lack of access to the Internet that play a role in who can be reached by Web-based interventions (Study III). However, as access

to the Internet increase in society [235], a larger group of the population will have the opportunity and skills to make use of Web-based support.

However, this dissertation also reveals challenges that might occur during the introduction of eHealth interventions into regular care (Study I). Integrating new routines such as secure e-mail can be also challenging, and skepticism among care providers about use of secure e-mail in routine care exists [256,257]. Fear of potentially being flooded with messages leading to an increased workload [118,135,174], and not being reimbursed for the time spent responding to messages [113,258,259] are well-known concerns. Concerns about increased workload were also mentioned as reasons for not participating when hospitals declined participation in study III. Lessons learned, however, are that patients do not send many e-mails to their health care providers (Study II and III). These results are in line with other studies showing e-mail volume to be low [129,174,260], and indicate that secure e-mail should be manageable and possible for health care providers to handle. In addition, the e-mail service was highly used by patients with high illness burden combined with low social support (Study II), indicating that this could be a good way to provide support to this group.

In a time with growing complexity in care, new ways to communicate and provide support are needed. In Norway, people seem to expect a future with more eHealth services [88]. Patients also expect to be able to communicate with their health care providers through e-mail [256,261,262]. To meet these expectations, we need to provide systems that are easy to use, useful to patients, and possible to implement and maintain in clinical care. Fit with regular workflow was described as one challenge among nurses who used Choice in regular care (Study I). The secure e-mail service in study III was administered by a team of 3 to 4 nurses at each location, trained and responsible for answering the e-mails. The e-mails thus did not interfere with the workflow of the whole staff, which might make the service easier to implement and maintain. The nurses performed the new task of answering the e-mails during regular working hours, without any incentives, indicating that the e-mail service could be a feasible means of communication between patients and nurses or physicians. The e-mails were primarily answered by nurses and were only passed on to physicians if needed. The nurses answered the majority (78%) of the e-mails, with physicians answering the rest (22%), indicating that the e-mail service can successfully be managed by nurses as the first line of response. Further, as nurses are described as having a holistic approach to patients, focusing on emotional issues, consequences of disease and illness information [263], they are well

equipped to answer questions and concerns from patients. Nurses have also been found to be sensitive and able to respond well to emotions expressed through e-messages [264].

eHealth interventions such as Web-based self-management support and communication interventions allow patients to be involved in their own care and decisions regarding health, as increasingly requested by patients [29]. However, as revealed in study I, introduction of new eHealth interventions in clinical practice can lead to a need for support and new competencies to make it possible to perform the new tasks. Leaders have to be prepared for unexpected changes that may arise in order to take advantage of the possibilities offered through eHealth interventions. To foster uptake of effective eHealth intervention in clinical practice, health care providers must have the necessary skills to operate these systems, and systems for reimbursement should also be considered.

5.2 Methodological considerations

Originally, it was planned that all data in this dissertation would be obtained from study III. However, as described in the method section, the initial collaborating hospital withdrew just before patient recruitment was about to start, resulting in a significantly delayed start-up of study III. The decision was therefore made to include two additional studies (study I and II) to make it possible to study factors important for translation of eHealth interventions into practice, specifically to examine effectiveness, use and uptake of eHealth interventions. The pragmatic decision [194] to include heterogeneous materials from three different studies may limit the generalizability of the results because the different dimensions in RE-AIM were not addressed within one study. However, the main results complemented by additional findings from the three studies offer richness in different aspects of eHealth and address all dimensions of the RE-AIM framework, strengthening the dissertation results and identifying new questions for future research. The combination of the three studies also provides a broad picture of factors important for uptake, use and effectiveness of eHealth interventions. The findings from the three studies supplement and support each other, contributing unique information to the field of eHealth. A multi-method approach introduces methodological challenges and involving experts within each type of methodology is of essence [199]. For this dissertation, a team of researchers with expertise within the different methods was therefore established. The opportunity to be in an environment with experts on quantitative and qualitative methods, IT developers and statistical experts both made the multi-method approach in this dissertation possible and provided an excellent training opportunity.

In the following, methodological considerations related to the three different studies are discussed.

5.2.1 Study I

Study I was a qualitative study using focus group interviews and a qualitative content analysis to explore nurses' experiences of benefits and barriers to maintaining use of Choice in clinical practice.

5.2.1.1 Researchers' pre-understanding

In qualitative research, results and process are formed by the researcher perspective. As the researcher is instrumental in both collecting and analyzing data, it is important to be aware of one's own pre-understanding and qualifications [265, p566]. According to Malterud [266] these pre-understandings include personal and professional experiences and qualifications, beliefs about how things are and what is to be investigated. Pre-understandings are not the same as bias, but need to be mentioned and considered throughout the research. As the principal investigator of this dissertation, my experience and qualifications for conducting focus groups are based on experiences from managing and leading groups as a nurse leader as well as through leading group therapy sessions for people with drug addiction. I have also completed courses in qualitative methods and group leadership.

The team of researchers that developed the interview guide and conducted the focus groups were familiar with the units and the implementation process for the Choice intervention. This might have influenced the interviewer's pre-understanding and may have impacted the participants' willingness to discuss challenging issues. On the other hand, this knowledge provided insight into what questions were important to ask and which statements needed elaboration. As the nurses raised several sensitive topics during the focus groups, this could be considered both a strength and a limitation. The researchers who conducted the analyses had not been involved in the implementation or follow-up process of the Choice intervention. As such, the material from the focus groups could be analyzed with "fresh eyes", without the influence of previous history.

5.2.1.2 Trustworthiness

Trustworthiness is regarded as the gold standard for qualitative research [219, p.430], and has parallels to the standards of reliability and validity in quantitative research. To ensure

trustworthiness of this study, the design, participants, procedure for data collection and description of analyses are provided in the method section of the dissertation. Core concepts in trustworthiness are credibility, dependability, confirmability and transferability [219, p.430]. Even though we separate the different aspects of trustworthiness, they should be viewed as intertwined and interrelated [217].

Credibility, a parallel to internal validity in quantitative research, deals with the focus of the research and refers to confidence in how well data and processes of analysis address the intended focus [219, p.430]. The participating nurses in study I had experiences with use of Choice in routine care and, as such, gave us insight into real-life use of the intervention. The breadth of the sample in experience, age, gender and unit employment also strengthens the study, shedding light on topics in the focus groups from various perspectives. Focus group interviews were chosen as the method for data collection based on the qualities of both interviews and discussions [213] as well as the benefit from group dynamics [214]. Credibility was achieved through the participants' opportunity to challenge and verify each other's opinions during the focus group discussion. In addition, experienced and less experienced nurses were divided into separate groups so that experienced nurses did not dominate the discussions [215]. Further credibility was ensured through providing sufficient time to collect and analyze the data. In addition, a researcher experienced in qualitative methods with no previous knowledge of Choice or the implementation process was part of the analyzing process.

Dependability refers to the stability of data over time and conditions, and corresponds to the stability aspect of reliability in quantitative studies. Data for study I were collected over a brief period of five weeks, which should reduce the risk of inconsistency which may arise when data is collected over a long time. However, because the nurses were asked for their experiences of using Choice during the last year, this might have impacted their recall of experiences.

Confirmability corresponds to the reliability objectivity aspects in quantitative studies [219,p430]. The involvement of an external researcher contributed, in addition to credibility, to better ensure dependability and confirmability in the study. The analyzing process also included discussions with other researchers, to strengthen credibility and dependability. In addition, a thorough description was provided of the collection of data and of how the analysis was performed, including examples of the process from meaning units to themes

(Table 4). However, because a text never implies just one meaning, but rather the most probable meaning from a particular perspective [216, p.28], our interpretation of the findings should be seen as one possible understanding of use of Choice in clinical cancer practice.

Transferability refers to the extent to which findings can be transferred to other settings and groups, and corresponds to the concept of generalizability in quantitative studies. Participants' demographics and context are described in depth in the method section to help readers judge transferability [219, p.435]. Since the findings are context specific and different interventions have different characteristics, these results are not necessarily transferrable to other contexts and eHealth interventions. The study findings are also limited to nurses' experiences of use. Having input from other health care providers using Choice (e.g., physicians) would provide a more comprehensive picture of clinicians' experiences. However, this was not feasible at the time, and as nurses were in the frontline using Choice, we chose to gain information from this group. In addition, input from unit leaders could add to this picture, as has been done by one of our colleagues (results currently under review).

5.2.2 Study II

5.2.2.1 Design

Study II was an exploratory secondary analysis of a previous RCT [7]. An important aspect in secondary analyses is to evaluate the quality of the data [219, p.236]. A strength of this study was the access to the original study protocol and description on how data were collected. In addition, the original questionnaires filled in by the patients at baseline, the complete SPSS data files and a detailed log of how the participant used WebChoice and the separate components, were available. Access to such detailed study information provided an excellent opportunity to assure the quality of data used to explore user characteristics and user patterns.

5.2.2.2 Study sample

Study participants were self-selected, recruited through advertisement and pamphlets and had to have Internet access. As higher education and Internet access are associated with higher willingness to participate in research studies, use of the Internet, the above-mentioned factors may limit generalizability. The participants in the study were younger than the average age of patients diagnosed with prostate and breast cancer in Norway [267,268]. A self-recruited sample could also mean a highly motivated sample, which again might limit generalizability.

However, potential users of Web-based support systems have to be interested and motivated for use, and we therefore assume that our sample is representative of the target population (breast cancer patients with access to the Internet), but might not be representative of cancer patients. Another limitation to generalizability is that we do not know if the observed differences between breast cancer and prostate cancer patients were related to the two diagnoses or to gender. Therefore, to clarify this, future studies should include patients with cancer diagnosis that are non-gender specific.

5.2.2.3 Method for data collection and outcome measures

Because all respondents had completed baseline questionnaires before being randomized into the two study groups, there were no missing data for the baseline questionnaires used in the secondary analyses in study II. Data from the server log provided detailed information on overall and component-specific use of WebChoice on individual and group levels, allowing for the types of analysis presented here. The outcome measures included in the analysis were based on the available data, and as this was an exploratory study, all outcomes and their association with system use were tested.

5.2.2.4 Data analysis

The use of a robust new method to identify subgroups that share specific characteristics; Latent Class Analysis (LCA) [225], adds to the strengths of the study. To our knowledge, LCA had never been used to analyze use patterns of eHealth interventions before, and hence adds to methods that can be used for this purpose. The relatively small sample, however, put some constraints on the choice of statistical models and we chose to stratify all statistical models by diagnosis/gender, thus making the comparison groups even smaller. In addition, the prostate cancer group was smaller than the breast cancer group, which may have further limited statistical power. The small sample size also reduced the number of variables that we were able to include in the LCA models. Given the limited statistical power, we chose to categorize our variables using tertiles and in doing so, we might have lost some information on differences in the underlying population. On the other hand, when fitting the models with categorical variables we were able to detect a direction in how low or high scores were associated with different use patterns.

5.2.3 Study III

5.2.3.1 Design

Study III involved an RCT, comparing effects of WebChoice and secure e-mail to usual care among breast cancer patients. Due to the nature of the interventions, participants were not blinded to group allocation. Patients completed baseline questionnaires before randomization, hence their group assignment did not impact any baseline responses. Knowledge about whether they are receiving the intervention or not may impact the way respondents feel, and as such also their subjective assessment on follow-up questionnaires [269].
The randomization was performed by an external research office, independent of researchers and clinicians in the study, avoiding selection bias. The block size (42 - stratified by site) was not known to the researchers before analysis of the data. Because the initially calculated sample was not obtainable, the large block size caused differences in the number of respondents in the three study groups. A lesson learned is to define smaller block sizes in future studies because recruitment to eHealth studies is sometimes lengthy and reaching all individuals can be challenging. However, the effect sizes in the study were larger than anticipated and statistically significant differences could be detected nevertheless.

5.2.3.2 Study sample

Among the strengths of this study is the inclusion of a sample with cancer diagnosis verified in the medical record. Many Web-based studies rely on self-report of diagnosis, which may reduce the accuracy of the sample description and impact the generalizability of results. As mentioned in the discussion of the Reach dimension, a limitation in the study was that participants were younger than those declining participation, with higher than average Norwegian education levels, suggesting that they were not representative. On the other hand, the patients were recruited from three different hospitals across the country, increasing generalizability of findings across practice settings.

Another generalizability limitation involves the retention rates. During six months of follow-up, a 14% (24/167) withdrawal rate was observed. This is lower than the withdrawal rates of 21% to 23% described in reviews of Web-based interventions [156,157]. As in other studies [6,62], higher withdrawal rates, albeit not statistically significant, were observed in the intervention groups than in the usual care group (WebChoice: 16% (10/64); e-mail 18%

(8/45); usual care 10% (6 /58)). There was however no association between baseline characteristics and study attrition.

Intervention adherence, a known challenge in eHealth research [22] reflects another study limitation. In the WebChoice group 64% logged on to the intervention more than once, and 40% in the secure e-mail group used this service. However, there were no differences between users and non-users in either group on any demographic or disease-related variables, and because results detected in study III were mostly unconnected to whether a patient was a user or not, low intervention adherence might not have represented a large problem in the study.

Finally, the included sample was fairly homogenous, including women with breast cancer within the first year of diagnosis (median 1 month after diagnosis). Nearly 50% of the participants were included immediately after diagnosis. However, the other half was included from one to ten months post diagnosis. Participants were thus in different phases of treatment and experienced different side effects at the time of questionnaire completion. This might have influenced the symptoms reported on the MSAS and HADS. The small study sample did not permit subgroup analysis of the effectiveness of the interventions at different treatment phases, and this is a topic for further exploration. On the other hand, this variability in time since diagnosis could strengthen the results regarding the intervention's effect, suggesting generalizability across treatment time.

5.2.3.3 Method of data collection and outcome measures

If no response was received to questionnaires within two weeks, a letter with a reminder was sent once but participants were also informed that they could withdraw from the study at any time. It was important for us to minimize the possible additional burden that participating in a study might cause, particularly as the participants included in this study were in a stressful phase; recently diagnosed with breast cancer and undergoing treatment. This procedure ensured that minimal pressure was put on participants to complete questionnaires. This could however have contributed to the observed withdrawal rate.

A strength of the study is that the questionnaires were first tested among 15 pilot participants in order to detect weaknesses before RCT start-up. The questionnaires were found to perform well. However, when checking data before analysis, it was observed that the MSAS was not always fully completed. Several of the respondents did not fully rate symptom frequency, severity, and distress. We were able to calculate instrument scores based on the available data

according to guidelines. However, this indicates that MSAS can be challenging to complete for some respondents. One way to ensure more completed questionnaires might be to offer information at baseline collection on how to fill in the form. If this is not possible, another way may be to use the MSAS short form instrument that only asks for rating of symptom distress.

All SPSS data entry was double-checked. Chronbach's alpha coefficient (ranging from 0.76-.0.96) was calculated to check that the instruments had acceptable internal consistency and reliability (see the method section for details). It should however be noted that repeated use of the same instruments every two months could have led to memory effect in the respondents' answers.

A possible weakness of self-reported questionnaires is the process of retrieving information about symptoms from memory. To minimize this weakness, the instruments MSAS and HADS ask for the respondent's experience during the last week.

5.2.3.4 Data analysis

Among the strengths of the study is the use of an intention-to-treat approach and the use of linear mixed models for repeated measures to analyze changes over time. This modern statistical method allows usage of all available data at each time point and can handle missing data without the need for imputations.

A limitation, however, is that a smaller sample size than initially calculated combined with the withdrawal rate during the study reduced statistical power for analyses. Because participant inclusion had to be stopped before the a priori calculated sample size was obtained, block randomization led to different sample sizes in the three groups, with the fewest participants in the secure e-mail group. In addition, the e-mail group had the lowest number of completers of questionnaires at six months. The limited study size calls for additional research to further confirm the results. Post hoc analysis of usage and its relation to outcomes was based on an even smaller sample, comparing users and non-users, and must be viewed as an exploratory analysis only.

5.3 Contribution to science

This dissertation provides important insight into factors essential for translation of eHealth interventions into regular care. The use of the RE-AIM framework guides the dissertation by directing the focus to aspects important in design as well as evaluation of eHealth interventions.

Study I adds knowledge and contributes to bridge the gap between research on eHealth interventions effective in clinical trials and maintenance of such interventions in regular clinical practice. The findings add information about experienced benefits from, and barriers to, the uptake of an interactive tailored patient symptom assessment and communication intervention, as experienced by nurses. To implement and maintain use of the advantages of eHealth interventions, it is important to acknowledge the benefits of the intervention and be willing to change routines and competences.

In study II, a method new to the evaluation of eHealth interventions was introduced to analyze user patterns: Latent Class Analysis (LCA). LCA was found to be a useful technique to identify subgroups of users through enabling detection of clusters of user characteristics linked to use of different Web Choice system components. The findings showing patients with high symptom burden and low social support to be high users of secure e-mail correspondence with cancer nurses can provide important knowledge when aiming to better tailor interventions in the future. LCA can be recommended in future studies of user patterns of eHealth interventions.

Study III adds to the limited literature on eHealth intervention components and their contribution to effect by comparing a single component to multiple components of a Web-based self-management support intervention. Results from study III support the growing evidence of significant positive effects from Web-based self-management support on patient outcomes for cancer patients. The positive effect of the secure e-mail service alone on patient outcomes highlights the potential of this component, both as part of multi-component interventions and as a stand-alone service. Study III collected data on most dimensions of RE-AIM and is thus an example of how the framework can enrich the reporting of eHealth studies. In addition to its results on patients' outcomes, this study draws attention to some of the challenges facing eHealth research, including recruitment of participants and the rapid technological development challenging design and the types of methods to use.

5.4 Implication for clinical practice

The findings from this dissertation have multiple implications for clinical practice, as they confirm that eHealth interventions can improve patient outcomes. In addition, this dissertation elicited factors important for maintaining eHealth interventions in regular care.

Dissertation findings show that interactive tailored patient assessment tools such as Choice can be implemented into regular care, are seen as helpful for patients and nurses in eliciting symptoms, increase patient participation and enhance communication between patients and nurses. This suggests that more widespread use of such tools could improve the quality of care for many patients.

However, this dissertation also revealed that implementation and use of electronic support tools in regular care is not straightforward. To implement and maintain use, it is important to be aware of new challenges that may arise in the use of technology that are not necessarily related to the technology itself. These challenges include the need for better communication skills and competencies in patient-provider interactions revealed in study I, role changes, lack of time, inter-professional and cultural issues and the need for changing routines. Addressing such challenges and being prepared for unexpected consequences are crucial for successful implementation of new eHealth interventions into clinical practice.

Web-based self-management support, through its ability to reduce symptom distress, depression and anxiety scores, can be a contributor to care for breast cancer patients and likely also for patients with other chronic illnesses. The fact that secure e-mail services, shown to reduce depression scores, can successfully be managed and responded to by nurses, holds promise that such services can feasibly be introduced into regular care and have great potential as communication channels between patients and health care providers. Nurse-administered e-mail services have the potential to reach large groups of patients and they could be offered in routine care in addition to traditional face-to-face and telephone services. This will also meet patients' growing interest in using e-mail communication with health care providers, and can contribute to improvement of patient outcomes through a relatively "simple" intervention.

We might however still have a long way to go before eHealth interventions, shown to be effective in clinical studies, are implemented and maintained in clinical practice. As observed in study III, only three of the 11 hospitals approached agreed to participate in the study. These

hospitals were not asked to implement the secure e-mail service as routine clinical practice, only to participate in a study for a limited time. The hesitance to participate highlights how hard it can be to introduce new interventions and change existing ways to work. eHealth interventions that only include patients may have a greater potential for being widely adopted than interventions requiring actions from health care providers. However, as the opportunity to communicate with health care providers is associated with positive impact on patient outcomes, incentives are needed for implementing such technologies and placing greater emphasis on factors that motivate changes in routines and implementation of new interventions.

Today's health care system is continuously faced with implementations of new interventions and systems. Results from this dissertation suggest that there is a need for new routines and competencies in order to benefit fully from the possibilities offered through eHealth interventions. Health care providers should also be active participants in the development and work processes related to these interventions to make them fit in the routine care settings. To improve competencies and attitudes as well as to increase willingness towards use of eHealth interventions, education about such interventions and how to make use of them should also be a part of the education of health care providers in the future. In addition, to speed up translation of effective eHealth interventions into clinical practice, health care managers need knowledge of these interventions and, through education, need to be provided with skills to implement and maintain new solutions.

5.5 Recommendations for future research

This dissertation highlights several aspects where further research is needed. More studies are needed to test long-term effects of Web-based self-management support, as well as whether there are special phases in the treatment of cancer where such interventions are especially effective. The observed effects of WebChoice in study III on reduction of symptom distress, anxiety or depression were detected although only 64% of participants were users of the system. In line with other studies, whether a patient was a user or non-user was not connected to the observed effects [7,158,160,181]. This might relate to the psychological effects of having the possibility to use the system if needed. However, the mechanisms behind this are not known and need further exploring. In addition, how the use of various components, other than secure e-mail, is connected to patients' outcomes, as well as how many components are needed to achieve positive effects, remains to be tested.

In study II, a high level of computer experience and no additional illnesses besides cancer increased the probability of using WebChoice. No such associations were observed in study III however, indicating that examining which factors influence whether a person becomes a user or not is of importance for research. Study II identified people with high symptom burden accompanied by low social support as high users of the secure e-mail and advice components. Further insight into user characteristics and user pattern can provide guidance for targeting interventions to different groups of people.

Like the observed effects in the WebChoice group, reduction of depression scores in the secure e-mail group was not connected to whether a person used the system or not. The exploratory analyses of the secure e-mail group revealed that those who sent e-mail, compared to non-users, had a reduction in anxiety scores. Further studies are needed to confirm these exploratory results. How the option to communicate with health care providers might impact well-being is another topic for further studies.

In study III, the secure e-mail service was administered and mainly answered by nurses at the hospital where patients were treated. Further studies are warranted to test whether services administered by a team of nurses, compared to services answered by a single health care provider (e.g. a physician), have a similar or different impact on patient outcomes. Similarly, there is a need to explore whether the type of service has an impact on the number of messages received, topics in the messages, patient and provider satisfaction and experiences

with use. How access to known providers can affect the results, compared to services with unknown providers, is also a topic for further research.

Based on findings from study I, exploring nurses' experiences of the use of Choice in regular care, future research could benefit from conducting qualitative studies examining health care providers' experiences of use of eHealth interventions. As eHealth interventions are often complex systems, it is important to study user experiences as well as effects on patient outcomes. To obtain a broad picture, it will be important to include different groups of health care providers that use the intervention. This again can help identify facilitating factors to implementation and maintenance of the interventions.

Similar to the recent observations by Baker et al. regarding reduced system use of Web-based self-management support systems [163], less use of WebChoice was observed in study III than study II. Reasons for this are not known, but the availability of other channels for social interactions, such as Facebook and personal blogs, might provide some explanation. However, this needs to be further studied to make it possible to develop eHealth interventions that offer components of interest to the potential users.

Finally, the rapid pace of technical development will continue to challenge design and methods measuring effects of eHealth interventions. There is a need to speed up eHealth research to keep up with technological development, which in turn requires a focus on methods facilitating more rapid inclusion of study participants, as well as more studies on tailored interventions.

6. Conclusions

This dissertation suggests that, from nurses' perspectives, integration of interactive tailored assessment tools in clinical practice offer many benefits for communication and enhancement of patients' strengths, contributing to patient-centered care. However, to reap these benefits, use of such tools must receive equal priority to other routines and requires sufficient time, space and competence.

This dissertation also provides evidence that different user characteristics are associated with different use patterns of Web-based self-management support. Such information is crucial in order to target Web-based support systems for different patient groups. In study II, e-mail and self-management advice were highly used components for patients who had low levels of social support and high illness burden, suggesting that patients with these characteristics may find such tools particularly useful.

Finally, this dissertation shows that a Web-based self-management support intervention can be an important contributor in care for breast cancer patients, through reduction of symptom distress, anxiety and depression scores. The secure e-mail component alone contributed to reduced depression scores, which indicates that secure e-mail can be an important part of multi-component systems and can also effectively be offered as a stand-alone service. Despite the concerns identified in the literature that health care providers will be flooded by messages if they offer e-mail services, only modest use was observed in study II and III, indicating that e-mail is manageable to integrate in routine health care.

In summary, through multi-study and multi-method findings, this dissertation provides important new information on aspects of uptake, use and effectiveness of eHealth interventions. The results and knowledge gained can be used to significantly improve and inform the process of designing systems, conducting research and implementing and maintaining eHealth interventions in routine health care.

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FORESPØRSEL TIL HELSEPERSONELL OM DELTAKELSE I DISKUSJONSGRUPPE PROSESSEVALUERING CHOICE

Du blir herved forespurt om å delta i en diskusjonsgruppe hvor vi ønsker å få tilbakemelding på hvorvidt vi har nådd de målene vi satte oss med Choice, eller om det er områder vi kan forbedre både mht. selve verktøyet og implementeringen.

Diskusjonsgruppen inngår som en del av en større studie; CONNECT (Care Online: Novel Networks to Enhance Communication and Treatment), om å utvikle og teste en tilleggsmodul til elektronisk pasientjournal (EPJ) for kommunikasjon og informasjonsutveksling mellom pasient og helsepersonell.

Hensikten med CONNECT er å:

1. Utvikle og teste CONNECT, en tilleggsmodul til EPJ for kommunikasjon og informasjonsutveksling mellom pasient og helsepersonell.
2. Utforske krav og utfordringer knyttet til bruk av felles elektronisk pasientjournal gjennom mobile terminaler (for eksempel mobiltelefoner).
3. Kartlegge hvilke behov pasienter og helsepersonell har for dokumentasjon, informasjon og felles data for å understøtte pasientmedvirkning, behandling av sykdom og gi kontinuitet i sykepleie.
4. Kartlegge om standardiserte terminologier for helse kan benyttes i pasientens journal. Utvikle verktøyer som kan oversette mellom pasientvennlig språk og termer benyttet av helsepersonell.

Deltakelse i diskusjonsgruppen varer i ca 2 timer. Opplysninger som fremkommer vil benyttes i videre utvikling av Choice og CONNECT, samt frambringe kunnskap om hvordan verktøy best kan innføres i praksis.

Diskusjonsgruppens innspill vil bli tatt opp på lydbånd. Utfylte skjema og lydbåndopptak vil bli oppbevart i et låst arkivskap ved Senter for pasientmedvirkning og sykepleieforskning. Innspillene dine vil bli behandlet konfidensielt. Alle data vil bli avidentifisert, og ingen svar vil kunne tilbakeføres til deg som person når resultater skal presenteres. Rikshospitalet HF vil behandle opplysningene i samsvar med gjeldende lovverk.

Selv om du sier ja til å delta, kan du trekke deg når du måtte ønske det, uten å oppgi noen grunn, og uten at det vil ha noen konsekvenser. Dine data vil da bli slettet.

Vi regner med at studien i sin helhet vil være avsluttet etter 2015. Alle data vil være slettet senest 10 år etter dette, dvs. før 31.12.2025. Du har rett til innsyn i hva som er registrert av opplysninger om deg og til å kreve at eventuelle feil rettes.

Om du har spørsmål om deltakelse eller selve studien kan du ringe prosjektleder Professor Cornelia M. Ruland ved Senter for pasientmedvirkning og sykepleieforskning og på telefon 23 07 54 60.

Samtykkeskjema

Ta vare på første side av dette samtykkeskjemaet.

Jeg samtykker i å være med i diskusjonsgruppen slik den er beskrevet ovenfor. Jeg er informert om at min deltakelse er helt frivillig. Selv om jeg sier ja til å delta i dag, kan jeg trekke meg når jeg måtte ønske det, og uten at det vil ha konsekvenser for meg .

Dato:_____

_____
Navn: (blokkbokstaver):

_____
Signatur

FORESPØRSEL OM DELTAKELSE I STUDIEN

Internett-støtte til kreftpasienter

Du blir herved forespurt om å delta i en studie som utgår fra Rikshospitalet – Radiumhospitalet HF med støtte fra Kreftforeningen. Hensikten med studien er å (1) få mer kunnskaper om informasjons- og støttebehov til mennesker som har fått kreft slik at de kan møtes bedre, og (2) teste nytten av en Internett-basert informasjons- og støttetjeneste for kreftpasienter, kalt WebChoice. WebChoice gir informasjon og veiledning som er skreddersydd til den enkelte pasients problemer og informasjonsbehov via Internett. Videre kan en ta kontakt med en kreftsykepleier som vil svare på spørsmål, eller med andre pasienter i samme situasjon.

Om du velger å delta, vil du være med i studien i 12 måneder. Det innebærer at vi vil sende deg spørreskjema i posten i starten som omhandler noen spørsmål om din helse og informasjonsbehov og igjen etter 3, 6, 9 og 12 måneder. Vi vil be deg fylle det ut og returnere til oss i en vedlagt ferdig frankert konvolutt.

Etter vi har fått tilbake spørreskjema sammen med dette skjema som kalles "Informert samtykke" undertegnet av deg, vil du bli trukket ut til å tilhøre en av to grupper. Vi kan dessverre ikke påvirke hvilken gruppe du vil tilhøre. Dersom du blir trukket ut til den første gruppen vil du få adgang til Internett-tjenesten umiddelbart. I så fall vil vi sende deg alt du trenger for å komme i gang med å bruke tjenesten.

Et mindre utvalg av pasientene i den første gruppen vil også bli bedt om et intervju senere i studien, og det kan hende at du er blant dem som vil bli spurt. Intervjuet, som varer ca 1 time, vil blant annet omhandle hvilket behov du har for informasjon, i hvilken grad WebChoice har møtt dine behov, samt din opplevelse av programmets nytte og brukervennlighet. Om du ikke ønsker å delta i er slikt intervju kan du likevel være med i studien.

Hvis du blir trukket ut til å tilhøre den andre gruppen vil vi sende deg noen adresser til kvalitetssikrede, sykdomsrelevante nettsider. Ellers vil du få de samme spørreskjemaene som den første gruppen.

Svarene dine fra spørreskjemaet, evt. intervju og informasjonen du utveksler via WebChoice vil bli behandlet strengt konfidensielt, og vil ikke bli utlevert til andre. Som bruker av WebChoice vil du få et eget brukernavn som er forskjellig fra ditt eget. All informasjon som utveksles er uten personidentifikasjon og beskyttet gjennom strenge datatekniske sikkerhetstiltak. Informasjon du utveksler vil bli kryptert (ingen andre kan lese det, eller gjenkjenne deg) og liggende i et lukket system ved Rikshospitalet-Radiumhospitalet HF. Utfylte skjema vil bli oppbevart i et låst arkivskap på prosjektleders kontor. Alle opplysninger som samles inn får en tallkode og er ikke knyttet til navn.

Vi vil analysere data fra spørreskjema, fra systemloggen som forteller oss om hyppighet, varighet og hvilke deler i WebChoice som blir mest brukt, meldinger til og fra kreftsykepleier og innlegg i diskusjonsforum, og fra intervjuer med brukerne. Alle data vil bli avidentifisert, og ingen svar vil kunne tilbakeføres til deg som person når resultater under analysen eller senere av studien skal presenteres. Studien er tilrådd av Regional etisk komité for medisinsk forskningsetikk og Datatilsynet.

Deltakelse i studien medfører ingen kostnader for deg og du får ingen betaling for å delta. Det er ingen risiko forbundet med denne studien, men kanskje du vil synes at det er slitsomt å fylle ut spørreskjema. Vi vil gjøre vårt ytterste for å redusere denne ulempen. Kunnskapen som fremkommer av studien kan hjelpe kreftpasienter til å få en lettere hverdag. Studien vil gi helsearbeidere økte kunnskaper om kreftpasienters problemer/symptomer samt hvilket informasjonsbehov de har. Videre kan studien være med på å gi helsevesenet et redskap som kan sikre pasienter individuell oppfølging, informasjon og støtte på vei mot et mer pasientvennlig helsevesen.

Selv om du sier ja til å delta i studien nå, kan du trekke deg fra studien når du måtte ønske det, uten å oppgi noen grunn, og uten at det vil ha noen konsekvenser. Dine data vil da bli slettet.

Rikshospitalet-Radiumhospitalet HF er ansvarlig for å ivareta sikkerheten til personopplysninger som behandles i studien og databehandlingsansvarlig. Formålet med behandlingen i WebChoice er å legge til rette for oppfølging av deg som pasient mellom sykehusopphold. Rikshospitalet-Radiumhospitalet HF vil behandle opplysningene i samsvar med gjeldende lovverk.

WebChoice vil ha en brukerdatabase som inneholder ditt navn, personnummer og adresse som er hentet fra Folkeregisteret. Persondata som navn, adresse, mobiltelefon og e-postadresse vil ikke utleveres til utenforstående. Du har rett til innsyn i de opplysninger WebChoice har om deg. Bruk av løsningen er frivillig, og dette samtykket er en betingelse for å få tilgang til tjenesten.

Vi regner med at studien i sin helhet vil være avsluttet etter 2008. Alle data vil være slettet senest etter 10 år, dvs. før 31.12.2015.

Om du har spørsmål om deltakelse eller selve studien kan du ringe prosjektleder Dr. Cornelia M. Ruland ved Senter for sykepleieforskning og pasientmedvirkning på telefon 23 07 54 60.

Om du ønsker å delta i studien ber vi deg signere siste siden på dette ”Informert samtykke” skjema, fylle ut vedlagte spørreskjema og sende det tilbake til oss i vedlagte konvolutt. Dersom du ikke ønsker å delta, kan du se bort fra denne henvendelsen.

Informert samtykke

Jeg samtykker i å være med i studien slik den er beskrevet ovenfor. Jeg er informert om at min deltakelse i studien er helt frivillig. Selv om jeg sier ja til å delta i dag, kan jeg trekke meg fra studien eller avbryte intervjuene når jeg måtte ønske det, og uten at det vil ha konsekvenser for min nåværende eller fremtidige behandling ved sykehuset.

Dato:_____

_____

Navn: (blokkbokstaver):

_____

Signatur

Jeg er også villig til å bli forespurt om å delta i et intervju, enten hjemme hos meg selv, eller ved Rikshospitalet-Radiumhospitalet. I så fall vil mine reiseutgifter bli dekket.

JA___ NEI___

Hvis du vil delta i studien fyller du ut og signerer svarslippen, river ut siden og legger den i den lille ferdigfrankerte konvolutten og sender det til Senter for pasientmedvirkning og sykepleieforskning.

Forespørsel om deltakelse i forskningsprosjektet
Effekt av internettstøtte for kreftpasienter som en del av klinisk praksis (WebChoice 2.0).

Bakgrunn og hensikt
Dette er en forespørsel til deg om å delta i et forskningsprosjekt for å teste ut effekten av et internettbasert støtteprogram som er utviklet for mennesker med kreft (WebChoice 2.0). Tilbudet er utviklet for støtte mellom og etter opphold ved sykehuset. WebChoice 2.0 har flere komponenter: mulighet til å nedtegne de problemer/plager man har, database med tiltak man iverksette mot disse plagene i hjemmesituasjonen, kvalitetssikrede internettlinker til informasjon om sykdom og behandling, diskusjonsforum med andre pasienter i samme situasjon, samt mulighet til å stille spørsmål via e-post i et sikkert system (spørsmål- og svartjeneste) til sykepleier ved sykehuset. Ved behov kan spørsmål videreformidles til lege eller sosionom ved sykehuset eller rådgiver hos Helseøkonomiforvaltningen (HELFO). Vi ønsker å undersøke om denne tjenesten eller deler av den kan hjelpe pasienter til å håndtere sykdommen og mestre hverdagen bedre. Vi vil også undersøke om bruk av tjenesten kan ha betydning for utgifter knyttet til sykdommen, samt behov for helse- og sosialtjenester fra det offentlige.

Studien utgår fra Oslo universitetssykehus HF, Rikshospitalet. Du forespørres om å delta i studien fordi du er pasient ved et av våre samarbeidende sykehus.

For å undersøke om denne internettjenesten er nyttig, vil studiedeltakerne bli inndelt i tre grupper; én gruppe som får tilgang til spørsmål- og svartjenesten, én gruppe som får tilgang til alle komponentene i WebChoice 2.0 og én sammenligningsgruppe som får det vanlige tjenestetilbudet fra sykehuset, uten disse spesielle tjenestene. Hvis du sier ja til å delta i studien, vil du bli tilfeldig trukket ut til å inngå i én av gruppene.

Hva innebærer studien?
Deltagelse i studien går over 18 måneder, hvorav bare de første 12 månedene fordrer noen aktivitet fra din side. Dersom du blir trukket ut til å være med i gruppen som får tilbud om å bruke spørsmål- og svartjenesten eller hele WebChoice 2.0, innebærer det at du i 12 måneder vil kunne benytte deg av tjenesten så mye du ønsker. Som bruker av tjenesten logger du deg på slik du logger deg på din nettbank. Dette vil du få nærmere forklaring på. All informasjon som utveksles er beskyttet gjennom strenge datatekniske sikkerhetstiltak og vil bli kryptert og liggende i et sikkert system ved Oslo universitetssykehus HF, Rikshospitalet.
Enten du kommer i den gruppen som får tilgang til spørsmål- og svartjenesten, WebChoice 2.0 eller sammenligningsgruppen, vil vi be deg fylle ut noen opplysninger om deg selv på spørreskjemaer ved oppstart. Vi vil så sende deg spørreskjemaer etter 2, 4, 6, 8 og 12 måneder, som inneholder spørsmål om hvordan du har det i forbindelse med sykdom og behandling. Disse vil du bli bedt om å returnere til oss i en vedlagt ferdigfrankert konvolutt. Det vil ta ca ½ time å fylle ut skjemaene. Dersom du kommer i den gruppen som får tilbud om å bruke WebChoice 2.0 eller spørsmål- og svartjenesten vil du tillegg motta spørreskjema som omhandler hvor nyttig og brukervennlig du opplevde tjenestene.

I tillegg til data som samles inn gjennom spørreskjema ber vi om din tillatelse til å innhente følgende:

- Data for hvordan du benytter tjenestene (hva som benyttes, hvor ofte, hvor lenge, innhold i meldinger, notater og kommunikasjon med andre pasienter).
- Opplysninger fra offentlige registre (se utdyping under avsnittet om personvern) 12 og 18 måneder etter din oppstart i studien om offentlige ytelser forbundet med sykdommen og bruk av helse- og sosialtjenester, evt. sykehusinnleggelser i aktuelle periode, samt ytelser til reseptbelagte legemidler.
- Enkelte opplysninger om nåværende sykdom og behandling fra din journal ved sykehuset.

Om du ikke ønsker å delta i denne studien, vil du motta vanlig behandlingstilbud ved den avdelingen du behandles ved.

Mulige fordeler og ulemper
Studien medfører ingen kostnader for deg og det er ingen risiko forbundet med studien. Gjennom din deltakelse vil du, enten du deltar i en av de to gruppene som prøver ut tjenestene eller i sammenligningsgruppen, bidra til viktig kunnskap om hvordan et tilpasset program for internettstøtte kan være til hjelp for mennesker med alvorlig sykdom.

Fordeler for deg, dersom du blir trukket ut til å være med i den gruppen som får tilgang til spørsmål- og svartjenesten, vil være at du får mulighet til å benytte tjenesten etter og mellom sykehusopphold. Du kan stille spørsmål via elektroniske meldinger og få råd og veiledning fra sykepleier, og ved behov kan dine spørsmål videreformidles til lege og sosionom ved sykehuset eller rådgiver ved HELFO. De som besvarer meldingene fra deg har spesialkunnskap om din sykdom og behandling. Rådgivere ved HELFO vil få videreformidlet aktuelle spørsmål i anonymisert form fra sykepleier som betjener spørsmål- og svartjenesten. Dersom du blir trukket ut til gruppen som får tilgang til WebChoice 2.0 vil du i tillegg få tilgang til kvalitetssikret informasjon om tiltak som du kan iverksette selv mot sykdomsrelaterte plager. Du vil også få mulighet til å registrere egne plager, for eksempel som forberedelse til legebesøk, og mulighet til å kommunisere med mennesker i samme situasjon. Å kunne stille spørsmål og få svar fra fagpersoner uansett hvor du oppholder deg, samt ha tilgang til kvalitetssikret informasjon om sykdommen kan kanskje hjelpe deg å håndtere sykdommen og eventuelle komplikasjoner bedre når du er hjemme.

Det er få ulemper og ubehag knyttet til deltakelse i studien. Noen vil kanskje oppleve det som slitsomt å svare på spørreskjemaer.

Hva skjer med informasjonen om deg?
Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode (studie-ID) knytter deg til dine opplysninger gjennom en navneliste. Navnelisten er atskilt fra alle opplysninger vi samler om studiedeltakerne. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Hvis det kommer frem noe i korrespondansen i spørsmål- og svartjenesten som er viktig for din behandling ved sykehuset, vil dette bli dokumentert i pasientjournalen.
Det er innhentet nødvendig konsesjon fra Datatilsynet for å kunne sammenstille opplysninger fra NAV, HELFO, Norsk Pasientregister og Reseptregisterets databaser med studieopplysninger. All informasjon om deg vil slettes etter at studien er avsluttet, senest 31.12.2025.
Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Studien er godkjent av Regional Etisk Komité (REK) Sør-Øst, Protokollutvalget og Personvernombudet ved Oslo universitetssykehus HF, Rikshospitalet.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke deg fra studien uten at det påvirker din øvrige behandling. Du kan i så fall også be om at de opplysninger vi allerede har fått fra deg blir slettet.

Dersom du har spørsmål om studien, kan du kontakte prosjektleder Cornelia Ruland, tlf 23 07 54 60, stipendiat Elin Børøsund, tlf 23 07 54 52 eller studiesykepleier Kristin Iren Jensen, 77 66 92 12.

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunnsinformasjon om studien:
Mennesker med alvorlig sykdom kan oppleve mange problemer og bekymringer. Når de er hjemme mellom eller etter behandling er det ofte begrenset tilgang til profesjonell hjelp. Internettbaserte tjenester har vist seg å være nyttige i forhold til å støtte pasienter til å mestre daglige utfordringer og behov. Derfor vil vi undersøke i hvilken grad WebChoice 2.0 eller kun en spørsmål– og svartjeneste kan hjelpe pasienter i en slik situasjon, med tanke på å ha det bedre gjennom sykdom og behandling, med mindre symptomer/plager og bekymringer, og bedre livskvalitet. Når en kan få hjelp umiddelbart når problemer oppstår, kan dette kanskje også bidra til raskere rehabilitering, forhindre komplikasjoner, styrke egenkompetanse, redusere medikamentbruk og å kunne komme raskere tilbake i arbeid.

Hvis denne studien viser at det er nyttig for deltakerne, vil det i framtiden være aktuelt å utvikle tilsvarende tjenester som kanskje kan bli en del av det ordinære tjenestetilbudet til pasienter med alvorlig sykdom.

Kriterier for å delta i studien er at du er over 18 år, behersker norsk skriftlig og muntlig, har tilgang til internett og bruker nettbank med BankID som påloggingsnøkkel.

Kapittel B - Personvern, økonomi og forsikring

Personvern
Data som vil bli registrert om deg den tiden du deltar i studien er:

- opplysninger innhentet gjennom spørreskjema
- kommunikasjon med helsepersonell i spørsmål- og svartjenesten
- bruk av spørsmål- og svartjenesten og de ulike delene i WebChoice 2.0 (fra systemlogg)
- opplysninger om nåværende sykdom og behandling fra pasientjournalen
- sykefravær og ytelser til, rehabilitering, attføring eller uføretrygd (fra NAV)
- besøk hos fastlege, spesialist, fysioterapeut eller bruk av dietetiske næringsmidler (fra HELFO)
- sykehusopphold i form av poliklinikkbesøk eller innleggelser (Norsk Pasientregister)
- utgifter til legemidler relatert til smerter, angst, depresjon og søvn (Reseptregisteret)

Det foreligger konsesjon fra Regional etisk komité for dette og databehandlerkontrakt vil bli utarbeidet før innhenting av data fra eksterne registre. Opplysningene fra NAV, HELFO og Norsk Pasientregister innhentes fra deres respektive databaser av personer som har tjenestemessig tilgang til disse databasene. De vil få tilsendt studiedeltakernes personnummer og deres studie-ID fra oss på en CD-ROM og henter ut de aktuelle opplysningene om studiedeltakerne fra sin database via

personnummeret. Når opplysningene returneres til oss på CD-ROM (enten med kurer eller som rekommandert sending), vil personnummer være slettet, og kun studie-ID knytter opplysningene til hver enkelt studiedeltaker. Ved ankomst til navngitt medlem av forskningsteamet lagres data umiddelbart på sikker server for forskning ved sykehuset, og CD-ROM destrueres.
Norsk Pasientregister forvaltes av Helsedirektoratet og Reseptregisteret av Folkehelseinstituttet. Ved Reseptregisteret vil data bli innhentet ved at vi på tilsvarende måte overfører filer med personnummer og opplysninger fra studien som skal ses opp mot data fra Reseptregisteret. Filene vil bli videresendt til Statistisk sentralbyrå (SSB) for avidentifisering og påføring av pseudonyme personnummer tilsvarende de som brukes i Reseptregisteret. Når vi mottar datafilene fra Reseptregisteret og lagrer dem på vår sikre forskningsserver, vil dataene være knyttet til pseudonymnummer. Dataene fra Reseptregisteret vil på denne måten ikke kunne spores til hver enkelt studiedeltaker, men være fullstendig anonymiserte.
Kun navngitte medlemmer av forskningsteamet vil der ha tilgang til dataene. De vil ikke være tilgjengelige for personell som kommuniserer med pasientene i WebChoice 2.0. Alle medlemmene av forskningsteamet har taushetsplikt.
Oslo universitetssykehus HF, Rikshospitalet ved administrerende direktør er databehandlings-ansvarlig.

Rett til innsyn og sletting av opplysninger om deg
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Helse Sør-Østs rolle
Studien er finansiert gjennom forskningsmidler fra Helse Sør-Øst, og bekostes også av Oslo Universitetssykehus HF, Rikshospitalet, Universitetssykehuset i Nord-Norge HF, Tromsø, Sykehuset Vestfold HF, Tønsberg og Sørlandet sykehus HF, Kristiansand. Det er ingen interessekonflikter å melde.

Forsikring
Du er forsikret på samme måte som ved ordinære opphold/konsultasjoner ved sykehuset.

Informasjon om utfallet av studien
Som deltaker i studien har du rett til å få informasjon om utfallet/resultatet av studien.

WebChoice 2.0

Reg. Nr: | | | |

Initialer: | | | |

Samtykke til deltakelse i studien

"Effekt av internettstøtte for kreftpasienter som en del av klinisk praksis" (WebChoice 2.0)

Jeg er villig til å delta i studien:

----------(navn i blokkbokstaver)

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Intervjuguide fokusgrupper med sykepleiere vår 2008

Åpning *Ikke båndopptaker*	• **Presentasjon: moderator og ass. moderator og deres rolle i intervjuet.** • **Hensikten med intervjuet:** • **Om å ta samtalen opp på bånd – sikring av konfidensialitet.** • **Regler for samtalen.** • **Respondentene presenterer seg.**
Introduksjon *Båndopptaker*	**Respondentene forteller hvor lenge de har jobbet (evt hvilken rolle de har hatt i forhold til innføringen)**
Nøkkel- tema: **Hvordan benyttes Choice?** **Erfaringer**	**Dere har nå brukt Choice siden starten av 2007:** • **Kjenner alle til Choice?** • Kan dere beskrive **hvordan dere benytter Choice** i det daglige arbeidet? (innkomst, underveis, ved utreise?) • **Erfaringer med Choice?** Pos./neg.?
Kartlegge pasientens symptomer, problemer og prioriteringer for hjelp **Reduseres symptomer og plager?**	1. **I hvilken grad opplever dere at Choice fanger opp pasientens symptomer, problemer og prioriteringer for hjelp? Hvordan?** (muligheter/barrierer?) 2. **En av hensiktene med Choice er å bidra til reduksjon av pasientens symptomer og plager. Har dere noen erfaringer med dette?** Utdyp I hvilke situasjoner synes du det hjelper, ikke hjelper?

(Jeg hører du nevner ... Kan du si mer om det? Til de andre: Når X sier dette, hva sier det dere? Hvor er dere i forhold til det? Ingen har nevnt ... Spiller det ingen rolle for dere? Kan du være mer konkret!)

Klargjøre for helsepersonell symptomer og problemer	3. **Hvordan opplever dere at Choice får fram de symptomer og problemer som er viktigst for pasientene?** Kan noen fortelle om en gang du opplevde dette? Hvordan gikk du fram? **Hender det at pasienten er opptatt av andre ting eller prioritere plagsomhet annerledes enn du forventer?** Eksempler? **Hvordan bruker dere oppsummeringen fra pasienten?** (Når? I hvilken sammenheng?) Hvordan kunne den evt blitt brukt annerledes? Barrierer? Hva kan være vanskelig? (Samtalen, temaene, mangler tiltak?) **Hvordan er det å få utskriften fra pasientene?**
Endring av kommunikasjon med pasienten?	4. **Hvordan har Choice påvirket kommunikasjonen med pasientene?** Hvilke tilbakemeldinger gir pas. på Choice? Utfordringer? Muligheter? Var det som forventet? Fortell om gode/dårlige samtaler Hvorfor skjedde dette? Hva kan vi lære av det?
Mestring/medvirkning	5. **Hvordan opplever dere at Choice har vært til hjelp for pasienten i mestring av egen sykdom?** På hvilken måte kunne Choice evt. ha blitt brukt annerledes? Eks? **Hvordan innvirker Choice i forhold til å gi pasientene mulighet til medvirkning?** (utdyp)
Pleieplanlegging	6. **Hvordan bruker dere Choice i forhold til pleieplanlegging?** **Har det skjedd noen endring med pleieplanlegging etter at Choice ble innført?** (Hvordan før/hvordan nå?) **Hvordan kunne Choice blitt brukt i pleieplanleggingen,** hva kunne vært gjort bedre?

(Jeg hører du nevner ... Kan du si mer om det? Til de andre: Når X sier dette, hva sier det dere? Hvor er dere i forhold til det? Ingen har nevnt ... Spiller det ingen rolle for dere? Kan du være mer konkret!)

	(Muligheter/Barrierer?) Har dokumentasjon i EPJ endret seg etter innføring av Choice? **Erfaringer med Choice som hjelpemiddel i arbeidssituasjonen deres?** (Fordeler, ulemper?).
Tverrfaglig samarbeid:	7. **Hvordan brukes Choice i de ulike helsepersonellgruppene?** Utdyp. **Har det skjedd noen endring i forhold til tverrfaglig samarbeid?** Utdyp Hvordan benyttes Choice i samarbeidet med legene? (andre yrkesgrupper?). Andre måter Choice kunne blitt bruk på? Hvordan kunne du evt. gjort dette annerledes?
Barrierer mht til å "ta" Choice	8. **Opptelling fra siste uke viser at xx av pasienten har gjennomført Choice kartlegging.** Hva kan være **barrierer** i forhold til å ta Choice? **Muligheter?**
Opplæring før:	9. **Hvordan opplevde dere opplæringen i forkant av innføringen av Choice?** Hva var nyttig, hva var ikke nyttig? Hva kunne evt vært gjort annerledes? Noe som manglet? Ønsker? **Hvordan har støtte/hjelp til å benytte Choice underveis vært?** (Tilstrekkelig? Andre ønsker? Oppfølging?)
Opplæring underveis:	10. **Hvilke opplæringsbehov dukket opp underveis i prosessen?** Hva ble gjort i forhold til dette? Hva nyttig, hva mindre nyttig? Hva kunne evt vært gjort annerledes? Ønsker? **Har Choice avdekket behov for annen kunnskap/behov for faglig oppdatering på spesielle tema?** Utdyp

Holdninger til Choice **Momenter som har hatt innvirkning på innføring?** **Å drive Choice på egenhånd?**	**11. Hva syntes dere om Choice ved innføringen?** Hva synes dere **nå?**(noe som har endret seg?). **12. Var det andre nye systemer/arbeidsmåter som ble iverksatt på samme tid?** (Hvis ja: Hvilken innvirkning tror dere det hadde på innføring av Choice?) **Andre momenter** som har hatt innvirkning på innføring av Choice? (tid? tempo i avd? nye medarbeidere? **13. Hva skal til for at dere kan drive Choice videre på egenhånd?** Hva vil dere trenge av støtte? Hvordan sikre at nye sykepleiere og leger læres opp i bruk av Choice? Er det noe dere savner ved Choice? Utdyp.
Avslutning	**Moderator eller respondenter oppsummerer hva som er diskutert** ca. 10 min. **Ass. moderator:** • Etter et kort overblikk over hensikten med intervjuet: Har vi fått med alt eller mangler vi noe? Er det noe vi ikke har vært inne på som er viktig å få frem. NB! Tåle taushet!! • Til slutt noen prosess-spørsmål *uten båndopptaker* (hvordan det har vært å være med i fokusgruppen). Takk for oppmøtet! **Debriefing etter fokusgruppen med moderator og ass. moderator (**Tas opp på bånd). Hva var de viktigste temaene som ble diskutert? På hvilken måte skilte disse seg ut fra det vi forventet? På hvilken måte skilte de seg fra det som skjedde i tidligere grupper? Hvilke punkter skal med i rapporten? Hvilke sitater må vi ta med? Var det uventede funn? Skal noe endres til neste gruppe?

(Jeg hører du nevner ... Kan du si mer om det? Til de andre: Når X sier dette, hva sier det dere? Hvor er dere i forhold til det? Ingen har nevnt ... Spiller det ingen rolle for dere? Kan du være mer konkret!)

ID: _____ Dato: _____

0	3	6	9	**12**
(Fylles ut av senteret)				
B				

Spørreskjemaer

Dato for utfylling av spørreskjema: _____

Vennligst legg ferdig utfylte spørreskjema i returkonvolutten og returner til oss.

I samme returkonvolutt, husk å også legge ved den ferdig utfylte DAGBOKEN som du fikk sammen med de forrige spørreskjemaene.

Det kan hende du synes at enkelte spørsmål ikke helt passer til din opplevelse. Vi ber deg likevel om å forsøke å velge det svaret som ligger nærmest opp til det du mener/opplever, heller enn å la være å svare.

ID: _____ Dato: _____

BAKGRUNNS SPØRSMÅL

Vennligst fyll inn eller sett et kryss ved det som passer:

Alder: ___ år

Sivil status:

☐ Gift ☐ Ugift ☐ Skilt

☐ Samboer ☐ Separert ☐ Enke

Antall barn: _____

Høyeste utdanning fullført:

☐ Grunnskolen ☐ Universitets- og/eller høgskole opptil 4 år

☐ Videregående skole ☐ Universitets- og/eller høgskole mer enn 4 år

Husholdningens totale årsinntekt:

☐ Under 200 000 ☐ 400 000 – 600 000

☐ 200 000 – 400 000 ☐ 600 000 – 800 000 ☐ Over 800 000

Din kreftdiagnose:_____

Når fikk du din kreftdiagnose? :_____ (måned/år).

Kryss av for alt som passer:

☐ Førstegangsdiagnose

☐ Kreften har kommet tilbake

☐ Spredning

For kvinner:

Hvilken behandling har du gjennomført for din nåværende kreftsykdom så langt?

☐ Operert bort brystet ☐ Stråling mot brystet og/eller lymfeknuter

☐ Brystbevarende operasjon ☐ Cellegiftbehandling

☐ Operert bort lymfeknuter ☐ Antihormonbehandling ☐ Herceptin

☐Annet:_____

ID: _____ Dato: _____

_____

For menn:

Hvilken behandling har du gjennomført for din nåværende kreftsykdom så langt?

☐ Fjernet prostata ☐ Stråling mot prostata

☐ Hormonbehandling (tabletter) ☐ Hormonbehandling (sprøyte)

☐ Fjernet testikler ☐ Cellegiftbehandling

☐ Annet: _____

_____

Har du andre sykdommer? ☐ Nei ☐ Ja **Hvis ja; hvilke?**

_____

_____

Hvor mye erfaring har du med å bruke datamaskin?

☐ Ingen ☐ En del

☐ Litt ☐ Ganske mye ☐ Mye

ID: _____ Dato: _____

Dine symptomer eller plager

Her ber vi deg angi hvilke symptomer og plager du har eller har hatt i forbindelse med din sykdom i løpet av den siste uken. Slik gjør du dette:

Vennligst les gjennom hvert symptom. Dersom du har hatt symptomet, markerer du **hvor plagsomt det har vært** i boksen til høyre under '**Hvis ja, hvor plagsomt?'** Sett ring rundt det tallet som passer best. Dersom du ikke har hatt symptomet, sett et kryss i kolonnen under '**Nei' (ikke hatt symptomet)** og gå videre til neste.

Se eksempel: Dersom du ikke har hatt smerter, men har vært plaget en del med lite energi, ville du fylt ut spørsmålene som vist nedenfor.

Har du hatt noen av følgende symptomer eller plager den siste uken?	**Nei** (ikke hatt symptomet)	**Hvis ja, hvor plagsomt?**				
		Ikke	Litt	En del	Mye	Svært mye
Smerter	**X**	0	1	2	2	4
Har lite energi		0	1	(**2**)	2	4

Vennligst gå til neste side for å begynne!

ID: _____ Dato: _____

Har du hatt noen av følgende symptomer eller plager den siste uken?	**Nei** (ikke hatt symptomet)	**Hvis ja, hvor plagsomt?**				
		Ikke	**Litt**	**En del**	**Mye**	**Svært mye**
1. Vanskelig å konsentrere meg		0	1	2	3	4
2. Smerter		0	1	2	3	4
3. Har lite energi		0	1	2	3	4
4. Hoste		0	1	2	3	4
5. Føler meg nervøs		0	1	2	3	4
6. Tørr i munnen		0	1	2	3	4
7. Kvalme		0	1	2	3	4
8. Søvnig, mye trett		0	1	2	3	4
9. Nummen/prikker i hender/føtter		0	1	2	3	4
10. Søvnvansker		0	1	2	3	4
11. Luft i magen/ oppblåst		0	1	2	3	4
12. Problemer med vannlating		0	1	2	3	4
13. Kaster opp		0	1	2	3	4
14. Kortpustet		0	1	2	3	4
15. Diaré		0	1	2	3	4
16. Føler meg trist		0	1	2	3	4
17. Svette		0	1	2	3	4
18. Bekymrer meg		0	1	2	3	4
19. Problemer med seksuallyst/seksuell aktivitet		0	1	2	3	4
20. Kløe		0	1	2	3	4
21. Manglende matlyst		0	1	2	3	4
22. Svimmel/ør i hodet		0	1	2	3	4
23. Vanskelig å svelge		0	1	2	3	4
24. Føler meg irritabel		0	1	2	3	4
25. Sår i munnen		0	1	2	3	4
26. Maten smaker annerledes		0	1	2	3	4
27. Vekttap		0	1	2	3	4
28. Mistet håret		0	1	2	3	4
29. Treg mage/forstoppelse		0	1	2	3	4
30. Hoven i armer og ben		0	1	2	3	4
31. ”Jeg ser ikke ut som meg lengre”		0	1	2	3	4
32. Forandringer i huden		0	1	2	3	4

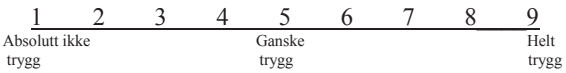
ID: _____ Dato: _____

Om å håndtere kreftsykdom

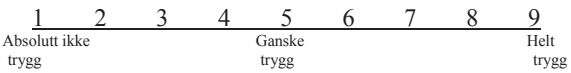
Hvor trygg føler du deg på at du vil håndtere din kreftsykdom? Sett en ring rundt det tallet på linjen som passer best for deg.

Jeg føler meg trygg på at jeg klarer å:

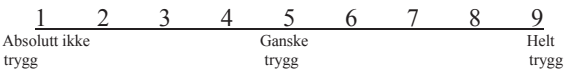
1. Beholde min uavhengighet



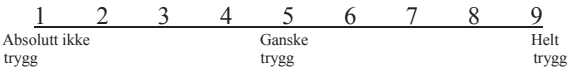
2. Beholde en positiv holdning



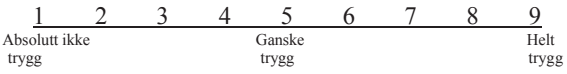
3. Akseptere at jeg har kreft



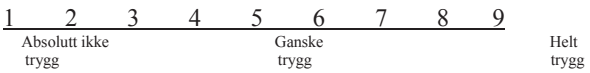
4. Fortsette å arbeide



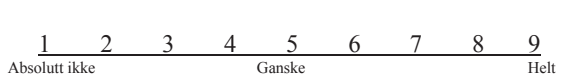
5. Stille sykepleierne spørsmål



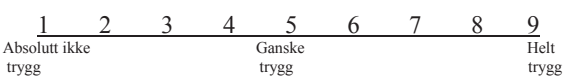
6. Beholde roen gjennom behandlingen og ikke la skremmende tanker gjøre meg bekymret



7. Søke støtte fra andre utenom familien



8. Opprettholde en daglig rutine



ID: _____ Dato: _____

Jeg føler meg trygg på at jeg klarer å:

9. Stille spørsmål til annet helsepersonell (stråleterapeuter, bioingeniører etc)

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

10. Mestre håravfall

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

11. Skyve bekymringer omkring sykdommen i bakgrunnen

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

12. Beholde roen gjennom behandlingen

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske tygg — Helt trygg

13. Mestre fysiske forandringer

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

14. Ignorere ting som ikke kan håndteres i øyeblikket

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

15. Delta aktivt i bestemmelser om min behandling

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

16. Dele bekymringer med andre

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trrygg

17. Beholde roen selv om jeg må vente minst 1 time på legeavtalen min

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

ID: _____ Dato: _____

Jeg føler meg trygg på at jeg klarer å:

18. Gi uttrykk for personlige følelser som sinne eller motvilje

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

19. Søke informasjon om kreft eller kreftbehandling

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

20. Gi uttrykk for negative følelser i forhold til kreftsykdommen

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

21. Holde meg opptatt med aktiviteter

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

22. Finne en utvei

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

23. Redusere angst knyttet til å ta blodprøve

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

24. Beholde humoristisk sans

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

25. Akseptere fysiske forandringer eller begrensninger oppstått pga kreftbehandling

1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

26. Søke trøst

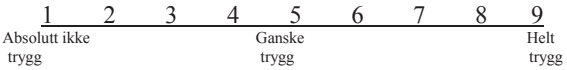
1 2 3 4 5 6 7 8 9

Absolutt ikke trygg — Ganske trygg — Helt trygg

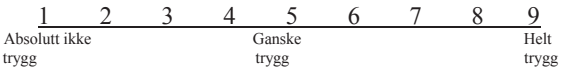
ID: _____ Dato: _____

Jeg føler meg trygg på at jeg klarer å:

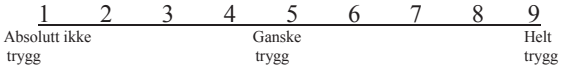
27. Redusere kvalme i forbindelse med behandling



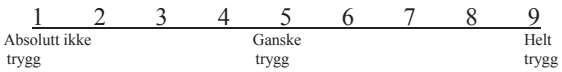
28. Opprettholde håp



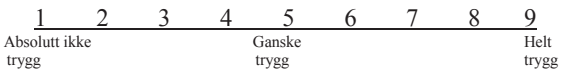
29. Stille leger spørsmål



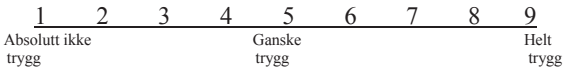
30. Gjøre noe, hva som helst



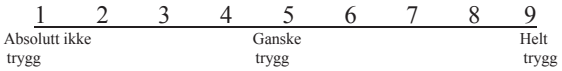
31. Håndtere smerte



32. Håndtere kvalme og brekninger



33. Ha kontroll over de negative følelsene i forbindelse med kreften



ID: _____ Dato: _____

Livskvalitet

(New 15D/Harri Sintonen)

Vennligst les gjennom alle svaralternativene til hvert spørsmål før du plasserer et kryss (x) for det alternativet som best beskriver din nåværende tilstand. Fortsett på samme måte for alle 15 spørsmålene. Gi bare ett svar på hvert spørsmål.

1. BEVEGELIGHET

1 ☐ Jeg er i stand til å gå normalt (uten vanskelighet) innendørs, utendørs og i trapper

2 ☐ Jeg er i stand til å gå uten vanskelighet innendørs, men utendørs og/eller i trapper har jeg litt problemer

3 ☐ Jeg er i stand til å gå uten hjelp innendørs (med eller uten hjelpemiddel), men utendørs og/eller i trapper bare med betydelig vanskelighet eller med hjelp fra andre

4 ☐ Jeg er i stand til å gå innendørs kun med hjelp fra andre

5 ☐ Jeg er fullstendig sengeliggende og ute av stand til å bevege meg omkring

2. SYN

1 ☐ Jeg ser normalt, dvs. jeg kan lese aviser og tekst på TV uten vanskelighet (med el. uten briller)

2 ☐ Jeg kan lese aviser og/eller tekst på TV med litt vansker (med eller uten briller)

3 ☐ Jeg kan lese aviser og/eller tekst på TV med betydelige vansker (med eller uten briller)

4 ☐ Jeg kan ikke lese aviser og/eller tekst på TV verken med briller eller uten, men jeg kan se godt nok til å gå omkring uten hjelp

5 ☐ Jeg kan ikke se godt nok til å gå omkring uten hjelp, dvs. jeg er nesten eller helt blind

3. HØRSEL

1 ☐ Jeg hører normalt, dvs. normal tale (med eller uten høreapparat)

2 ☐ Jeg hører normal tale med litt vansker

3 ☐ Jeg hører normal tale med betydelige vansker; i samtaler må stemmer være høyere enn normalt

4 ☐ Jeg hører selv sterke stemmer dårlig; jeg er nesten døv

5 ☐ Jeg er helt døv

4. PUST

1 ☐ Jeg er i stand til å puste normalt, dvs. uten å være kortpustet eller ha andre pustevansker

2 ☐ Jeg er kortpustet under tungt arbeid eller sport, eller når jeg går raskt på flat mark eller i slak motbakke

3 ☐ Jeg er kortpustet når jeg går på flat mark med samme tempo som andre på min alder

4 ☐ Jeg blir kortpustet selv etter lett aktivitet, f.eks. når jeg vasker meg eller kler på meg

5 ☐ Jeg har pustevansker nesten hele tiden, selv i hvile

ID: _____ Dato: _____

5. SØVN

1 ☐ Jeg er i stand til å sove normalt, dvs. jeg har ingen problem med å sove

2 ☐ Jeg har lette søvnproblemer, f.eks. vanskelig for å falle i søvn eller våkner av og til om natten

3 ☐ Jeg har moderate søvnproblemer, f.eks. forstyrret søvn eller føler at jeg ikke har sovet nok

4 ☐ Jeg har store søvnproblemer, f.eks. må bruke sovemedisiner ofte eller rutinemessig, eller våkner om natten og/eller for tidlig om morgenen

5 ☐ Jeg lider av alvorlig søvnløshet, f.eks. er søvn nesten umulig selv med bruk av sovemedisiner, eller jeg forblir våken det meste av natten

6. SPISING

1 ☐ Jeg er i stand til å spise normalt, dvs. uten hjelp fra andre

2 ☐ Jeg er i stand til å spise selv med mindre vansker (f.eks. langsomt, kløvete, skjelvende eller med spesielle hjelpemidler)

3 ☐ Jeg trenger noe hjelp fra en annen person for å spise

4 ☐ Jeg er ute av stand til å spise selv i det hele tatt, slik at jeg må mates av en annen person

5 ☐ Jeg er ute av stand til å spise i det hele tatt, slik at jeg mates enten med slange eller intravenøst

7. TALE

1 ☐ Jeg er i stand til å tale normalt, dvs. klart, hørbart og flytende

2 ☐ Jeg har lette vansker med å snakke, f.eks. famler av og til etter ord, mumler eller endrer stemmeleiet

3 ☐ Jeg kan gjøre meg forstått, men min tale er f.eks. oppstykket, nølende, stotrende eller stammende

4 ☐ De fleste mennesker har store vansker med å forstå hva jeg sier

5 ☐ Jeg kan bare gjøre meg forstått med fakter

8. VANNLATING / AVFØRING

1 ☐ Min blære og tarm fungerer normalt og uten problemer

2 ☐ Jeg har lette problemer med min blære- og/eller tarmfunksjon, f.eks. vansker med å urinere eller løs eller hard avføring

3 ☐ Jeg har betydelige problemer med min blære- og/eller tarmfunksjon, f.eks. ”uhell” av og til, eller alvorlig forstoppelse eller diaré

4 ☐ Jeg har alvorlige problemer med min blære- og/eller tarmfunksjon, f.eks. regelmessige ”uhell”, eller behov for kateterisering eller klyster

5 ☐ Jeg har ikke kontroll over min blære- og/eller tarmfunksjon

ID: _____ Dato: _____

9. VANLIGE AKTIVITETER

1 ☐ Jeg er i stand til å utføre mine vanlige aktiviteter (f.eks. arbeid, studier, husarbeid, fritidsaktiviteter) uten vanskelighet

2 ☐ Jeg er i stand til å utføre mine vanlige aktiviteter noe mindre effektivt eller med litt vanskelighet

3 ☐ Jeg er i stand til å utføre mine vanlige aktiviteter mye mindre effektivt, med betydelig vanskelighet, eller ikke fullt ut

4 ☐ Jeg kan bare klare en liten del av mine vanlige aktiviteter fra tidligere

5 ☐ Jeg er ute av stand til å klare noen av mine vanlige aktiviteter fra tidligere

10. MENTAL FUNKSJON

1 ☐ Jeg er i stand til å tenke klart og logisk, og min hukommelse fungerer godt

2 ☐ Jeg har litt vansker med å tenke klart og logisk, eller min hukommelse svikter meg av og til

3 ☐ Jeg har merkbare vansker med å tenke klart og logisk, eller min hukommelse er noe redusert

4 ☐ Jeg har store vansker med å tenke klart og logisk, eller min hukommelse er betydelig nedsatt

5 ☐ Jeg er stadig forvirret eller desorientert for sted og tid

11. UBEHAG OG SYMPTOMER

1 ☐ Jeg har ikke fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc.

2 ☐ Jeg har lett fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc.

3 ☐ Jeg har tydelig fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc.

4 ☐ Jeg har alvorlig fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc.

5 ☐ Jeg har uholdbart fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc.

12. DEPRESJON

1 ☐ Jeg føler meg overhodet ikke trist, melankolsk eller deprimert

2 ☐ Jeg føler meg litt trist, melankolsk eller deprimert

3 ☐ Jeg føler meg middels trist, melankolsk eller deprimert

4 ☐ Jeg føler meg svært trist, melankolsk eller deprimert

5 ☐ Jeg føler meg ekstremt trist, melankolsk eller deprimert

13. STRESS

1 ☐ Jeg føler meg overhodet ikke engstelig, stresset eller nervøs

2 ☐ Jeg føler meg litt engstelig, stresset eller nervøs

3 ☐ Jeg føler meg middels engstelig, stresset eller nervøs

4 ☐ Jeg føler meg svært engstelig, stresset eller nervøs

5 ☐ Jeg føler meg ekstremt engstelig, stresset eller nervøs

ID: _____ Dato: _____

14. LIVSKRAFT

1 ☐ Jeg føler meg frisk og energisk
2 ☐ Jeg føler meg litt sliten, trett eller svak
3 ☐ Jeg føler meg middels sliten, trett eller svak
4 ☐ Jeg føler meg svært sliten, trett eller svak, nesten utslitt
5 ☐ Jeg føler meg ekstremt sliten, trett eller svak, totalt utslitt

15. SEKSUELL AKTIVITET

1 ☐ Min helsetilstand har ingen ugunstig innvirkning på min seksuelle aktivitet
2 ☐ Min helsetilstand har en liten innvirkning på min seksuelle aktivitet
3 ☐ Min helsetilstand har en betydelig innvirkning på min seksuelle aktivitet
4 ☐ Min helsetilstand gjør seksuell aktivitet nesten umulig
5 ☐ Min helsetilstand gjør seksuell aktivitet umulig

ID: _____ Dato: _____

SOSIAL STØTTE

Hvor ofte er hver av de nedenfor nevnte typer støtte tilgjengelig for deg når du trenger det?

Kryss av ved det som passer best ved hvert spørsmål	**Aldri**	**Enkelte ganger**	**Av og til**	**Meste parten av tiden**	**Hele tiden**
1. Noen som hjelper deg når du må holde sengen					
2. Noen som du regner med vil høre på deg når du har behov for å snakke					
3. Noen som gir deg gode råd i forbindelse med en krise					
4. Noen som følger deg til legen når du har behov for det					
5. Noen som gir deg kjærlighet og omsorg					
6. Noen som du har det hyggelig sammen med					
7. Noen som gir deg informasjon for å hjelpe deg til å forstå situasjonen/problemet					
8. Noen som du betror deg til, eller snakker med om deg selv eller dine problemer					
9. Noen som gir deg en klem					
10. Noen som du slapper av sammen med					
11. Noen som lager mat til deg hvis du ikke kan gjøre det selv					
12. Noen som gir deg råd du virkelig ønsker					
13. Noen å gjøre ting sammen med for å hjelpe deg til å komme på andre tanker					
14. Noen som hjelper til med de daglige gjøremål hvis du er syk					
15. Noen å dele dine mest private bekymringer og redsler med					
16. Noen å henvende deg til for å få råd om hvordan du kan håndtere et personlig problem					
17. Noen å gjøre noe hyggelig sammen med					
18. Noen som forstår dine problemer					
19. Noen å elske og som får deg til å føle deg ønsket					

ID: _____ Dato: _____

DEPRESJON

Vennligst sett et kryss under det tallet som markerer hvor ofte du har følt det slik i løpet av den siste uken	**0 Sjelden eller aldri** (mindre enn en gang i uken)	**1 Noen ganger** (1-2 dager i uken)	**2 Ofte** (3-4 dager i uken)	**3 For det meste/ hele tiden** (5-7 dager i uken)
1. Jeg ble plaget av ting som vanligvis ikke plager meg				
2. Jeg følte at alt jeg gjorde var en kraftanstrengelse				
3. Jeg følte at jeg var like bra som andre mennesker				
4. Jeg hadde problemer med å konsentrere meg om det jeg holdt på med				
5. Jeg følte meg trist				
6. Jeg følte meg redd				
7. Jeg følte meg ensom				
8. Jeg hadde gråtetokter				
9. Jeg snakket mindre enn vanlig				
10. Jeg sov urolig				
11. Jeg gledet meg over livet				
12. Jeg følte at jeg ikke ble kvitt det å være nedtrykt selv med hjelp fra familie/venner				
13. Jeg følte at livet mitt var mislykket				
14. Jeg var lykkelig				
15. Jeg hadde ikke noe initiativ				
16. Jeg følte meg optimistisk i forhold til fremtiden				
17. Folk var uvennlige				
18. Jeg hadde ikke lyst til å spise; matlysten var dårlig				
19. Jeg følte meg deprimert				
20. Jeg følte at folk mislikte meg				

9012

Reg. Nr: | | | | |

Initialer: | | | |

Spørreskjemaer til deltakere i studien:

"WebChoice 2.0"

Effekt av internettstøtte for kreftpasienter som en del av klinisk praksis

DATO FOR UTFYLLING: | | | . | | | . | | | | |

dag ***måned*** ***år***

(Fylles ut av pasient)

Vennligst les hvert spørsmål nøye før du svarer. Hvis du er usikker hva du skal svare på et spørsmål, svar så godt du kan. Husk at det er ingen riktige eller gale svar.

Du kan oppleve at noen av spørsmålene overlapper hverandre. Grunnen til dette er at vi bruker standardiserte skjemaer som gjør det mulig å sammenligne resultatene fra denne studien med andre studier. Vi kan derfor ikke fjerne spørsmål fra disse skjemaene, og ber deg besvare alle, selv om du kansje allerede har besvart de et annet sted i heftet.

Dine svar på dette spørreskjemaet vil bli behandlet strengt konfidensielt, og de vil bare bli brukt til forskning. Informasjonen du gir vil bli bearbeidet sammen med svarene fra andre pasienter som også fyller ut skjemaet, slik at det ikke blir mulig å finne tilbake til svarene fra enkeltpersoner.

Utfylling av skjema:

1. Bruk bare blå eller sort kulepenn (ikke blyant)
2. Kryss innenfor rutene: ☒
3. Skjemaet må ikke brettes (gir streker i skjemaet ved optisk lesing)
4. Skriv tydelig

BAKGRUNNSOPPLYSNINGER

Vennligst sett kryss eller fyll inn det som passer:

1. Sivilstatus: (Sett ett kryss)

- ☐ Gift/samboer
- ☐ Skilt/separert
- ☐ Ugift
- ☐ Enke/enkemann

2. a) Hvor mange barn har du?

b) Hvor mange barn bor du sammen med (helt eller delvis)?

3. Høyeste fullførte utdanning: (Sett ett kryss)

- ☐ Grunnskole
- ☐ Videregående skole
- ☐ Universitet og/eller høgskole opptil 4 år
- ☐ Universitet og/eller høgskole mer enn 4 år

4. Arbeid/studier per i dag: (Sett gjerne flere kryss)

- ☐ Heltidsarbeid
- ☐ Deltidsarbeid
- ☐ Hjemmearbeidende
- ☐ Studier
- ☐ Uførepensjon
- ☐ Alderspensjon
- ☐ Arbeidsledig/permittert
- ☐ Sykmeldt (helt)
- ☐ Sykmeldt (delvis)
- ☐ Rehabilitering/yrkesrettet attføring
- ☐ Hvis annet, spesifiser:

5. Husholdningens totale årsinntekt: (Sett ett kryss)

- ☐ Under 200 000
- ☐ 200 000 - 399 999
- ☐ 400 000 - 599 999
- ☐ 600 000 - 799 999
- ☐ 800 000 - 1 000 000
- ☐ Over 1 000 000

6.

Hvor ofte benytter du deg av følgende tjenester på internett?	Minst en gang hver hverdag	Minst en gang i uken, men ikke hver dag	Minst en gang i måneden, men ikke hver uke	Mindre enn en gang i måneden	Aldri
Sender e-post	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Mottar e-post	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Benytter banktjenester	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Kjøper varer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Bestiller billetter	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Spiller eller laster ned spill og/eller musikk	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Leser eller laster ned nyhetssider	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Leser eller laster ned fakta/bakgrunnsstoff	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Leser eller laster ned helseinformasjon	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Deltar i nettsamfunn	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Reg. Nr: | | | | |

TILLEGGSSYKDOMMER (SCQ-18)

Det følgende er en liste over vanlige medisinske problemer. Sett ett kryss for hvert problem om hvorvidt du har problemet nå (ja eller nei). Hvis du HAR problemet, så svar på spørsmålene om behandling og aktiviteter til høyre. Hvis du IKKE HAR problemet, gå videre til neste problem.

Problem	Har du problemet?	HVIS JA: Får du behandling for det?	HVIS JA: Begrenser det dine aktiviteter?
1. Hjertesykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
2. Høyt blodtrykk	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
3. Lungesykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
4. Diabetes	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
5. Magesår/magesykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
6. Tarmsykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
7. Nyresykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
8. Leversykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
9. Anemi eller annen blodsykdom	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
10. Hodepine	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
11. Depresjon	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
12. Slitasjegikt/artrose	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
13. Rygg/nakkesmerter	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
14. Leddgikt/revmatoid artritt	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
15. Sykdom i bindevev eller muskulatur	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
16. Hudlidelser	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
17. Andre medisinske problemer (angi)			
		☐ Ja ☐ Nei	☐ Ja ☐ Nei
		☐ Ja ☐ Nei	☐ Ja ☐ Nei
		☐ Ja ☐ Nei	☐ Ja ☐ Nei

9012

Reg. Nr: | | | | |

SYMPTOMLISTE (MSAS)

Veiledning: Vi har listet opp 32 symptomer nedenfor. Les hvert av dem nøye. Hvis du har hatt symptomet i løpet av siste uken, la oss få vite hvor ofte du hadde det, hvor kraftig det var det meste av tiden, og hvor mye det plaget eller bekymret deg, ved å sette ett kryss i den ruten du synes passer best. Hvis du IKKE HAR HATT symptomet, sett ett kryss i den ruten merket HAR IKKE HATT symptomet.

I løpet av den siste uken: **Har du hatt noen av de følgende symptomene?**	**Har ikke hatt symptomet**	**Hvis JA: Hvor ofte hadde du symptomet?**				**Hvis JA: Hvor kraftig var symptomet, det meste av tiden?**				**Hvis JA: Hvor mye plaget eller bekymret symptomet deg?**				
		Sjelden	Av og til	Ofte	Nesten hele tiden	Svakt	Moderat	Kraftig	Svært kraftig	Ikke i det hele tatt	Litt	En del	Ganske mye	Svært mye
Vanskelig å konsentrere seg	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Smerter	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Har lite energi	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hoste	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Føler meg nervøs	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Tørr i munnen	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kvalme	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Søvnig, mye trøtt	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nummen/prikker i hender/føtter	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Søvnvansker	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Luft i magen/oppblåst	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Problemer med vannlating	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kaster opp	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kortpustet	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Diaré	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Føler meg trist	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Svette	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Bekymrer meg	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Problemer med seksuallyst/ aktivitet	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Reg. Nr: | | | | |

SYMPTOMLISTE (MSAS) - del 2

I løpet av den siste uken: **Har du hatt noen av de følgende symptomene?**	**Har ikke hatt symptomet**	**Hvis JA: Hvor ofte hadde du symptomet?**				**Hvis JA: Hvor kraftig var symptomet, det meste av tiden?**				**Hvis JA: Hvor mye plaget eller bekymret symptomet deg?**				
		Sjelden	Av og til	Ofte	Nesten hele tiden	Svakt	Moderat	Kraftig	Svært kraftig	Ikke i det hele tatt	Litt	En del	Ganske mye	Svært mye
Kløe	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Manglende matlyst	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Svimmel/ør	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Vanskelig å svelge	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Føler meg irritabel	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Sår i munnen	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Maten smaker annerledes	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Vekttap	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Mistet håret	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treg mage/forstoppelse	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hoven i armer og ben	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
"Jeg ser ikke ut som meg selv lengre"	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Forandringer i huden	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Hvis du har hatt noen andre symptomer i løpet av den siste uken, vennligst skriv de opp nedenfor, og angi hvor mye det plaget eller bekymret deg.

		Ikke i det hele tatt	Litt	En del	Ganske mye	Svært mye
Annet:		☐	☐	☐	☐	☐
Annet:		☐	☐	☐	☐	☐
Annet:		☐	☐	☐	☐	☐

OM HVORDAN DU FØLER DEG (HADS)

Reg. Nr: | | | | |

Disse spørsmålene er utformet for å hjelpe oss til å forstå hvordan du føler deg. Les hvert spørsmål og sett kryss i boksen for det svar som best beskriver dine følelser den siste uken.
Ikke tenk for lenge på svaret - de spontane svarene er best.

1. Jeg er nervøs eller anspent
- ☐ For det meste
- ☐ Ofte
- ☐ Noen ganger
- ☐ Ikke i det hele tatt

2. Jeg gleder meg fremdeles over ting jeg pleide å glede meg over
- ☐ Avgjort like mye
- ☐ Ikke fullt så mye
- ☐ Bare lite grann
- ☐ Ikke i det hele tatt

3. Jeg har en urofølelse som om noe forferdelig kommer til å skje
- ☐ Helt sikkert og svært ille
- ☐ Ja, men ikke så veldig ille
- ☐ Litt ille, men det bekymrer meg ikke så mye
- ☐ Ikke i det hele tatt

4. Jeg kan le og se det morsomme i situasjoner
- ☐ Like mye som jeg alltid har gjort
- ☐ Ikke like mye nå som før
- ☐ Avgjort ikke så mye nå som før
- ☐ Ikke i det hele tatt

5. Jeg har hodet fullt av bekymringer
- ☐ Veldig ofte
- ☐ Ganske ofte
- ☐ Av og til
- ☐ En gang i blant

6. Jeg er i godt humør
- ☐ Aldri
- ☐ Noen ganger
- ☐ Ganske ofte
- ☐ For det meste

7. Jeg kan sitte i fred og ro og kjenne meg avslappet
- ☐ Ja, helt klart
- ☐ Vanligvis
- ☐ Ikke så ofte
- ☐ Ikke i det hele tatt

8. Jeg føler det som om alt går langsommere
- ☐ Nesten hele tiden
- ☐ Svært ofte
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

9. Jeg føler meg urolig liksom jeg har sommerfugler i magen
- ☐ Ikke i det hele tatt
- ☐ Fra tid til annen
- ☐ Ganske ofte
- ☐ Svært ofte

10. Jeg har sluttet å bry meg om hvordan jeg ser ut
- ☐ Ja, helt klart
- ☐ Jeg bryr meg ikke så mye som jeg burde
- ☐ Det kan nok hende jeg ikke bryr meg nok
- ☐ Jeg bryr meg om utseendet like mye som jeg alltid har gjort

11. Jeg er rastløs som om jeg stadig må være i aktivitet
- ☐ Uten tvil svært mye
- ☐ Ganske mye
- ☐ Ikke så veldig mye
- ☐ Ikke i det hele tatt

12. Jeg ser med glede frem til hendelser og ting
- ☐ Like mye som jeg alltid har gjort
- ☐ Heller mindre enn jeg pleier
- ☐ Avgjort mindre enn jeg pleier
- ☐ Nesten ikke i det hele tatt

13. Jeg kan plutselig få en følelse av panikk
- ☐ Uten tvil svært ofte
- ☐ Svært ofte
- ☐ Ikke så veldig ofte
- ☐ Ikke i det hele tatt

14. Jeg kan glede meg over en god bok eller et radio- eller TV- program
- ☐ Ofte
- ☐ Fra tid til annen
- ☐ Ikke så ofte
- ☐ Svært sjelden

Reg. Nr: | | | | |

OM Å HÅNDTERE KREFTSYKDOM (CBI)

Hvor trygg føler du deg på at du vil håndtere din kreftsykdom? Vennligst sett ett kryss i den ruten som passer best for deg (ett kryss for hvert spørsmål).

Jeg føler meg trygg på at jeg klarer å:

	Absolutt ikke trygg							Ganske trygg	Helt trygg
1. Beholde min uavhengighet	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
2. Beholde en positiv holdning	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
3. Akseptere at jeg har kreft	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
4. Fortsette å arbeide	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
5. Stille sykepleierne spørsmål	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
6. Beholde roen gjennom behandlingen og ikke la skremmende tanker gjøre meg bekymret	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
7. Søke støtte fra andre utenom familien	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
8. Opprettholde en daglig rutine	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
9. Stille spørsmål til annet helsepersonell (stråleterapeuter, bioingeniører osv.)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
10. Mestre håravfall	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
11. Skyve bekymringer omkring sykdommen i bakgrunnen	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
12. Beholde roen gjennom behandlingen	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
13. Mestre fysiske forandringer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
14. Ignorere ting som ikke kan håndteres i øyeblikket	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
15. Delta aktivt i beslutninger om min behandling	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
16. Dele bekymringer med andre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9

Jeg føler meg trygg på at jeg klarer å:

	Absolutt ikke trygg								Helt trygg
17. Beholde roen selv om jeg må vente minst 1 time på legeavtalen min	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
18. Gi uttrykk for personlige følelser som sinne eller motvilje	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
19. Søke informasjon om kreft eller kreftbehandling	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
20. Gi uttrykk for negative følelser i forhold til kreftsykdommen	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
21. Holde meg opptatt med aktiviteter	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
22. Finne en utvei	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
23. Redusere engstelse knyttet til å ta blodprøve	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
24. Beholde humoristisk sans	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
25. Akseptere fysiske forandringer eller begrensninger oppstått pga kreftbehandling	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
26. Søke trøst	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
27. Redusere kvalme i forbindelse med behandling	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
28. Opprettholde håp	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
29. Stille leger spørsmål	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
30. Gjøre noe, hva som helst	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
31. Håndtere smerte	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
32. Håndtere kvalme og brekninger	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
33. Ha kontroll over de negative følelsene i forbindelse med kreften	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9

Reg. Nr: | | | | |

OM USIKKERHET MAN KAN OPPLEVE VED SYKDOM (MUIS)

Dette spørreskjemaet er laget for å få vite noe om den usikkerheten man kan oppleve når man er syk.

Vennligst les hver påstand nøye. Svar på hver påstand ved å sette et kryss for det svaralternativet som passer best for hvordan du har det i dag. Hvis du er enig i en påstand, kan du krysse av for "helt enig" eller "enig". Er du uenig i en påstand, kan du krysse av for "helt uenig" eller "uenig". Hvis du er usikker på hvordan du har det, så kryss av for "usikker". Det er ikke noe svar som er "riktig" eller "galt".

	Helt enig	Enig	Usikker	Uenig	Helt uenig
1. Jeg vet ikke hva som feiler meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Jeg har mange ubesvarte spørsmål	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Jeg er usikker på om sykdommen min blir bedre eller verre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Det er uklart hvor ille smertene mine vil bli	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Forklaringene som helsepersonell gir om min tilstand virker uklare for meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Jeg forstår hensikten med hver behandling	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Når jeg har smerter vet jeg hva det vil si om sykdomstilstanden min	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Jeg vet ikke når jeg kan forvente at det skal gjøres noe med meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. Symptomene mine fortsetter å endre seg uforutsigbart	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. Jeg forstår alt som forklares for meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. Legene sier ting til meg som kan ha forskjellig betydning	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12. Jeg kan forutsi hvor lenge sykdommen min vil vare	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13. Den behandlingen jeg får er så kompleks at jeg ikke forstår den	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. Det er vanskelig å vite om behandlingen eller medisinene jeg får hjelper	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. Det er så mange forskjellige yrkesgrupper at det er vanskelig å vite hvem som er ansvarlig for hva	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	Helt enig	Enig	Usikker	Uenig	Helt uenig
16. Siden sykdommen min er så uforutsigbar, er det vanskelig å planlegge for framtiden	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
17. Sykdomstilstanden forandrer seg hele tiden. Jeg har mine gode og dårlige dager	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. Jeg er usikker på hvordan jeg vil klare meg når jeg forlater sykehuset	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19. Jeg har fått mange forskjellige synspunkter på hva som feiler meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20. Det er uklart hva som vil skje med meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
21. Jeg vet vanligvis om jeg vil få en god eller dårlig dag	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
22. Svarene på prøvene mine er ikke i samsvar med hverandre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
23. Virkningen av behandlingen er usikker	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
24. Det er vanskelig å fastslå hvor lang tid det vil ta før jeg kan klare meg selv	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
25. Jeg kan generelt forutsi sykdomsforløpet mitt	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
26. Hva jeg kan og ikke kan gjøre forandrer seg som en følge av behandlingen	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
27. Jeg er sikker på at de ikke vil finne noe annet galt med meg	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28. Det er kjent at den behandlingen jeg får pleier å hjelpe	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
29. De har ikke gitt meg noen bestemt diagnose	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
30. Mine fysiske plager er forutsigbare. Jeg vet når de blir bedre eller verre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
31. Jeg kan stole på at sykepleierne er der når jeg trenger dem	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
32. Alvorlighetsgraden av sykdommen min er fastslått	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
33. Legene og sykepleierne bruker et alminnelig språk så jeg kan forstå hva de sier	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Reg. Nr: | | | | |

LIVSKVALITET (15D)

Vennligst les gjennom alle svaralternativene til hvert spørsmål før du plasserer et kryss (x) for det alternativet som best beskriver din nåværende tilstand. Fortsett på samme måte for alle 15 spørsmålene. Gi bare ett svar på hvert spørsmål.

1. BEVEGELIGHET

☐ Jeg er i stand til å gå normalt (uten vanskelighet) innendørs, utendørs og i trapper

☐ Jeg er i stand til å gå uten vanskelighet innendørs, men utendørs og/eller i trapper har jeg litt problemer

☐ Jeg er i stand til å gå uten hjelp innendørs (med eller uten et hjelpemiddel), men utendørs og/eller i trapper bare med betydelig vanskelighet eller med hjelp fra andre

☐ Jeg er i stand til å gå innendørs kun med hjelp fra andre

☐ Jeg er fullstendig sengeliggende og ute av stand til å bevege meg omkring

2. SYN

☐ Jeg ser normalt, dvs. jeg kan lese aviser og tekst på TV uten vanskelighet (med eller uten briller)

☐ Jeg kan lese aviser og/eller tekst på TV med litt vansker (med eller uten briller)

☐ Jeg kan lese aviser og/eller tekst på TV med betydelige vansker (med eller uten briller)

☐ Jeg kan ikke lese aviser og/eller tekst på TV verken med briller eller uten, men jeg kan se godt nok til å gå omkring uten hjelp

☐ Jeg kan ikke se godt nok til å gå omkring uten hjelp, dvs. jeg er nesten eller helt blind

3. HØRSEL

☐ Jeg hører normalt, dvs. hører normal tale (med eller uten høreapparat)

☐ Jeg hører normal tale med litt vansker

☐ Jeg hører normal tale med betydelige vansker; i samtaler må stemmer være høyere enn normalt

☐ Jeg hører selv sterke stemmer dårlig; jeg er nesten døv

☐ Jeg er helt døv

4. PUST

☐ Jeg er i stand til å puste normalt, dvs. uten å være kortpustet eller ha andre pustevansker

☐ Jeg er kortpustet under tungt arbeid eller sport, eller når jeg går raskt på flat mark eller i slak motbakke

☐ Jeg er kortpustet når jeg går på flat mark med samme tempo som andre på min alder

☐ Jeg blir kortpustet selv etter lett aktivitet, f.eks. når jeg vasker meg eller kler på meg

☐ Jeg har pustevansker nesten hele tiden, selv i hvile

5. SØVN

☐ Jeg er i stand til å sove normalt, dvs. jeg har ingen problemer med å sove

☐ Jeg har lette søvnproblemer, f.eks. vanskelig for å falle i søvn eller våkner av og til om natten

☐ Jeg har moderate søvnproblemer, f.eks. forstyrret søvn eller føler at jeg ikke har sovet nok

☐ Jeg har store søvnproblemer, f.eks. må bruke sovmedisiner ofte eller rutinemessig, eller våkner om natten og/eller for tidlig om morgenen

☐ Jeg lider av alvorlig søvnløshet, f.eks. er søvn nesten umulig selv med bruk av sovemedisiner, eller jeg forblir våken det meste av natten

6. SPISING

☐ Jeg er i stand til å spise normalt, dvs. uten hjelp fra andre

☐ Jeg er i stand til å spise selv med mindre vansker (f.eks. langsomt, kløvete, skjelvende eller med spesielle hjelpemidler)

☐ Jeg trenger noe hjelp fra en annen person for å spise

☐ Jeg er ute av stand til å spise selv i det hele tatt, slik at jeg må mates av en annen person

☐ Jeg er ute av stand til å spise i det hele tatt, slik at jeg mates enten med slange eller intravenøst

7. TALE

☐ Jeg er i stand til å tale normalt, dvs. klart, hørbart og flytende

☐ Jeg har lette vansker med å snakke, f.eks. leter av og til etter ord, mumler eller endrer stemmeleiet

☐ Jeg kan gjøre meg forstått, men min tale er f.eks. oppstykket, nølende, stotrende eller stammende

☐ De fleste mennesker har store vansker med å forstå hva jeg sier

☐ Jeg kan bare gjøre meg forstått med fakter

8. VANNLATING/AVFØRING

☐ Min blære og tarm fungerer normalt og uten problemer

☐ Jeg har lette problemer med min blære- og/eller tarmfunksjon, f.eks. vansker med å urinere eller løs eller hard avføring

☐ Jeg har betydelige problemer med min blære- og/eller tarmfunksjon, f.eks. "uhell" av og til, eller alvorlig forstoppelse eller diaré

☐ Jeg har alvorlige problemer med min blære- og/eller tarmfunksjon, f.eks. regelmessige "uhell", eller behov for kateterisering eller klyster

☐ Jeg har ikke kontroll over min blære- og/eller tarmfunksjon

9. VANLIGE AKTIVITETER

- ☐ Jeg er i stand til å utføre mine vanlige aktiviteter (f.eks. arbeid, studier, husarbeid, fritidsaktiviteter uten vanskeligheter)
- ☐ Jeg er i stand til å utføre mine vanlige aktiviteter noe mindre effektivt eller med litt vanskelighet
- ☐ Jeg er i stand til å utføre mine vanlige aktiviteter mye mindre effektivt, med betydelig vanskelighet, eller ikke fullt ut
- ☐ Jeg kan bare klare en liten del av mine vanlige aktiviteter fra tidligere
- ☐ Jeg er ute av stand til å klare noen av mine vanlige aktiviteter fra tidligere

10. MENTAL FUNKSJON

- ☐ Jeg er i stand til å tenke klart og logisk, og min hukommelse fungerer godt
- ☐ Jeg har litt vansker med å tenke klart og logisk, eller min hukommelse svikter meg av og til
- ☐ Jeg har merkbare vansker med å tenke klart og logisk, eller min hukommelse er noe redusert
- ☐ Jeg har store vansker med å tenke klart og logisk, eller min hukommelse er betydelig nedsatt
- ☐ Jeg er stadig forvirret og desorientert for sted og tid

11. UBEHAG OG SYMPTOMER

- ☐ Jeg har ikke fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc
- ☐ Jeg har lett fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc
- ☐ Jeg har tydelig fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc
- ☐ Jeg har alvorlig fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc
- ☐ Jeg har uholdbart fysisk ubehag eller plager, f.eks. smerte, verk, kvalme, kløe, etc

12. DEPRESJON

- ☐ Jeg føler meg overhodet ikke trist, melankolsk eller deprimert
- ☐ Jeg føler meg litt trist, melankolsk eller deprimert
- ☐ Jeg føler meg middels trist, melankolsk eller deprimert
- ☐ Jeg føler meg svært trist, melankolsk eller deprimert
- ☐ Jeg føler meg ekstremt trist, melankolsk eller deprimert

13. STRESS

☐ Jeg føler meg overhodet ikke engstelig, stresset eller nervøs

☐ Jeg føler meg litt engstelig, stresset eller nervøs

☐ Jeg føler meg middels engstelig, stresset eller nervøs

☐ Jeg føler meg svært engstelig, stresset eller nervøs

☐ Jeg føler meg ekstremt engstelig, stresset eller nervøs

14. LIVSKRAFT

☐ Jeg føler meg frisk og energisk

☐ Jeg føler meg litt sliten, trett eller svak

☐ Jeg føler meg middels sliten, trett eller svak

☐ Jeg føler meg svært sliten, trett eller svak, nesten utslitt

☐ Jeg føler meg ekstremt sliten, trett eller svak, totalt utslitt

15. SEKSUELL AKTIVITET

☐ Min helsetilstand har ingen ugunstig innvirkning på min seksuelle aktivitet

☐ Min helsetilstand har en liten innvirkning på min seksuelle aktivitet

☐ Min helsetilstand har en betydelig innvirkning på min seksuelle aktivitet

☐ Min helsetilstand gjør seksuell aktivitet nesten umulig

☐ Min helsetilstand gjør seksuell aktivitet umulig