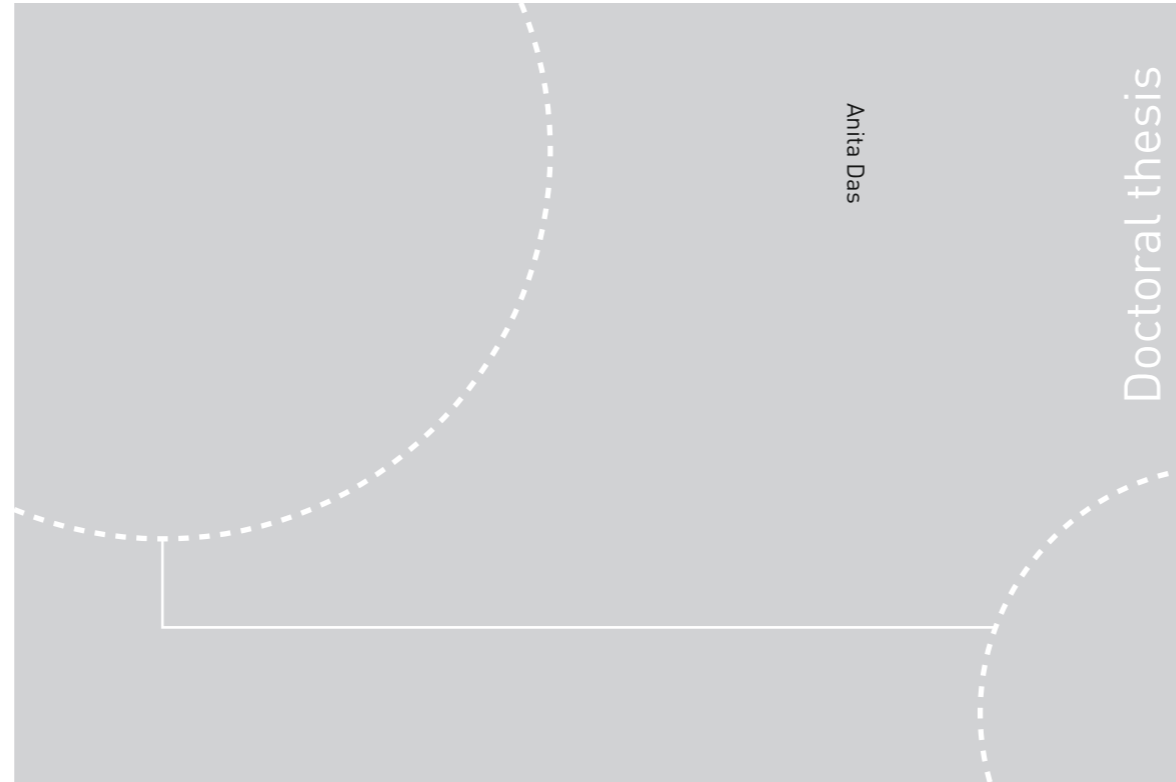


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- from Idea to Evaluation

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Norwegian University of  
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Thesis for the Degree of  
Philosophiae Doctor  
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## Norsk sammendrag

### **MOBESITY: eHelse for pasienter som gjennomgår vektreduserende behandling, fra idé til evaluering.**

Fedme er ansett som en kronisk sykdom og krever store økonomiske og helsemessige ressurser. Vektreduksjon har gunstige helseeffekter på fedmerelatert komorbiditet og dødelighet, og etterspørselen etter vektreduserende behandling har derfor økt. Vellykkede resultater og langsiktig vedlikehold av vektøstet krever egenmestringsaktiviteter og forpliktelser til atferdsendring, men studier viser at pasienter ikke etterlever dette og at de opplever vektøkning etter en stund. Det er behov for nye tilnæringsmåter for å støtte pasienter som gjennomgår vektreduserende behandling, hvor eHelseløsninger tilbyr muligheter for å fasilitere pasienter i løpet av et behandlingsforløp. Utviklere av eHelseløsninger har imidlertid vært fokusert på teknisk innovasjon fremfor nytteverdien av disse verktøyene for pasienter og tilbydere, noe som har resultert i eHelsesystemer med lav oppslutning og bruk. Brukersentrert design innebærer et sett av metoder, verktøy og tilnæringsmåter for å involvere sluttbrukere i designprosesser, men har i liten grad vært brukt ved utforming av løsninger for helsevesenet. De overordnede målene med denne forskningen var å utforske brukersentrert design i utformingen av en pasientsentrert eHelseløsning (studie I), og å karakterisere erfaringene til pasienter og helsepersonell vedrørende bruk av en slik løsning som del av behandlingsforløpet i forbindelse med fedmeoperasjon (studie II). En multimetode tilnærming i form av en eksplorerende casestudie med både kvalitative og kvantitative metoder er blitt gjennomført. Resultatene fra Studie I indikerer at en brukersentrert designprosess av en eHelseløsning for anvendelse i en terapeutisk kontekst er nyttig for å kunne identifisere sluttbrukernes behov samt sentrale aspekter som er viktige å adressere i løpet av en design-og utviklingsprosess av denne typen løsning. Brukersentrert design fordrer imidlertid spesifikke hensyn som må tas til etterretning under gjennomføringen av denne typen prosesser sammen pasienter og helsepersonell. Resultatene fra studie II viser at pasienter er motiverte for å bruke et sikkert nettbasert forum som del av behandlingsforløpet, for å søke etter og for å gi sosial og informativ støtte, men opplever at aktiv bruk begrenses grunnet bekymring for å utlevere og eksponere seg selv. Helsepersonell opplever fordeler med å bruke en eHelse portal for

å kommunisere med pasienter, og rapporterer dette som en læringsarena ved at de får innsikt og informasjon om pasientene. eHelseløsningen byr på en ny tilnæringsmåte for å kunne fasilitere pasienter og gir mulighet for å nå ut til enkelte de ikke lykkes i å følge opp via tradisjonelle kommunikasjonskanaler. Helsepersonell rapporterer imidlertid om organisatoriske utfordringer og personlige begrensninger i å benytte et slikt verktøy, noe som må adresseres for å innfri dens potensial. Denne studien har flere begrensninger, men tilbyr noen implikasjoner vedrørende eHelse design, implementering og videre forskning.

**Navn kandidat:** Anita Das

**Institutt:** Institutt for nevromedisin

**Veiledere:** Arild Faxvaag, Dag Svanæs, Ronald Mårvik

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Habit is Second Nature



## **Abstract**

Obesity is considered a chronic disease and requires enormous economic and health costs. Weight reduction has beneficial health effects on obesity-related comorbidities and mortality, and the demand for weight loss interventions has risen. Successful outcomes and long-term weight maintenance require self-management activities and commitment to behavior change, however, studies report patients' non-adherence and patients regaining weight after some time. Novel approaches to facilitate patients undergoing such treatment are required for improved health outcomes for this group. eHealth solutions impose opportunities and imply benefits of promoting and sustaining weight loss and maintenance. Developers of eHealth solutions have been engaged with technical innovation rather than the utility of these tools for patients and providers, resulting in eHealth systems with low adaptation and use. Human-centered design (HCD) offers a set of approaches, tools, and methods for involving end users in the lifecycle of a design process, but the adaptation of HCD has been limited when designing solutions for healthcare. The overall aim of this research was to (Study I) explore the use of human-centered methodology in the design of a patient-centered eHealth solution, and to (Study II) characterize the experiences of patients and their healthcare providers of using such a solution in a bariatric surgery program. A mixed-methods approach of an explorative case study involving both qualitative and quantitative methods has been undertaken. The results of Study I indicate that using HCD in the design of an eHealth solution for use in a therapeutic context is useful to identify user requirements and various aspects that are important to address in systems design and development, but that there are particular considerations that need to be addressed when conducting such approaches with patients and providers. The results of Study II show that patients are motivated to use a secure online forum as part of the bariatric surgery program to search for and provide social and informational support, but are restrained in enabling such a solution due to concerns regarding self-disclosure. Healthcare professionals experience benefits of using an eHealth portal in communicating with patients because it provides information and an approach to facilitate the patients. However, they report on organizational challenges and personal constraints in enabling such a tool that needs to be addressed in order to fulfill its potential. This study has several limitations but impose implications for eHealth design, implementation, and further research.



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I am thankful to the participants in this study, who took part in different stages of this project; to those who contributed with their innovative ideas, perspectives, and suggestions; to those who evaluated the various versions of the eHealth system; to those who participated in the case study trial; and to those who contributed with their experiences, insights, and viewpoints about the tested solution and service. I appreciate the time and contributions from all of you.

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## **Abbreviations**

BMI	Body Mass Index
CHI	Consumer Health Informatics
GUI	Graphical User Interface
HCD	Human-centered Design
HCI	Human Computer Interaction
ISO	International Standardization Organization
PAM	Patient Activation Measure
PC	Personal Computer
PD	Participatory Design
SMS	Short Message Service (text messaging on mobile telephones)
SPSS	Statistical Package for the Social Sciences
UCD	User-centered Design
WHO	World Health Organization

## List of Publications

### Paper 1

Das, A., Faxvaag, A., Svanæs, D. *Management of weight loss: Patients' and healthcare professionals' requirements for an e-health system for patients*, in M. Kurosu (Ed.): Human Centred Design, HCII 2011, Lecture Notes in Computer Science, Volume 6776, pp. 285-294. Springer 2011.

### Paper 2

Das, A., Svanæs, D. *Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment*. International Journal of Medical Informatics, 2013; 82 (11): pp. 1075–1091.

### Paper 3

Das, A., Faxvaag, A. *What influences patient participation in a facilitated online forum for weight loss surgery? A qualitative case study*. Interactive Journal of Medical Research, 2014; 3 (1).

### Paper 4

Das, A., Faxvaag, A., Svanæs, D. *The impact of an eHealth portal on healthcare professionals' interaction with patients: Qualitative study*. Journal of Medical Internet Research, 2015; 7, (11).

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## Part 1





## Introduction

Population growth, demographic changes with an aging population, and rising numbers of people suffering from obesity and chronic diseases have resulted in an increasing demand for healthcare services [1]. Correspondingly, the healthcare systems in many countries are undergoing major changes to provide more cost-efficient solutions. Political forces of delivering timely and quality care, the enhancement of patient safety, and the empowerment of patients are underlying causes driving this change.

eHealth refers to health services and information delivered or enhanced through the Internet or related technologies [2], and provides opportunities for improved cost-effectiveness by reducing pressure on the healthcare system and delivering quality care to the recipients [3-7]. Thus, the design and development of eHealth solutions for patients have become increasingly relevant. The clinical case in this research has been obesity with a focus on people suffering from severe obesity and who require weight loss intervention and treatment in specialist healthcare.

Obesity is considered a chronic disease [8] and requires enormous economic and health costs [9]. Weight reduction has beneficial health effects on obesity-related comorbidities and mortality [10-12], and the demand for weight loss interventions has therefore risen [1, 13]. There are a variety of therapeutic approaches to achieve weight reduction, from conventional treatment programs such as lifestyle therapy or pharmacotherapy, to more invasive interventions such as bariatric surgery [14-16]. However, a number of studies show that long-term maintenance is a challenge and that people regain weight after some time [17-20]. It is increasingly understood that successful outcomes and long-term weight loss maintenance require self-management activities and commitment to behavior change [14, 17, 18, 21-24], but studies report patients' non-adherence to recommended behavioral changes, with maladaptive eating behaviors and lack of physical activity behaviors [21, 25-27]. Studies of eHealth interventions for physical activity and dietary behavior change show mixed results related to the effectiveness of such interventions [28-35]. Recent reviews support the use and potential of eHealth interventions as treatment options for obesity [34, 35] and imply benefits of promoting and sustaining weight loss and weight maintenance

behavior changes through such means [30, 35, 36]. There are few studies exploring eHealth solutions in a healthcare service context for patients undergoing weight reduction treatment. Hence, what requirements patients and their healthcare providers have towards such an eHealth solution in a specialist healthcare weight reduction program have so far not been investigated.

Factors such as social support, better coping strategies, and the ability to handle life stress are factors associated with successful weight maintenance [22]. The Internet has become an important healthcare medium, providing people the opportunity to search for information, guidance, tools, and social support. Online social support through, e.g., the use of online forums, may include benefits such as enhanced health literacy, improved quality of life, and patient empowerment [37-40]. Few studies have been done with bariatric surgery patients and about their experiences of using online forums, thus, little is known about their motivating and restraining factors of using such a forum. eHealth portals offers a number of potential benefits to healthcare providers including administrative efficiencies, improved responsiveness to patients' needs, decreased utilization of health services, more effective care, and cost savings [41]. Despite the potential advantages, the expansion and adoption of such solutions have been low [4, 41, 42]. Successful implementation depends on the degree of acceptance by its users, where healthcare professionals are key stakeholders to adaption and use [43, 44]. There is limited research that has explored eHealth portals in bariatric surgery, and there is little knowledge about what benefits and challenges healthcare providers experience with using an eHealth portal in communication with bariatric surgery patients.

Developers of eHealth solutions have been engaged with the technical elegance and innovation of new technologies rather than with the utility of these tools for patients and providers [4]. A number of health information systems have poor usability and do not consider the contextual aspects. This is because of limited understandings and knowledge about the targeted user groups' needs and the products' use context [44, 45]. Human-centered design offers a set of approaches, methods, and tools for involving users in the different stages of the lifecycle of a design process. User involvement provides insights and knowledge about the particular user groups under study, their needs, use contexts, preferences, etc.—factors that are critical for eHealth

adaption and use. Despite knowledge about the value of user involvement, the adaption of human-centered design has been limited when designing solutions for healthcare. Healthcare is a complex domain with unforeseen incidents, changing use contexts, and multiple stakeholders with particular needs, interests, roles, expectations, and power. This requires particular attention when it comes to the design, development, and implementation of technology in this particular field. Designers of eHealth solutions face a number of challenges, including the fact that various illnesses and patient groups are diverse requiring particular considerations when conducting human-centered processes. Lack of knowledge and insights about the user groups have resulted in systems that have failed to encourage people to change behavior within the complex contexts of their lives [3], and caused low adaption and use of patient-centered eHealth technologies [41, 42]. To address these challenges, increased knowledge about conducting human-centered design processes with patients and healthcare providers is required in order to gain understandings about considerations that need to be undertaken in such activities.

The focus of this thesis has been on patients (in weight loss treatment) and healthcare providers as collaborative partners in human-centered design processes of an eHealth technology and appurtenant service, and on investigating the experiences of patients and their healthcare providers of using such a solution in a bariatric surgery program.

## Research Questions and Objectives

Overall aim of this research: Explore human-centered methodology in the design of a patient-centered eHealth solution, and to characterize the experiences of patients and their healthcare providers of using such a solution in a bariatric surgery program.

The research questions were:

1. What are the requirements of patients undergoing weight loss treatment and their healthcare providers towards an eHealth solution?
2. How to engage patients and healthcare professionals in the design process of an eHealth tool?
3. What are the motivating and restraining factors of bariatric surgery patients' use of a secure online forum?
4. What benefits and challenges do healthcare providers experience with the use of an eHealth portal in communication with patients?

This research project has been carried out in two phases: first phase focused on the design development process of an eHealth solution and appurtenant service applying human-centered methods with key stakeholders; the second phase focused on bariatric surgery patients and their healthcare providers, where the designed eHealth solution was implemented in a bariatric surgery clinic, tested out, and evaluated.

**Table 1: The relation between the research questions and the research papers**

Research question	Research Paper			
	Paper 1	Paper 2	Paper 3	Paper 4
(1) What are the requirements of patients undergoing weight loss treatment and their healthcare providers towards an eHealth solution?	•			
(2) How to engage patients and healthcare professionals in the design process of an eHealth tool?		•		
(3) What are the motivating and restraining factors for bariatric surgery patients' use of a secure online communication forum?			•	
(4) What benefits and challenges do healthcare providers experience with the use of an eHealth portal in communication with patients?				•

## **Thesis Outline**

This thesis consists of two parts: Part I is the synopsis of the conducted research, and Part II is the collection of research articles.

### **The outline of Part I is as follows:**

*Chapter 1* is the current introduction to the thesis, with an outline of overall research aim and specific research questions.

*Chapter 2* presents the background of this research in which the clinical case of obesity is presented and the theoretical and methodological framework is outlined.

*Chapter 3* gives an overview of the research design, methods, and materials in this research.

*Chapter 4* summarizes the research papers.

*Chapter 5* discusses the strengths and limitations of the current work, and presents implications and recommendations for future work.

*Chapter 6* concludes the work of this thesis.

### **Part II consists of the four research articles:**

*Paper 1* Das, A., Faxvaag, A., Svanæs, D. *Management of weight loss: Patients' and healthcare professionals' requirements for an e-health system for patients.*

*Paper 2* Das, A., Svanæs, D. *Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment.*

*Paper 3* Das, A., Faxvaag, A. *What influences patient participation in a facilitated online forum for weight loss surgery? A qualitative case study.*

*Paper 4* Das, A., Faxvaag, A., Svanæs, D. *The impact of an eHealth portal on healthcare professionals' interaction with patients: Qualitative study.*



## **Background**

In this chapter, I present the theoretical background. I start with the clinical case of obesity and present the epidemiology, impact, and therapeutic approaches. Thereafter, the importance of self-management, patient-provider interaction, and social support in relation to obesity is presented. Further, I describe the concept of eHealth and outline human-centered design as the methodological framework of this research.

### **Obesity**

The global burden of obesity is considerable and has become a significant and increasing public health challenge, entailing enormous economic and health costs. The World Health Organization (WHO) defines overweight and obesity as abnormal or excessive fat accumulation that presents a risk to health in an individual [46]. The WHO criteria is based on the Body Mass Index (BMI) score, calculated by a person's weight in kilograms divided by the square of his/her height in meters ( $\text{kg}/\text{m}^2$ ). Overweight is defined as BMI equal to 25 or more, while obesity as a BMI of 30 or more (Table 2) [46]. In Norway, 27% of the adult population in 2012 were overweight (BMI >27), of these 10% were obese [47]. In 2014, it was estimated that 1.9 billion adults (18 years and older) worldwide were overweight, of these 600 million were obese, a number that has more than doubled since 1980 [46]. If this trend continues, projections on future prevalence of global adult obesity suggest that 42% (non-linear regression model) [48] to 51% (linear time trends) [49] of the world population in 2030 will be obese, depending on the model used.

Obesity increases the risk of developing diseases such as diabetes, cardiovascular diseases (e.g., heart diseases, hypertension, stroke), sleep apnea, strain injuries, and certain forms of cancer. In addition, depression, disabilities, and reduced quality of life are common among people with obesity [46, 50-58]. Obesity is considered to be a chronic condition with multiple factors of importance: genetics, environment, metabolism, lifestyle, and behavior components [59]. The primary cause of overweight is assumed to be reduced physical activity without a corresponding reduction in energy intake [60]. Genetic factors are assumed to cause different sensitivity for developing overweight, but environmental factors and lifestyle influence whether a person becomes obese or not. Because problems related to weight have increased during the past two to three decades, environmental factors are



suspected to be the causative agent, as genetic changes in a population require several generations to develop. Considering the severe impacts of obesity, a comprehensive approach to the management of obesity is required, from prevention of the condition and treatment of obesity, to maintenance of weight loss.

**Table 2: The International Classification of adult weight according to BMI. WHO 2000 [60]**

Classification	BMI (kg/m <sup>2</sup> )	Risk of comorbidities
<b>Underweight</b>	<b>&lt;18.50</b>	Low (increases risk to other clinical problems)
<b>Normal range</b>	<b>18.50 - 24.99</b>	Average
<b>Overweight</b>	<b>≥25.00</b>	Increased
Pre-obese	25.00 - 29.99	Increased
<b>Obesity</b>	<b>≥30.00</b>	
Obesity class I	30.00 - 34.99	Moderate
Obesity class II	35.00 - 39.99	Severe
Obesity class III/Extreme obesity	≥40.00	Very severe

### Therapeutic Approaches

The effects of obesity are reversible, and weight reduction has a beneficial impact on obesity related comorbidities and mortality [10-12]. Weight reduction can be achieved by conventional interventions such as health behavior modification (diet, exercise, pharmacotherapy, and behavioral therapy) and/or by surgical interventions such as various bariatric surgical procedures [14, 61-65]. Lifestyle intervention programs generally involve dietary changes, often with a combination of increased physical activity. The most effective lifestyle intervention programs are a combination of dietary changes and physical activity instructions with behavioral therapy to assist making and sustaining changes in habits [65, 66]. Such interventions result in significant initial weight loss and improvements in cardiovascular disease risk factors among the severely obese [16, 67].

Surgical interventions such as bariatric surgery have been shown to be the most effective intervention and to produce significant initial weight reduction in the great

majority of patients. Bariatric surgery has positive impacts on obesity related comorbidities and on the remission of diabetes and cardiovascular diseases [10-12]. The number of performed surgeries has therefore risen dramatically in recent years [68-70]. In Norway, bariatric interventions are mainly reserved for the severely obese (BMI  $\geq$ 40 or BMI  $\geq$ 35 and additional obesity related comorbidity) who fail to lose weight through conventional methods. About 3,000 people undergo such surgery in Norway each year.

Bariatric surgery to achieve weight loss includes either predominantly malabsorptive procedures or predominantly restrictive procedures, or mixed procedures. In the 1970s, malabsorptive procedures such as jejunioileal procedures were used, but are uncommon today due to severe complications of the surgery. From the mid-1980s to the mid-1990s, restrictive procedures were used, such as gastric banding, vertical gastro plastic, and gastric wrapping, with mixed results. Since 2001, the mixed procedures, biliopancreatic diversion with duodenal switch (BPD/DS), and gastric bypass (Roux-en-Y Gastric Bypass) were introduced in Norway [71]. As for today, gastric bypass, sleeve gastrectomy, adjustable gastric banding, and biliopancreatic diversion with duodenal switch are the most common procedures internationally. Gastric bypass is however considered the “gold standard” of weight loss surgery, and is the most commonly performed bariatric procedure both worldwide and in Norway.

The most prevalent challenges regarding weight loss interventions are difficulties with long-term weight maintenance, where studies report that regardless of intervention, people regain weight [17-19, 72]. Much effort is put into educational programs as part of the treatment process, but low health literacy levels and difficulties in maintaining the behavior changes are recurring challenges among patients undergoing weight loss treatment [73-77]. The objective of the bariatric surgery procedure is to restrict food intake, and it contributes to reduced absorption that leads to poor digestion and reduced uptake of several nutrients. Therefore, bariatric surgery candidates need to take particular considerations in regards to dietary habits, and are required to take lifelong vitamin supplements to avoid nutritional deficiencies [78, 79]. However, non-adherence with post-surgery recommendations results in a number of the patients experiencing nutritional deficiencies and weight regain post-surgically [17, 25, 26, 72-74, 79-82]. Facilitating bariatric surgery patients post-surgically has a potential high impact because nutritional problems and weight

regain can be prevented or treated [81, 83]. The need to explore novel approaches to how patients can improve and maintain the behavior change process after treatment is required for improved health outcomes and long-term weight maintenance for this patient group.

Over the past years, obesity has increasingly been recognized as a chronic condition requiring health interventions, and in 2013, the American Medical Association recognized obesity as a disease [8]. This implies that diagnosis and treatment of obesity is a professional obligation of physicians, and requires a range of medical interventions to advance obesity treatment and prevention. The healthcare system in Norway is run as a semi-centralized National Health Service model where the responsibility for primary care and secondary care are divided between different governmental levels, the funding is raised by taxation, and the main players are public [84]. The municipalities are responsible for primary healthcare and have the responsibility for prevention and treatment of obesity. The regional health authorities are responsible for specialized healthcare where the treatment of severe obesity most commonly takes place.

### **Self-Care Management**

Greater demands on healthcare have led to the fact that people are encouraged to take increased responsibility for their own health and treatment. Self-care management is a central point in this aspect and involves interventions, training, and skills of patients in order for them to be able to take care of themselves to an increased extent. Successful outcomes and long-term weight maintenance are associated with self-management activities, e.g., monitoring weight and commitment to behavioral changes in physical activity and dietary habits [17, 18, 21-24]. However, studies report that many do not achieve successful weight outcomes [17, 20, 25, 26, 72]. Research indicates that long-term success may get easier over time, if maintained for two to five years, the chances of long-term success prominently increases [18].

Patient empowerment refers to the ability of patients to actively understand, have choices, and influence their own health, and is defined as an educational process designed to help patients develop the knowledge, skills, attitudes, and degree of self-awareness required to effectively assume responsibility for health related decisions [85, 86]. An underlying factor for patient empowerment is the patients' health literacy

that involves the ability to understand and act on health information. It is well documented that health literacy is associated with knowledge of health conditions and therapy regimens, and related to health outcomes [87-91]. Obesity in children is associated with parents' health literacy, while obesity among adolescents and adults is strongly associated with their own health literacy [87, 92, 93]. Individuals with low health literacy have lower self-management skills and higher rates of chronic illnesses, and participate less frequently in preventive care activities [94]. These factors imply that strategies to prevent and treat obesity need to address health literacy in order to improve treatment outcomes for this group of patients. Self-management education is the foundation for the empowerment approach and is essential for how patients undergoing weight reduction treatment take decisions and manage their health in their daily life environment. It is particularly relevant for bariatric surgery candidates because studies show that they have difficulties in remembering surgery related patient information [73, 74], a factor important for patients' adherence to post-surgery recommendations. As opposed to traditional patient education programs that offer information and technical skills, self-management education teaches problem solving skills [95]. A central point of self-management is self-efficacy, entailing a person's confidence to carry out a certain behavior to reach a desired goal [96]. Corbin and Strauss [97] define three sets of tasks faced by people with chronic conditions: (1) medical: medical management of the condition such as taking medication, changing diet, or self-monitoring (weight/diet, etc.), (2) social: creating and maintaining new meaningful life roles regarding work, family, and friends, and (3) emotional: coping with the psychosocial aspects of having a chronic condition, such as anger, fear, frustration, and sadness. Self-efficacy theory says that attaining the required tasks is more important than the plan itself. Bodenheimer et al. [95] define two central points in self-management education: First, that patients learn problem solving skills useful to identify problems from their own point of view, and enable action plans to find solutions. Second, that these skills are applied to the three aspects of chronic illness: medical, social, and emotional. These factors are relevant for the group in this study as they need education, strategies, and tools to manage their health and daily life: (1) they have to cope with the medical factors of their health and illness, and the intervention required and implemented, (2) the social aspects of their health, weight, and illness, and how their network and social relations influence their

behavior, and (3) the emotional aspects of how they cope with their health condition and situation. Studies in diabetes management revealed that people had difficulties accessing face-to-face self-management education because of barriers such as work, caring responsibilities, disability, costs, and lack of transportation [98]. Norway has scattered settlement patterns, where travel costs and distances are factors influencing access to healthcare services. Health promotion and healthcare delivered through digital means is a possible solution to address this challenge. eHealth solutions can be accessed at home or anywhere with an Internet connection, have the potential for wide reach for low cost, and have potential to reduce health disparities [99].

### **Patient-Provider Interaction**

Up until only a few decades ago, healthcare services were organized with the mindset that healthcare professionals were the main sources and holders of health information, and therefore they made decisions for the patient with the belief that they knew what was best [100]. In recent years, the patient role has evolved from being a passive recipient of care, to slowly becoming an important contributor to their own care and treatment [101, 102]. More recently, patients have been acknowledged as experts on their own bodies, symptoms, and situations. The Internet has been an important factor for this transition, as it has become an important healthcare medium that enables people to access information and tools to manage their own health and illness.

Emanuel and Emanuel (1992) describe four models of the patient-physician interaction [100]: *The paternalistic model (also called the parental or priestly model), the informative model (also referred to as the scientific, engineering, or consumer model), the interpretive model, and the deliberate model*. Their models (see table 3) show that patient involvement and responsibility for their own health and clinical encounters are shaped by their interaction with healthcare providers. At one end of the scale, we have the paternalistic model characterized by low value formation, low level of autonomy, and low information disclosure. On the other end, we find the deliberate model with high value formation, high level of autonomy, and high information delivery. Various factors have influenced patient-provider interaction, where societal expectations, medical and technological advancements, and increased social diversity have contributed to new and more diverse access to medical information. Some studies show that patients prefer that physicians play the primary role in decision

making, and that physician quality impacts perceived information asymmetry between patients and physicians [103, 104]. The healthcare provider-patient relationship has crucial impacts on patient health outcomes since empirical evidence demonstrates that physician communication is highly correlated with improved patient treatment adherence [105]. Utilization of behavior services and more frequent contact between patients and clinicians (requiring adherence to behavior changes) have been associated with better long-term outcomes after bariatric surgery procedures [106-109]. Despite patients' need for follow-up after treatment, studies report that bariatric surgery patients tend to drop out (60–72%) of the follow-up program for unknown reasons [106, 110]. Individuals suffering from obesity are highly stigmatized and vulnerable to multiple forms of weight bias in healthcare settings [111, 112]. Puhl et al. reviewed research documenting bias and stigma, and identified negative attitudes towards people with overweight and obesity among healthcare professionals such as physicians, nurses, medical students, mental health professionals, fitness professionals, and dietitians [111]. They contend that people who have experienced such stigma in healthcare settings may delay or forgo essential preventive care [111]. There is reason to believe that this also might influence attendance to follow-up care. With the evolving development of Internet-based solutions, the possibility to communicate and interact with patients in new ways imposes both possibilities and challenges that are important to explore. Few studies have been done in the area of bariatric surgery, but a number of studies have been done with other patient groups. In a study by Andreassen et al., they found that online communication between patients and general practitioners improved communication and strengthened the patients' partnership with their doctors [113]. Lin et al. demonstrated that patients who used an online portal to communicate with physicians in a general internal medicine practice showed increased satisfaction with communication and overall care because of the portal's convenience, reduced communication barriers, and direct physician responses [114]. Bishop et al. interviewed leaders of medical groups that used digital communication with their patients, and found that it was perceived to be a safe, effective, and efficient means of communication that improved patient satisfaction and saved patients' time [115]. However, they discovered that such online communication tools increased the physicians' workload and therefore reduced providers' use [115]. Regardless of the potential advantages of eHealth solutions,

barriers to adoption have been identified, such as workload and workflow demands, technology literacy, concerns about expenditures, liability issues, confidentiality, and privacy risks [41, 116, 117]. These factors have resulted in low expansion and adoption of eHealth solutions [4, 41, 42, 115]. There is limited knowledge about patient-provider online communication in weight loss treatment. Considering the impacts providers' communication have on patients' adherence to behavior recommendations, and thus on patients' health outcomes, exploring potential benefits and challenges of using such solutions in weight loss treatment is important to gain extended knowledge in this area.

**Table 3: Emanuel and Emanuel's four models of patient-physician interaction**

Model	Physician Role and Patient Role	Conception of Patient Autonomy
<b>The paternalistic model</b>	Physician acts as patient's guardian, articulating and implementing what is best for the patient by using his own skills to determine the patient's medical condition, disease, tests, and treatments to restore the patient's health.	Patient assent. Limited patient participation.
<b>The informative model</b>	Physician provides the patient with all relevant information and facts without professional values. Patient's values are defined and known. Patient selects what s/he wants, and physician executes the selected intervention.	Patient control over medical decision-making.
<b>The interpretive model</b>	Physician acts as counselor or advisor, helping to elucidate patient's values, and suggesting what medical interventions to realize these values.	Patient moral self-understanding.
<b>The deliberate model</b>	Physician acts as teacher or friend, engaging the empowered patient in dialogue to help determine and choose the best health related values and course of actions realized in the clinical situation.	Patient self-development.

### **Social Support**

There is an extensive body of knowledge about the role of social support and its impact on health outcomes. Social support consists of structural characteristics of social networks and the functional support they provide, including the components of emotional (expression of empathy, trust, care), informational (advice, suggestions, information), appraisal (information useful for self-evaluation), and instrumental support (tangible aid and services) [118, 119]. Empirical evidence suggests that people who maintain strong social relationships are healthier and live longer [118]. Various aspects of social support can influence health outcomes in regards to self-

esteem, coping abilities, improving knowledge, health literacy, and healthy behaviors. Studies show that social support by friends and family, better coping strategies, and the ability to handle life stress are beneficial in weight loss and maintenance [22, 120]. A systematic review identified a positive association between attendance in social support groups after bariatric surgery and greater post-operative weight loss [121], and research implies that social support may encourage adherence with post-surgery recommendations [120-122]. However, not everyone has friends or family from whom they may receive social support, and both healthcare services and non-profit organizations have organized real life support groups for people who suffer from obesity. Increasing social support through both traditional means, but also online, may be an effective way to facilitate people in achieving and maintaining weight loss. Studies have evaluated the way people use social media such as Twitter, Facebook, blogs, forums, and YouTube to provide and achieve social support [122-125]. Engagement in online social networks can benefit patients in providing each other informational social support through status updates, and indirectly may assist with weight loss as part of a behavior change program [123]. Studies have been done with other patient groups and show that online social support may result in improved health literacy, quality of life, and patient empowerment [37-40], while few studies have been done with bariatric surgery patients. Although research suggests several benefits of using social media to give and/or achieve social support, a number of limitations of using it have also been identified. These are primarily related to quality concerns and lack of reliability, confidentiality, and privacy [125]. Most online social networks are dominated by peer-to-peer communication, without professional supervision or involvement [126], and the quality and credibility of the health information in such arenas have therefore raised concerns about their impact and value [127]. Research indicates that the information exchange needs to be monitored for quality and reliability, and that the users' confidentiality and privacy need to be better maintained [125]. Some studies imply that patients want professionals to take a more active role in such online communities [128], while others suggest that facilitated or moderated communities are more beneficial in terms of supporting compliance in maintaining healthy behaviors, reducing healthcare visits [129], preventing communication from disruptive individuals [130], and promoting participation [131].



## **eHealth**

The term eHealth is a broad term, covering a range of technical solutions, e.g., from health information websites and simple mobile health applications, to more complex and advanced systems, such as interactive electronic health records, clinical decision support systems, healthcare information systems, online communication portals, tailored health education programs, and telehealth/telemonitoring applications with sensors. eHealth was barely used before 1999, but has later been used to characterize and describe almost anything concerning Internet and medicine. A review (from 2005) of published definitions of the term identified 51 unique definitions of eHealth, where health and technology were the two universal themes [132]. One of the most used definitions is the one of Eysenbach who defined eHealth as *“health services and information delivered or enhanced through the Internet or related technologies,”* and who suggest not limiting the term to a technical development because it entails a whole mind-set [2]:

*“a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.”*

Consumer Health Informatics (CHI) is one form of eHealth and refers to patients (or healthy individuals) as primary users of digital health information related to healthcare. In the early 2000s, it was expected that eHealth solutions would influence greater patient empowerment, as to the patient being informed, having choices, and being involved in the decision making process [133, 134]. Recent studies provide some indications in those aspects where eHealth solutions are implied to influence improved patient empowerment, and consequently to improve their health status and quality of life [135, 136]. Over the past decade, a number of Consumer Health Informatics applications and systems have evolved, from smoking cessation programs, to dietary and lifestyle behavior recommendations, and medication adherence, but many of these do not have healthcare professionals or providers in active roles or responsibilities. More recently, eHealth solutions have been introduced for specific patient groups (e.g., COPD, asthma, diabetes, cancer) in healthcare contexts [137-142]. A newly published systematic review about the use of eHealth portals in the management of chronic disease showed significant improvements in patient self-management of their disease and improved quality of care given by the

providers [5]. Potential benefits of using eHealth portals in healthcare contexts are improved responsiveness to patients' needs, more effective care, decreased utilization of health services, administrative efficiencies, and cost savings [41]. Even though a number of studies have been done on investigating eHealth interventions in prevention and treatment of overweight and obesity [34], there is still a lack of evidence about the optimal use of eHealth technologies in weight loss interventions [35]. Few studies have explored using such technologies for patients in bariatric surgery programs. eHealth resources are particularly relevant for patients who may encounter barriers to obtaining information on self-management and coping strategies [126, 129], and to those who reject participation in traditional follow-up care. Considering the severe impacts bariatric surgery has on the patients' lifestyle and health, eHealth solutions hold potential as a means to promote self-care management, social support, and patient-physician communication that can facilitate the patients in their daily life.

### **Human-centered Design**

When designing and introducing technology in the healthcare domain, there are two main approaches to how this can be done. Enrico Coiera [143] distinguishes between technology driven approaches, concerning which problems will be solved with certain technology; and problem driven approaches, entailing how to solve particular problems. These two distinctions are underpinning for the approach one chooses to take.

Human-Centered Design (HCD) is a problem driven approach and a methodological process that identifies solutions by placing the end users at the center of each phase of the design process. The users are involved in the design process in order to express their own needs, requirements, constraints, opportunities, dreams, and desires. These insights are used in an iterative process to identify and produce design solutions. In the design of innovative solutions for healthcare, the concept of service design is important to consider. Service design addresses the functionality and form of the services from the user's perspective in order to ensure that the service interfaces are useful, usable, and desirable, as well as effective, efficient, and distinctive from the service provider's point of view [144]. Human-centered design is in ISO 9241-210 (2008) [145] presented as follows:

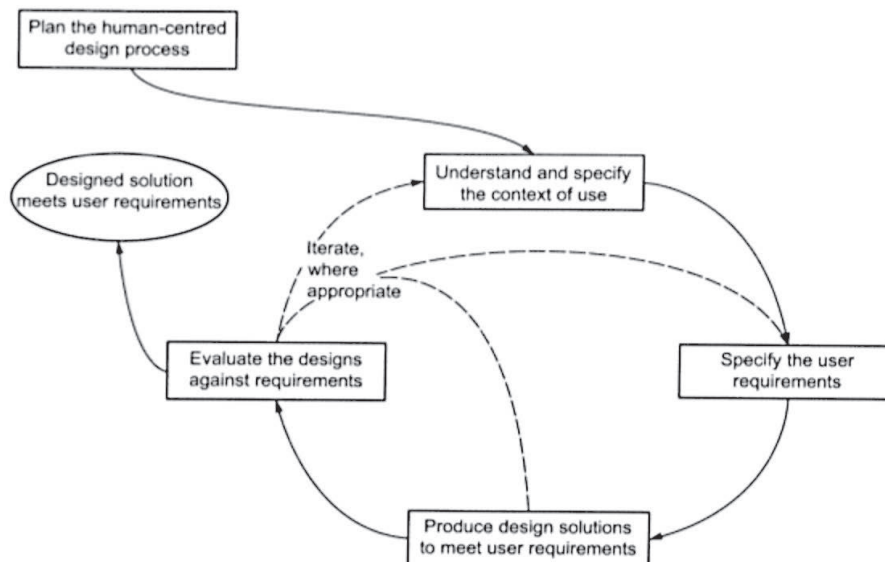
*“An approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques.”*

The standard specifies that the design process is iterative, but can bypass some phases when appropriate (Fig. 1). The five main phases are defined as:

- I. Plan the human-centered design process
- II. Understand and specify the context of use
- III. Specify the user requirements
- IV. Produce design solutions to meet user requirements
- V. Evaluate the designs against requirements

The design firm IDEO has simplified the HCD process to entail three main phases [146]: 1) inspiration, 2) ideation, and 3) implementation. The first phase involves user involvement: understanding and learning from the targeted population you are designing for. The next phase involves enabling the knowledge gained in the first phase: identifying design solutions and creating prototypes. The last phase involves bringing the solutions to life, and finally, to the market.

**Figure 1: Human-centered Design for Interactive Systems ISO 9241-210: 2010 [145]**



## User-centered Design and Participatory Design

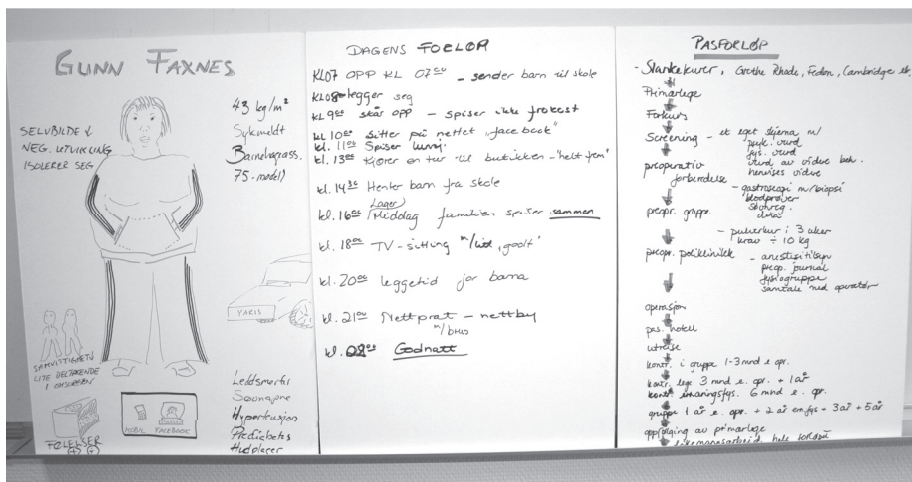
The central point of the HCD processes is to involve users in all phases of the design development process of a solution. Within the field of HCD, there are various approaches to how the design process can be undertaken, from user-centered to participatory approaches. The objective of User-centered Design (UCD) is to ensure that the product (or service, interface, etc.) meets the needs of the user. The users are involved, although not necessarily as active collaborators but have the role of informants or testers in the process, and are spoken for by the designer or researcher [147]. Participatory Design (PD) refers to a set of theories, practices, and studies on how to include end users as active design partners in the design process [148, 149].

End users can have different roles in the design process, from more passive informants to active collaborative partners, depending on how one chooses to involve them. Based on experience from design projects with children, Druin (2002) makes a distinction and discusses four different roles of end users in the design process: *user*, *tester*, *informant*, and *design partner* [150]. As a *user*, the participant's role involves contributing to the research and development process by using technology, while the researcher may observe, videotape, or test for skills. This is done to understand the technologies' impact on the user with the aim that future technologies can be changed or future environments enhanced. In the role of *tester*, end users test prototypes and are observed with the technology to capture their experiences, where the results work as input for the development process. The role of *informant* means that end users have an important part in the various stages of the design process, based on when the researchers believe that the participants can inform the process. This role varies from observation of participants using existing technologies, to the participants providing input on design sketches or low-tech prototypes. In the role of *design partner*, end users are considered to be equal stakeholders in the design of new technologies throughout the whole process [150].

Participatory Design (also referred to as cooperative design) originated in Scandinavia in the 1970s and 1980s, motivated to democratically empower workers and foster democracy in the workplace [151-153]. This emerged as a reaction to how computer-based systems were first introduced to the workplace, and to the deleterious effects these systems had on the workers [154, 155]. The objective of PD is to actively

involve people who are intended to use the system during the design process in cooperation between users and designers, to ensure that the final product is usable and meets the users' needs [149, 156]. PD includes a variety of methods such as ethnographical approaches, workshops, stories and storytelling activities, personas, games, and constructions [148, 155, 157]. Co-creation involves any act of collective creativity, i.e., creativity that is shared by two or more people, and is a broad term ranging from physical to metaphysical, and from the material to the spiritual [158]. Traditionally, the co-design activities are led by design professionals and are used in development processes of products, services, or organizations [158-160]. Sanders (2002) distinguish between three approaches to interacting with users in the design process: what people do, say, and make [147]. Marketing research has focused on what people say (focus groups, interviews, questionnaires), applied anthropology has focused on observational research in what people do, and PD has focused on what people make [161]. The make tools (what people create) are focused on what people produce from the toolkits designers provide them with, in order to facilitate them in expressing their thoughts, feelings, dreams, tacit knowledge, and desires. As part of the activities, the participants present and explain their artifacts and creations to reveal their insights, anecdotes, and stories related to the topic. The results are then used iteratively to inform the design process.

**Figure 2: Artifacts from a PD-session. A patient persona (to the left), description of an average day of the persona (in the middle), and the patient trajectory/customer journey (to the right)**



In general, it is important to acquire user information such as basic demographic information, knowledge, skills, experiences, training, physical attributes, habits, preferences, and capabilities [145]. However, design processes with patients involve specific considerations that extend beyond what the current HCD processes describe. The patient population differs from the average healthy technology users as they might be temporarily impaired (cognitive, physical, emotional) because of their illness, medication use, or health condition. They might have specific informational or educational needs due to their condition, and they must be treated with particular considerations because of ethical and privacy issues. A recent study that used PD-techniques together with patients with COPD revealed that factors such as age and level of creativity influenced their level of involvement and engagement in such activities [162]. Another study with cancer patients showed that illness severity and/or medication use significantly influenced patients' capability to enable eHealth technology [163]. The study implied that designers need to take particular consideration to these factors in the design processes and to the unique challenges of being a patient [163]. Other factors are that the circumstances of being ill are that patients might be restrained or unable to take part in HCD processes because of illness severity, and therefore are disqualified from such activities. According to Keates (2006), potential users are excluded from using technology for unnecessary reasons, often caused by a mismatch between designers' perceptions of the wants and needs of the end users and their actual requirements [164]. The complex use contexts in the healthcare domain are not to be underestimated. Offering new technologies that healthcare providers are to facilitate necessitates design thinking that embraces more than the specific technology, and that includes the service design concept about how the new technology and service will be undertaken, adapted, and used in the domain. It is crucial to involve all the stakeholders in order to design and develop solutions that will meet the users' requirements and needs, and that further on will be adapted and used.

### **Research Methods in HCD**

Even though knowledge about human-centered design has existed for decades, the principles and practices have not been enabled to a great extent, particularly not within healthcare. According to Sanders and Stappers [158], some of the reasons for the slow uptake of PD-approaches are the requirement of perceiving that all people

are creative (a not very common belief), and that co-design threatens the existing power structures by giving the end users the possibility to influence the design while challenging those who have been successful being in control. Even though a number of researchers have claimed positive impacts of user involvement, others have also mentioned challenges with conducting such activities. Already in the early 1980s, Hirschheim implied that PD was praised by the participants, but that PD-processes involved a number of difficulties including the complexity of the phenomenon, lack of formal evaluation, and that the techniques rarely were used a second time in the organization [165]. Later, Damoravan concluded that there were complex demands associated with effective user involvement because the outcomes of the PD-activities were uncertain, while the costs and managing of the processes were resource demanding [166]. Others have pointed to several shortcomings to enabling human-centered approaches. Kujala reviewed the benefits and challenges of user involvement practices, and found that such approaches in general have positive effects on user satisfaction and in identifying user requirements, but were challenging as to the cost-efficiency [167]. Winschiers explored cultural margins of designing information technology, and referred to projects in developing countries that had enabled PD techniques, but which subsequently failed. She contended that design methods, techniques, and tools needed to be evaluated in the local context (of use), in the same way that products are evaluated, because crossing cultural or disciplinary boundaries implied taking considerations to established assumptions, concepts, and habits [168]. These factors are also relevant when enabling, developing, and evaluating human-centered methods in the healthcare domain because of the particularities that characterize this specific area (people are ill, people are temporally disabled, privacy issues, ethical considerations, unforeseen incidents, etc.). Few studies report on applying human-centered design methods with stakeholders in weight reduction programs. Although studies have been done with other user groups in healthcare [162, 169-171], the specific characteristics of patients undergoing weight reduction treatment, their barriers, needs, and requirements are important to explore and consider, in order to develop eHealth solutions that will be enabled and adopted by both patients and professionals in this specific domain.

## **Materials and Methods**

This section presents the materials and methods of this thesis where I successively describe the overall research design and process. Thereafter, I present the various activities, materials, and methods in this research.

### **The Overall Research Design**

This research entails a mixed-methods approach of an explorative case study involving both qualitative and quantitative methods. Qualitative research is primarily exploratory research, where one seeks to understand concepts, reasons, motivations, attitudes, etc. Data are collected unstructured or semi-structured, typically through interviews or observations, and the sample is often limited. It is sometimes used to develop ideas and questions (hypothesis) for further quantitative research. Quantitative research entails quantifying a problem where numerical data or data can be used in statistical measures. The data collection is most commonly structured in the form of questionnaires and surveys, although these can be collected in various ways such as through online surveys, paper based surveys, street based surveys, etc. The sample in quantitative data is often large, where one can generalize the results.

The first phase of the project (Study I) involved mainly qualitative approaches, using both participatory and user-centered methods. The starting point of this research involved not knowing what technology or service that later was to be developed. This part of the project concerned the design and development of an eHealth solution, where the second article provides a detailed description of the methodological approach. The second part of the project (Study II) involved implementing and evaluating the results (product and service) from Study I, implementing the eHealth service and appurtenant service, and evaluating the impact of such a solution. The two last articles describe the qualitative and user-centered approaches that were undertaken as part of Study II. As part of this research project, some quantitative data have been collected through questionnaires.



## Research Process

The project followed an iterative design process with various activities from start to end (see table 4-5).

## Field Study

All design processes (independent of what you are designing) requires insights to the targeted user group(s), use context(s), and domain under study. In order to gain understandings and insights, I conducted a field study at the hospital. A field study is a general method for collecting data about users, products, surroundings, workflows, etc. in their natural settings and involves observations and interviews. The field study lasted over a time period of a month, and involved direct observations of patient consultations, a pre-treatment program, and pre- and post-surgery group meetings. In total, 10 settings were observed, effective observation time was 36 hours, while the actual time spent during the field study was significantly more due to waiting time, breaks, cancellation of appointments, etc. Also, informal semi-structured interviews were carried out as part of the field study.

Table 4: General overview of methods in Study I and Study II

Methods	Study I	Study II	Qualitative Data	Quantitative Data
User-centered methods	•	•	•	•
Participatory design methods	•		•	
Field study observations	•	•	•	
Participant observations (online)		•	•	
Informal interviews	•	•	•	
Group interviews	•		•	
Individual in-depth interviews		•	•	
Contextual interviews		•	•	
Questionnaires	•	•		•
System log data		•		•

When patients were referred from primary care for treatment in specialist healthcare, the patients had to undergo a process to obtain knowledge about what treatment would be the most appropriate and beneficial for the individual (bariatric gastric surgery or lifestyle intervention). This process involved a fairly comprehensive investigation involving attendance in a compulsory pre-treatment program and a

screening process, and where the further process depended on the treatment chosen (decided in collaboration between the patient and healthcare professionals).

#### **Observation of Pre-Treatment Program**

The first step involved the patients who were required to attend a compulsory pre-treatment program at the hospital that lasted for two days, six hours each day (except for a lunch break). One hundred patients attended this program during the field study. The program consisted of a series of lectures by various healthcare professionals (physiotherapists, physicians, psychologists, dieticians, nurses) who talked about aspects of the two weight reduction interventions (bariatric gastric surgery and lifestyle therapy). In addition, laypersons that had undergone the two interventions presented their experiences and perspectives. During these two days, the participants had the opportunity to ask questions and discuss various themes in plenary. The objectives of the observation study were to gather information about the medical aspects and treatment process, the patients' attitudes, interactions, and questions (themes of interest), etc. The participants were informed about my attendance and objectives of attending the pre-treatment program. During this field study, my role was a passive observer where I took notes. As part of this field study, we conducted a baseline survey to assess the patients' access and use of technology. This was a self-reported questionnaire that we developed for this study and covered questions about the patients' access and use of the Internet, mobile telephones, and frequency of use of online activities such as reading newspapers, using online banking, booking tickets, social media, etc. The response rate was 98%. The collected data were merely used to identify the users' technology competence, and have not been used for other purposes.

#### **Observation of Patient Consultations**

After the patients had attended the pre-treatment program, they had to undergo a "screening-process" which involved consultations with various healthcare professionals such as nurses, dieticians, endocrinologists, psychologists, and eventually surgeons (if qualified for surgery). During the field study, I observed in total six patient consultations: three patient consultations with nurses, and three patient consultations with dieticians. The consultations had a duration of approximately one hour each. Initially I had planned to observe a higher number of consultations, but because a number of patients did not attend the scheduled

consultations, I ended up observing six consultations. The objectives of the observations were to get insights into the patient experiences and stories, the medical procedures, the interaction and communication practices between the patient and the professional that unfolded in these consultations, and to gather domain knowledge. During the consultations, I took field notes, and semi-structured interviews were carried out with the professionals to clarify the observations and get insights to the process and patient trajectory.

### **Observation of Pre- and Post-surgery Group Meetings**

At the clinic where this research was undertaken, an average of 70 patients have undergone bariatric surgery each year since 2007. After completing the first screening process, those who qualified for surgery and who were motivated for such treatment, were required to attend a one-day pre-surgery program before operation. These meetings were arranged as group-based meetings with several patients. The patients were allowed to bring along their partner or next of kin. A nurse facilitated the group meetings, which consisted of a combination of a series of lectures by some of the speakers from the pre-treatment program (e.g., surgeon, endocrinologist, physiotherapist, dietician, lay persons) and group discussions. After surgery (about three months after), the patients were invited to participate in a group-based post-surgery program, lasting for a day, and which had the same structure as the pre-surgery program. According to information from the clinic, approximately 70–80% of those undergoing surgery attend the post-surgery program.

As part of the field study, I observed in total three group based meetings (one pre-surgery and two post-surgery). Each meeting lasted six hours excluding lunch break. In each of the group-based meetings, about 20–30 patients took part; in addition, some partners/next of kin were present. All participants were informed about my attendance and objectives, and my role was mostly a passive observer. The objectives were to get insights into the topics, themes, and discussions that took place in order to gain more information about the patients' experiences, challenges, attitudes, positive experiences, and so on. During the breaks, I conducted unstructured interviews with the participants (patients and healthcare professionals) in order to gain information about the patient group and about their experiences and perspectives.

**Table 5: General overview of activities**

What? Activity	How many? Number	Where? Context	How long? Duration	Who? Participants (n)
<b>Field study</b>	10	Hospital	36 h	Healthcare profs. Patients
In total:	<b>10 observed settings</b>		<b>36 hours</b>	<b>200 participants</b>
<b>Workshop 1</b>	1	Usability laboratory	3 h each	Healthcare professionals (n=8)
<b>Workshop 2</b>	1	Usability laboratory	3 h each	Patients, lifestyle therapy (n=6)
<b>Workshop 3</b>	1	Usability laboratory	3 h each	Patients, bariatric surgery (n=6)
<b>Workshop 4</b>	1	Usability laboratory	3 h each	Participants, ws 1-3: (n= 5 pat. & 5 prof.)
In total:	<b>4 workshops</b>		<b>12 hours</b>	<b>20 participants</b>
<b>Usability evaluations</b>	8	Usability laboratory	45-60 min each	Healthy Participants (n=8)
<b>Usability evaluations</b>	6	Usability laboratory	45-60 min each	Patients (n=6)
<b>Usability evaluations</b>	6	Usability laboratory	45-60 min each	Healthcare professionals (n=6)
In total:	<b>20 usability evaluations</b>		<b>20 hours</b>	<b>20 participants</b>
<b>Observation of online setting (eHealth portal)</b>	Several times daily during trial period	Online	Unknown	Healthc. prof. (n=5) Patients (n=60)
<b>Contextual interviews</b>	Average: once a week during trial period	Bariatric surgery clinic	20-60 min each	Healthc. prof. (n=5) Patients (random)
In total:	<b>6-7 month period</b>		<b>Not defined</b>	<b>65 participants</b>
<b>Individual interviews</b>	7	Work office	1 h each	Patients (n=7)
<b>Individual interviews</b>	3	Hospital clinic	1 h each	Healthcare prof. (n=3)
In total:	<b>10 individual interviews</b>		<b>10 hours</b>	<b>10 participants</b>

## Workshops

The second phase of the design process involved a series of participatory design workshops. Such workshops are characterized by collaborative design activities (co-creation) between the participants and the designers. Central for the activities are that the participants are given tools and techniques in order to contribute actively in the design process. The activities may also work as an approach to gain insight into the

tacit knowledge of the users. In total, four workshops were conducted (table 5) with: healthcare professionals, patients in the lifestyle therapy program, patients in the bariatric surgery program, and participants from the three initial workshops.

The objectives of the PD-workshops were to let the various stakeholder groups have the roles as collaborative partners in the design process of the future eHealth solution. The initial field study provided insight to the domain and knowledge about the patient group that was relevant for planning the procedures and activities for each workshop. We also identified which stakeholders were central in the treatment program, and thus relevant to be involved in the design process. Traditionally, PD-workshops are conducted with various stakeholders together in the same workshop, in order to communicate and commit shared goals, strategies, and outcomes [148]. Intentionally, we planned and conducted the three first workshops with separate stakeholder groups (patients/professionals) in each workshop, due to the power balance between patients and professionals observed in the field study. The workshops were structured as future workshops with three stages that allow the participants to develop new concepts and initiatives for potential solutions: (1) critiquing the present, (2) envisioning the future, and (3) implementing—moving from the present to the future [148, 172, 173]. As we worked exploratory, we set no limitations about what services or technology were to be created. The fourth and last workshop had a slightly different procedure, and we involved the various stakeholders together, in order to achieve mutual understandings and goals for the future solution. The aim was to evaluate the developed technology and get input about the future service model that would include the eHealth technology.

**Figure 3: Illustration of participatory design workshop**



The workshops took place at the university area located close to the hospital. We had equipped the rooms where we carried out the workshops with video and sound recording to capture the interactions that took place. Each workshop lasted approximately three hours (including a break), and we were two researchers that facilitated the workshops. In some of the workshops, other project workers participated, e.g., in the last workshop the students responsible for developing the prototype technology presented the eHealth portal. During the workshops, we carried out PD-activities such as individual and collaborative brainstorming sessions, semi-structured group interviews, storytelling activities (scenarios), creating personas and constructions, group based presentations, card-sorting sessions, and plenary discussions. Details about the participants and procedures of each workshop are described in article 2 [174].

**Figure 4: Illustration of participant in PD-workshop**



### **Usability Evaluations**

As part of the development process, we conducted a number of usability evaluations (also referred to as usability tests) to evaluate the various versions of the eHealth portal. Usability is the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in specified use contexts (ISO 9241-11) [175].

### **The Usability Laboratory**

The evaluations took place in a usability laboratory that consisted of several rooms (a control room and various rooms used for testing), where we created a working space for the participants consisting of a table, chair, and a personal computer (with Tobii eye-tracking software). The laboratory was equipped with two pan-tilt-cameras fixed to the ceiling. One camera recorded the participants from the front, recording facial

expressions, and the other camera recorded a broad view of the participants to capture body language. To capture user verbalizations, we recorded with wireless microphones that went through a sound mixer into the soundcard of the computer in the control room. With Tobii software, we captured the users' display, with accompanying data about the participants' user patterns and eye tracking. Tobii eye tracking is sensor technology that enables a device to know exactly where the users' eyes are focused, and was used to get insights to gauge how the users read, searched and navigated through the eHealth portal, how much time they spent looking at certain places on the screen, etc. We could thereby identify, for example, which objects captured their attention and which features needed design improvements.

**Figure 5: Illustration of patient during usability test**



#### **Procedure Usability Evaluations**

As part of the study, we conducted three phases of usability evaluations with three user groups (see table 5):

- Healthy users
- Patients that had undergone weight loss treatment at the clinic
- Healthcare professionals from the clinic

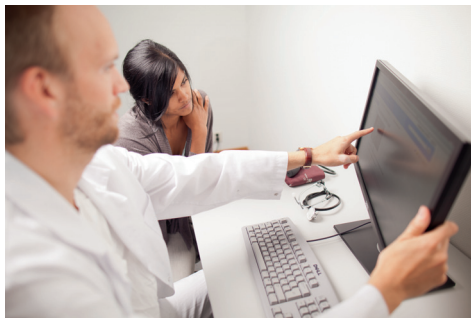
Each usability evaluation lasted approximately 45-60 minutes, and a facilitator was present together with the participant in order to give each task to the participant and to observe the tests. The test planning was guided by the requirements of the ISO/Common Industry Format [145] standard for reporting on usability tests, while the procedure followed the steps outlined by Tognazzini [156]. The usability tests involved the participants performing typical tasks and interacting with the eHealth portal. Tasks included log on to the portal, sending and attaining personal messages, information search and retrieval, writing and posting to the discussion forum, creating

events in their personal calendar, and appointment reminders to be sent to their own mobile telephone.

The overall procedure of the usability evaluations were as follows:

- 1) Introduction about the usability test, aims, and procedure.
- 2) Completing of questionnaires (demographic data and computer literacy).
- 3) The usability test. Calibration of Tobii software (to the users' eyes). The participants were instructed to think aloud (think-aloud protocol) during the session, a technique in which they were required to say (report loud) everything they thought and tried to do, in order for their thought processes to be externalized. The thinking aloud technique was developed by Erikson and Simon in order to examine peoples' problem solving strategies [156]. The users were given one task at a time, which was read out loud by the facilitator who thereafter provided the task in written form.
- 4) Completing of a questionnaire, System Usability Scale (SUS), a 10-item scale giving a global view of subjective assessments of usability. The SUS is a 5-point Likert scale in which a statement is made, and the respondents indicate their level of agreement or disagreement (1 strongly disagree to 5 strongly agree). The SUS produces a single number representing a composite measurement of the overall usability of the system being studied [176].
- 5) Finally, a post-test semi-structured interview was conducted so the participants could elaborate on their experiences, opinions, improvement, suggestions, etc. about the tested system.

**Figure 6: Illustration of post-test interview that was conducted as part of the usability evaluation**





### **Observation of Online Setting**

The eHealth portal was implemented at a bariatric surgery clinic and offered to their patients. The patients were in different stages of the treatment process, where some were waiting for surgery, most had recently undergone bariatric surgery (a few days/weeks ago), and a few had undergone surgery a while ago (one to two years ago). The inclusion period lasted from mid May to mid June 2011, and participants had access until Christmas 2011. The patients had access to the eHealth portal for a time period of approximately six months (some a bit longer due to the inclusion period). In total, 60 bariatric surgery patients (75% women and 25% men) got access, where 80% of them logged on to the system one time or more. At the clinic, five healthcare professionals got access in order to facilitate and communicate with the patients through the portal. In addition, I had the role of moderator and facilitator of the eHealth portal, and two technicians had the responsibility to operate the portal.

During the study period, online participant observation was conducted. Participant observation is a qualitative method of data collection to get first-hand knowledge about a certain group, where the researcher is acknowledged as part of the social setting [177], in this case the online setting. At the end of the study, we retrieved all postings to the online forum and analyzed the posts inductively using qualitative content analysis [178]. The analysis was performed in a stepwise process where two researchers (I and one of my co-authors) reviewed and coded the transcripts individually before the findings were compared and refined in a consensus decision-making process. English terms and concepts were used, and HyperRESEARCH software was enabled to facilitate the analysis. Findings are reported in article 3 [179].

### **Interviews**

A field study at the clinic was conducted consisting of contextual interviews with professionals during the six-month study period when the eHealth portal was tried out. Such interviews involved observing the people in their actual work environment, and speaking with them about their work and actions [180]. The contextual interviews typically lasted 20–60 minutes, were informal, and notes were taken. Also, a series of 10 individual in-depth interviews [181] were conducted with patients (n=7) and healthcare professionals (n=3). The interviews had a semi-structured form, and were carried out at the clinic or at the university (medical faculty). The interviews were

conducted in Norwegian, lasted one hour each, were sound-recorded, and transcribed verbatim before analysis. The qualitative material was analyzed inductively using thematic analysis, and English terms and concepts were used. HyperRESEARCH software was used to facilitate the process, involving a stepwise procedure in which two researchers (I and one of my co-authors) reviewed the material and created codes individually. Next, the codes were collated and concepts were generated in a mutual process. These were compared, contrasted, and discussed in light of relevant literature and theory, and the final themes were achieved via consensus. Findings are reported in article 3 [179] and article 4 [182].

### **Questionnaires**

As part of this research, various questionnaires were been used to collect quantitative data. Some of the questionnaires were developed for this study, such as questionnaires for demographics and evaluation of the eHealth portal. Among other questionnaires, the System Usability Scale (previously described) and the validated questionnaire Patient Activation Measure (Norwegian version PAM13) were used. The results from SUS were used for evaluating usability of the different versions of the eHealth portal. We have not reported data concerning PAM13 or the questionnaire for evaluating the eHealth portal and service. All questionnaires were analyzed using SPSS statistics software packages used for statistical analysis. Descriptive data, frequencies, and correlation analysis were produced.

### **The eHealth Portal**

As we had an explorative approach, we were not predetermined about what technology for which user group we would develop. We identified that people undergoing lifestyle therapy and bariatric surgery candidates had different requirements in regards to patient information and follow-up. Having one eHealth portal could potentially induce complications because of the particular informational and educational differences the two weight loss interventions required. The fact that bariatric surgery is the one treatment that is acknowledged for this patient population made it prevalent to create a solution for this patient group, and was emphasized to prioritize by the clinic. Designing a tailor made solution for the bariatric surgery population therefore became underpinning for the further process, and resulted in an online eHealth portal for this specific patient group.

**Table 6: General overview of the design development process**

	Activity	Methods	Design Development Process	
Study I	Field study	User-centered design	Gather domain knowledge Identification of stakeholders	
		Observations	Patient trajectory	
		Contextual interviews	Organizational workflow Design of PD-workshops	
		Workshop 1	Participatory design	User needs and requirements towards service and technology
		Workshop 2	Participatory design	User needs and requirements towards service and technology
	Workshop 3	Participatory design	User needs and requirements towards service and technology	
	Identification of technology available in market	Online search	Election of technology. Modification of available tech.	
	Workshop 4	Participatory design	System and service evaluation Input for redesign	
	Technical development	Systems design	New technical platform Prototype development	
	Usability evaluations	User-centered design	System evaluation	
	Technical development	Systems design	Prototype redesign & bug fix	
	Usability evaluations	User-centered design	System evaluation	
	Usability evaluations	User-centered design	System evaluation	
	Technical development	Systems design	Prototype redesign & bug fix Final version	
Design of service model	Service design	Service model		
Study II	Implementation in clinical practice	Service design	Service implementation	
	Observation of online setting (eHealth portal)	Qualitative obs. System logs.	Evaluation	
	Contextual interviews	User-centered design	Evaluation	
	Individual interviews	In-depth interviews	Evaluation	
	Questionnaires	Survey	Service Evaluation System Evaluation	

### **Technical Development Process and Portal Features**

The design process of the eHealth solution involved several iterations before it was considered ready for implementation in the clinic. Based on the requirements identified in workshops 1-3, a requirements specification was created. This became the working document for the technicians and the development process. In order to get a quick start for the development process, we searched the market for possible available platforms that we could use in this project. Cooperation was initiated with a local firm (Visma AS), and we customized their platform to match some of the identified requirements. Not all the requirements could be implemented in this platform, due to customization limitations of the product.

This first version of the eHealth solution was presented in the last workshop where the participants evaluated the product. In this workshop, we conducted card-sorting sessions about prioritizations of suggested features, and what impact various features would have for the individual patient, the healthcare professionals, and the service as a whole. A major challenge we identified was that this platform did not fulfill the users' requirements. The fixed structure of the eHealth platform posed difficulties in translating central aspects of the participants' requirements into the technical solution. As a consequence, we had to start a new development process. The platform was discarded, and we started a process of developing an eHealth portal based on combining and tailoring a set of open-source web components.

#### **The features of the first version of the eHealth portal included:**

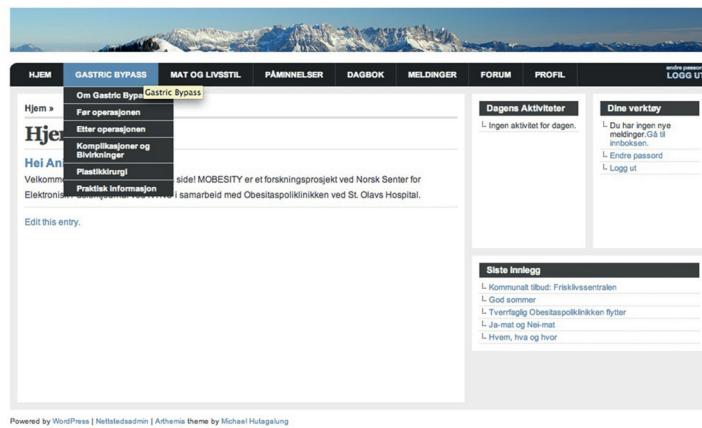
- An information module
- A personal (private) communication module (between patients and healthcare professionals)
- A personal self-management tool that included a calendar that could send sms-reminders to the users' mobile phone
- Discussion forum (with moderating features for professionals)

#### **Required features that could not be implemented in the first version of the portal:**

- Features for a personal diary for self-monitoring
- Patient-to-patient private messaging
- Patient control of calendar self-management tool

The final eHealth portal included the features that were identified as central and important in the PD-workshops. When these features were implemented, the redesign concerned adjustments of the graphical user interface (GUI) to achieve a satisfying level of usability and aesthetics, where the usability tests provided crucial input for this process.

**Figure 7: The graphical user interface of the final version of the eHealth portal**



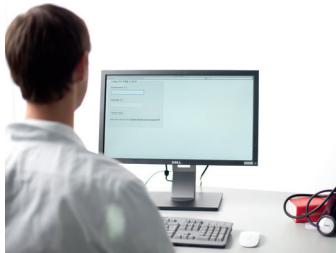
**The features of the final eHealth portal included:**

- Patient information module. Including information about:
  - Bariatric surgery
  - Pre- and post-surgical recommendations
  - Food, diet, nutritional facts
  - Lifestyle recommendations
  - Physical activity
  - Contact information and updates from the clinic
- Self-management tools:
  - Personal diary
  - Personal calendar
  - Personal reminders sent to users' mobile telephone (as sms)
- Communication module (informational and social support features):
  - Online discussion forum
    - All users who had access to eHealth portal could read and post

- Personal messaging (two-way online communication)
  - Patient-to-patient
  - Healthcare professional-patient

The final eHealth portal, MOBESITY (mobile + obesity) was launched with certain content but where the content in the patient informational module would change according to the patient's needs and requests, and due to updates from the clinic. Also, in the online forum, a weekly topic would be posted online. Thus, the eHealth portal would not be a static solution. All the information in the portal was provided and validated by the clinic. The additional medical information material (that was requested by the patients) were provided in close collaboration between the clinic and the research team, verifying that the medical information was according to the medical recommendations and in line with the current treatment program at the bariatric surgery clinic.

**Figure 8: Stepwise log on process to the eHealth portal**



(1) User enters username and password



(2) User receives one-time pin-code on sms



(3) User enters one-time pin-code on website



(4) User has access to all features in portal

### **Security and Privacy**

The eHealth portal was developed according to the security and privacy concerns that are required for such solutions in Norway. Access to the portal required log on procedures at the highest level of security (level 4) that involved a two-factor

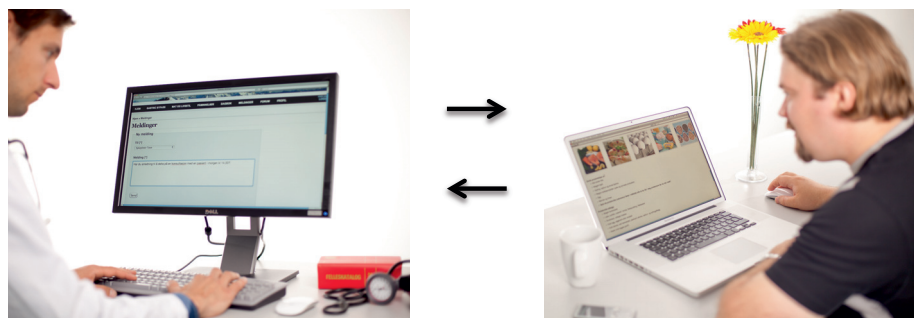
solution. Entry to the portal required log on procedures with username, password, and entering of a one-time pin-code sent to the user's mobile phone (stepwise process, figure 8). At the time of the study, eHealth portals provided by the healthcare services were uncommon, and few (if any) had experience providing such from specialist healthcare. Thus, we had a series of meetings with various people concerning security and privacy issues (e.g., head of security of the Electronic Patient Records at the hospital, head of security at Lånekassen) to learn about such aspects regarding online eHealth solutions for patients in specialist healthcare.

### **Service Model and Implementation in Clinic**

As part of the usability evaluation of the eHealth portal, we included a task where the users were involved in designing the service model. The patients were asked at what point in the patient trajectory they would like to get access to the eHealth portal and thereby the new health service, and whom of the professionals they would like to communicate with online. The healthcare professionals were asked the same questions and asked how they would like to organize this service. The healthcare professionals reported that it would be most feasible if the nurses or dieticians would have primary access to the eHealth portal, as the nurses were the ones the patients had most direct contact with. Since they knew that the patients had many questions regarding food and diet, they also considered it important that one of the dieticians had access. The doctors expressed that they did not want to be primary users of the eHealth portal due to their current duties and time pressures at work. They wanted to be contacted if they were required to answer patient requests through the portal, but preferred that the moderator or other healthcare professionals with access could do a first-phase filtration of what the doctors were required to respond to. Based on input from the participants, a service model was proposed before implementation in clinic. This resulted in one dietician, three nurses (one psychiatric nurse and two nurses at the clinic), and one administrative leader (in order to get an overview of their patients) got access to the portal with the responsibility to facilitate and communicate with the patients. One of the initial requests (from both patients and professionals) in the PD-workshops was that the portal needed to be moderated by professionals because of quality concerns and to avoid harassments that were observed in unmoderated forums. Therefore, one person from the research team (me), educated in nursing, had the overall responsibility to moderate the forum and could comment on postings that were

within the field of competence. Another emphasized aspect was the usefulness of peer-to-peer interaction, and that patients could interact and learn from each other. Thus, they requested to give access to patients in different stages of the treatment process.

**Figure 9: Healthcare professional – Patient communication via eHealth portal**



The eHealth portal was established and implemented in the bariatric surgery clinic. The healthcare professionals that acquired access got a brief introduction to the system when implemented in the clinic. The patients were recruited through the clinic, provided written consents to participate in the study, and were registered to the system (with name/telephone number/email address) in order to retrieve username and password. The inclusion period lasted about a month until all 60 patients had gained access to the eHealth portal. After getting access, they were free to use the solution according to their own needs. Each week a “topic of the week” would be posted to the discussion forum in the eHealth portal. The topic was either initiated by the patients (by posting a request on the forum) or initiated by the clinic. To notify the patients about the weekly topic, an auto-generated email was sent from the portal to the patients’ email when the topic was posted online.

The patients had no restrictions about when or how frequently they could use the eHealth portal and could post to the discussion forum or send personal messages (to peers or professionals) through the eHealth portal any time 24/7. The clinic was closed during weekends, so the professionals would answer during their working hours (Monday to Friday. 8:00–16:00). However, the moderator of the eHealth portal had the responsibility to moderate the forum 24/7. Also the technicians needed to be available 24/7 in case of technical problems. The eHealth portal was not to be used



for emergency purposes; this was specified in the portal. If such instances occurred, the users were to use traditional emergency units.

**Table 7: User roles and responsibility—eHealth portal**

User Role in eHealth Portal	Online	Responsibility	Competence
Patients	24/7	Not relevant	Not relevant
Facilitators: Healthcare professionals	Mon-Fri 08-16	Respond to patient requests. Observe interaction. Intervene and implement measures if necessary.	Nursing Nutrition Administration Psychiatry
Moderator/facilitator	24/7	Observe interaction. Intervene if necessary. Respond to patient request within field of competence	Nursing Research
Technician	24/7	Make sure that eHealth portal is stable. Do technical adjustments.	Computer and Information technology
Decision support (professionals)	When requested	Provide the primary users of healthcare professionals with information and decision support if requested.	Endocrinology Surgery Physiotherapy Pharmacotherapy

### **Ethical Considerations**

The studies were conducted according to the guidelines of the Declaration of Helsinki. Approval was obtained from the Regional Committees for medical and health research ethics (REK), Central Norway, and the Norwegian Social Science Data Services (NSD). Separate applications were sent for Study I and Study II. The reason for sending two separate applications were that, at the starting point of the project, we did not know what technology would be developed and what service we later would implement in the clinic. After the design development process (Study I), we sent the second applications to REK and NSD, concerning Study II.

All participants that took part in this research project provided written informed consent when enrolled in the study. Inclusion criteria for all participants were: age above 18 years, and basic proficiency in Norwegian language. Specific inclusion criteria were set for the various workshops, usability evaluations, and the case study trial. These are described in detail in each article.

## **Results**

This chapter provides a summary of the four articles presented in the second part of the thesis. The articles included in this dissertation are peer-reviewed and published.

### **Study I**

Research questions:

- (1) What are the requirements of patients undergoing weight loss treatment and their healthcare providers towards an eHealth solution?
- (2) How to engage patients and healthcare professionals in the design process of an eHealth tool?

### **Paper 1**

#### **Management of weight loss: Patients' and healthcare professionals' requirements for an e-health system for patients**

**Background:** eHealth systems in healthcare typically have multiple end-user groups with widespread backgrounds and interests. Patient-centered eHealth solutions are patient focused, but not always in conjunction with the disease management programs, in which healthcare professionals have a central role. Weight reduction treatment are resource demanding for the individual patient as well as for the healthcare services considering the time, economical costs, and resources required. Currently there is no unique solution that ensures long-term maintenance of lost weight. For long-term weight maintenance, the patients need to address lifelong behavior change including self-care management and self-monitoring activities. However, such activities are resource demanding and difficult to maintain. Creating new solutions to how one may support patients' behavior change processes and self-care management activities are important for improved long-term treatment outcomes. eHealth solutions hold potential benefits in this context, but there is a lack of knowledge about the requirements of patients undergoing weight loss treatment and their healthcare providers towards an eHealth solution to be used in a therapeutic context. In order to address this, our objectives were to involve patients and professionals in an iterative design process to explore their needs, perspectives, wants, and desires. The aim of the current study was to obtain and describe the multiple user groups' requirements and perspectives towards a future eHealth solution.

**Research contribution:** The involved user groups required a secure online eHealth solution with multiple features. Ethical and privacy issues were discussed and underlined to be important to address in a technical solution. The participating groups had rather similar requirements that consisted of validated patient information, self-management tools, and communication features. We discovered that gaining insights into the rationales and perspectives of the users were central in order for further prioritizations about what to develop, for what purpose, and about expected outcomes of use. Further, we recognized that patients undergoing the two different weight reduction interventions had different medical and social characteristics, and distinctive informational needs. The professionals provided information based on their experiences of working with a cohort of patients, addressing their clinical and professional needs, as well as conveying information about what they considered to be important for the patient group and for the healthcare service as a whole. The patients revealed their personal stories, needs, and desires that are crucial to get insights into, in order to design health services and technology that can meet their requirements and facilitate them in their daily life. The findings of this study imply that designing eHealth solutions for patients to be used in therapeutic contexts requires close user involvement with the key stakeholders in order to meet the different perspectives and requirements.

## **Paper 2**

### **Human-centered methods in the design of an e-health solution for patients undergoing weight loss treatment**

**Background:** Human-centered approaches are established methods within systems design, but enabled to a limited extent, particularly within healthcare. Such approaches are currently not established within eHealth system design and development processes. Few studies have been done with user groups that have particular user requirements that go beyond the requirements of the average healthy technology users. Patients might be temporarily impaired because of cognitive, physical or emotional disabilities, they may have specific informational and educational needs due to their condition, and they must be treated with particular considerations due to ethical and privacy issues. In order to gain an extended body of knowledge about how to engage and conduct design processes with particular user

groups in healthcare, our objective was to report on the methodological implications of human-centered design for patients undergoing weight loss treatment.

**Research contribution:** This study reported from a nine-stage design process, starting from the inspiration phase of a field study, to system evaluation through usability tests of the developed eHealth solution. We identified that by involving the end users (patients and professionals) in an iterative manner through various stages of the design process, letting them hold the roles of informants, design partners, testers, and users, we could ensure that the final eHealth solution were according to their needs, perspectives, and expectations. We found that some participatory design methods were easier to enable for some end-user groups than for others, and observed that it was important to conduct some PD-activities in separate groups rather than mixing the user groups together due to aspects relevant for this particular user group (power balance between stakeholders, stigma and shame among the patient groups). We also discovered that getting hold of the tacit knowledge of the users was important in order to design a satisfactory solution. Our findings imply the necessity of involving multiple user groups in the various stages of the design process, but that particular considerations need to be undertaken when designing with patients due to health related and personal issues.

## **Study II**

Research questions:

- (3) What are the motivating and restraining factors of bariatric surgery patients' use of a secure online forum?
- (4) What benefits and challenges do healthcare providers experience with the use of an eHealth portal in communication with patients?

## **Paper 3**

**What influences patient participation in a facilitated online forum for weight loss surgery? A qualitative case study.**

**Background:** People undergoing bariatric surgery require and seek social support, and many turn to online discussion forums to achieve this. However, the quality and credibility of the available information in such forums raises concerns about their impact and value. Self-management activities are associated with successful long-

term weight-maintenance, and studies imply that social support may encourage adherence with post-surgery recommendations. In the current study, a discussion forum, facilitated and moderated by healthcare professionals, was offered to patients in the context of the bariatric surgery treatment they received from the clinic. The aim of the study was to explore how the patients used the online forum, and to better understand what influenced their participation.

**Research contribution:** This study revealed that the patients were motivated to use the online forum to provide and seek social and informational support to/from peers and providers, and benefitted from using the forum regardless of passive or active participation. We discovered that some patients were restrained from active participation because of concerns regarding self-disclosure such as literacy and personal barriers, but experienced benefits of lurking (passive participation) online. The findings imply that a moderated forum has potential for use in a therapeutic context because the discussion forum fulfills the informational and supportive needs of the patients, and is particularly useful for those who exclude themselves from traditional programs or who experience barriers in making contact with professionals.

#### **Paper 4**

##### **The impact of an eHealth portal on healthcare professionals' interaction with patients: Qualitative study.**

**Background:** People who undergo bariatric surgery require a comprehensive treatment program to achieve successful outcomes. eHealth solutions such as online portals, create new opportunities for improved healthcare delivery and care, but depend on the organizational delivery systems and on the healthcare professionals providing it. However, these have received limited attention, and the overall adoption of eHealth solutions remains low. In this study, a secure online portal was implemented in a bariatric surgery clinic and offered to their patients. The portal features included patient information, patient self-management tools, and communication features for online dialogue between peers and providers. The healthcare professionals had the responsibility to facilitate and communicate with the patients online. The aim of the study was to characterize and assess the impact of an eHealth portal on healthcare professionals' interaction with patients in bariatric surgery treatment.

**Research contribution:** The healthcare professionals reported a number of benefits by using an eHealth portal in communication with their patients. They reported that the patients' online writings provided them with access to patients' revelations, in which they could identify patient challenges, act, and implement measures. The study revealed that professionals' communication with patients in such an online portal can prevent patient dropout from the treatment program and patients' health deterioration, factors that predict success of the surgery. However, the professionals reported barriers, such as organizational challenges and personal constraints, related to communicating in writing with the patients online. The study indicated that further guidelines and education about how to handle, prioritize, facilitate, and communicate with patients online is required for healthcare professionals, in addition to increased attention to organizational infrastructures, incentives, and rationales for enabling eHealth solutions in healthcare.



## **Discussion**

The overall aim of this research was to explore human-centered methodology in the design of a patient-centered eHealth solution, and to characterize the experiences of patients and their healthcare providers of using such a solution in a bariatric surgery program.

### **Contributions of the Thesis**

In Study I, we identified the requirements of patients and their healthcare providers towards an eHealth system to be developed and enabled as part of bariatric surgery treatment. The main requirements were self-management tools for self-monitoring, communication features for social and informational support by peers and providers, and validated patient information to avoid misunderstandings and misinformation. These are similar to those Khaylis et al. identified in their review of 21 studies of technology-based weight loss interventions; they found that self-monitoring, counselor feedback and communication, social support, use of a structured program, and use of an individually tailored program were successful in facilitating weight loss [33]. The fact that our study identified that human-centered design activities need to be planned and conducted with particular considerations to the user groups involved, indicate that designers need a certain domain knowledge in order to plan, conduct, and facilitate the activities accordingly. Even though the patient role has changed in medical encounters and where the patient-provider interaction can have varying forms such as described by Emanuel and Emanuel [100], the power imbalance between patients and providers may still be prevalent in certain medical settings, such as observed in our research (paper 2). Conducting activities with various stakeholders together in the same PD-workshops have been an established approach that is time-efficient and fruitful, but might not be suitable to reveal the subtle but critical aspects relevant in design processes for healthcare. Separating different users in certain human-centered activities is important because it allows the participants to participate actively and freely with their experiences and ideas, ensuring that their particularities, needs, and tacit knowledge come to surface.

In Study II, we revealed various aspects that characterized the experiences of patients and their healthcare providers in their online interactions and use of the eHealth portal. We identified that patients undergoing bariatric surgery were in need of and



searched for informational and emotional support because of the intervention's severe impact on their physical and emotional health, and that the eHealth forum became an important resource for this purpose. This finding is consistent with previous research that suggests that informational and social support are prominent reasons for online interaction [122]. Health literacy is associated with knowledge of health conditions, therapy and to health outcomes [87-91]. The fact that the eHealth forum was used as an important information source is promising because it implicates benefits for the patients in relation to patient knowledge, education, and literacy. We observed that the online forum served as a source for informational support, mutual social support, and networking with peers, but that not everyone having access was an active participant. Lurking is when people seek answers to questions, and view and browse others' postings, but do not contribute actively themselves [183-185], thus avoiding revealing their own presence in the forum. Lurking has been explained through personal and work-related reasons [183]. In our study, the consideration of self-disclosure, e.g., where to draw the boundary between what to share or not in an online space, was identified as a factor that restrained active participation. However, regardless of passive or active participation, the patients benefitted from having access to the contributions of their peers because these experiences closely resembled their own, and they reported learning from others' writings. This is in line with studies that report that those who read in online support groups benefit even though they are not active themselves [38, 186, 187], with the potential of health promotion through observing or listening on other conversations [186]. Online social support may result in improved health literacy, increased quality of life, and patient empowerment [37-40]. Creating arenas where peers can interact with each other might be an important supplement to traditional healthcare services because the experiential knowledge that peers hold exceeds what professionals can contribute, and are important for how the patients cope with and manage their situation. The fact that professionals can follow this interaction, as designed in our study, means that they can also learn and benefit from the patients' writings and revelations, and thereby can adjust their information and patient education programs accordingly. The particularity of the eHealth portal in this study was that healthcare professionals moderated it, and that patients could achieve contact with them. The fact that professionals were actively involved and with responsibility for the portal was by the patients perceived to increase its usefulness and trustworthiness. This study demonstrated that both

patients and healthcare providers benefitted from using an eHealth portal in communicating and interacting with each other, and revealed benefits of implementing such a portal in a bariatric surgery program.

The healthcare provider-patient relationship has crucial impacts on the patients' health outcomes since research shows that physicians' communication is highly correlated with improved patients' treatment adherence [105]. Adherence to scheduled visits and promoting health related behavior predict success of bariatric surgery [188], where professionals can use eHealth portals to promote such activities and post-surgical regimens. Non-adherence to the post-surgery recommendations results in a number of the patients experiencing nutritional deficiencies and weight regain following surgery [17, 25, 26, 72-74, 79-82]. Despite patients' need for follow-up after treatment, studies report that bariatric surgery patients tend to drop out of the follow-up programs for unknown reasons [106, 110]. The traditional communication arenas between bariatric surgery patients and their healthcare providers seem to have shortcomings. We found that some patients were restrained in their interaction with healthcare providers, a fact that might lead to severe consequences in terms of health outcomes and successful long-term weight maintenance. Puhl et al. identified that this patient group may delay or forgo essential preventive care because of shame and stigma [111], where our study implies that this is a factor that also needs to be considered in post-surgical follow-up care. The reason is that this seems to influence the lifespan of people who have suffered from such and the way they interact with healthcare services. We identified that the eHealth portal proved to be a possible gateway for professionals to communicate and interact with patients, particularly as a channel to a subgroup of patients who, for various reasons, do not use traditional communication forms (face-to-face, telephone consultations), and whom they would have lost to follow up. The fact that the professionals could observe the patients' online writings and revelations, and thereby identify the need to implement follow-up care and interventions, imply that such touch points between professionals and patients potentially can have high impact. This implies potential outcomes similar to previous findings, where using behavior services and more frequent contact between patients and clinicians has been associated with better long-term outcomes after bariatric surgery procedures [106-109]. eHealth portals for online communication can

be a supplement or even a substitute for certain patients, and valuable for addressing clinical concerns and needs.

Despite the potential advantages of using an eHealth portal in a bariatric surgery program, the professionals reported a number of challenges, such as organizational challenges, time constraints, workload, busy working hours, and lack of incentives. These findings are similar to the ones of the Hanberger et al. study in diabetes care in which practitioners had a hard time enabling an eHealth portal because of obstacles such as deep-routed working habits and many working tasks [189]. Our findings suggest that even though such a portal holds great potential and impact in bariatric surgery, a number of aspects need to be addressed in order to take full advantage of the benefits.

### **Methodological Considerations**

In this research, I have undertaken a human-centered research approach involving mixed methods. The research methodology undertaken, the research paradigm, study design, population, context (setting), data collection, and methods of analysis influence on the results and imply strengths and limitations.

### **Validity, Reliability, and Bias**

Using a human-centered approach with qualitative data has provided this research with rich and detailed data. This study is subject to several limitations including the methods used, sample size, and resources available to conduct this research. In order to strengthen the internal validity (credibility), concerning whether the results are representative for the cohort studied, we have undertaken close user involvement in which the involved stakeholders (patients and professionals) have been included and enabled with participatory tools in order to adjust, influence, and verify the results in different stages of the design-process and research. As part of each design activity, we included an end discussion about the methods and approaches used, and whether the participants considered the tasks and results as representative for the cohort under study. The issues of selection bias might have influenced the ones that were included in Study I. The healthcare professionals were recruited by convenient sampling, which implies limitations, as we were not able to include all the professionals at the clinic. The patients were included by strategic sample for inclusion, but those more interested or affluent might have participated. Considering Study II where we, in the

case study trial, requested all patients that had undergone bariatric surgery at the clinic during spring 2011 for inclusion, almost everyone was included in the study. Those who were waiting for surgery and those who had undergone surgery a longer time ago were few, and were included randomly only because they were in need of closer follow-up by the clinic. Reviewing the results, there are no indications that these few participants stood out from the rest of this cohort in demographics, experiences, or use of the eHealth portal. Concerning those who participated in the in-depth interviews, the issue of selection bias might be prevalent, as they were recruited through the online forum of the eHealth portal, and we might have come in touch with those who frequently accessed the eHealth portal compared to those who did not.

Using qualitative methods has its shortcomings as to the external validity involving generalizability to other populations. The limited number of participants in this study provides its shortcomings, and the results can therefore not be generalized directly, but the research as a whole indicates transferability in some aspects. These are mainly indications concerning enabling human-centered design methodology in the design of eHealth solutions that can be transferred to similar design processes with other patient groups. Some degree of transferability of the results might be prevalent as to the indications about considerations that need to be undertaken when implementing and introducing such solutions in a healthcare context, and might be relevant for other clinics, other patient populations, and other healthcare professional groups.

Concerning Reliability, whether the data are trustworthy has depended on the context that we have studied. It would be difficult to replicate the study because of its qualitative nature. Also, the fact that healthcare services are in continuous change, and the timing for when the study was conducted might influence the results., e.g., the treatment process and patient trajectory described in this dissertation was how it was undertaken at the clinic at the time of our research. This might have changed slightly in current medical practice because the clinic continuously works with improving the patient treatment, patient trajectory, and organizational infrastructures. This study might be exposed to researcher bias as all researchers have their own perspectives or feelings that might influence the process. The fact that I had several roles during this project—facilitator, designer, researcher, and moderator—might not have been optimal. However, the developed eHealth system was merely used for this project, and will not be a product available in the market so there are no economical or

business motivations behind it. Neither do I have any commitments to the clinic where the study was undertaken. In order to prevent researcher bias and to increase reliability, we have had several researchers involved in planning the research and activities, data collection, analysis, and discussion of the data. To reduce interpretation bias, we have been two researchers that have analyzed the collected data separately, and a discussion of results and outcomes among several researchers have been undertaken in both studies.

### **Implications**

In this thesis, I have explored the use of human-centered methodologies from idea to evaluation of an eHealth solution in weight loss treatment. This thesis is relevant for designers and developers of patient-centered eHealth solutions, for researchers in the field of medical informatics, human-computer interaction, or design. It is also applicable for clinicians and healthcare professionals that consider introducing such solutions in their clinical practice, for patients and patient organizations that are interested in patient empowerment and communication, and for policy makers and other stakeholders within healthcare.

This research indicates that conducting human-centered activities as part of the design process, from inspiration to evaluation of eHealth solutions is important in order to address various factors from user requirements and expectations to adaption and use of the solution. Designers need to take particular considerations when undertaking human-centered approaches with multiple user groups because of the power balance between the stakeholders, but also because some patients need special care. This necessitates designers to get an in-depth understanding of the users, use context, and stakeholders in the inspiration phase; to plan and conduct human-centered activities; and to evaluate technical solutions and service. This became particularly prevalent in this study because of the particularities of this patient group and their experiences of shame and stigma. Letting the users hold the roles as informants, design partners, testers, and users as suggested by Druin [150] provides invaluable contributions throughout the process and increases users acceptance.

The findings of this research imply that an eHealth portal in bariatric surgery has potential for use in a therapeutic context. The results indicate that both patients and providers experience benefits but also barriers in using such an eHealth portal, which

are important to take into consideration when introducing such a solution into a healthcare setting and use context. A moderated discussion forum for bariatric surgery patients has potential for use in a therapeutic context, as it fulfills the patients' needs for informational and social support, and is particularly useful for those who exclude themselves from the traditional treatment program and who experience barriers to expressing their own needs. Even though our findings imply that the patients benefit from using the forum regardless of active or passive participation, restraining factors such as considerations on self-disclosure must be further investigated to prevent certain users from being excluded from participation. Our findings imply that by providing an eHealth tool in a bariatric surgery program, healthcare professionals can observe patients' writings and revelations, and thereby capture patient challenges, thus act and implement measures necessary. The results indicate that healthcare professionals' interaction with patients through the eHealth portal can prevent patient dropout from the follow-up program and deterioration of patients' health condition. However, enabling such a tool also represented some difficulties, and the professionals report on organizational challenges and personal constraints of communicating with patients in writing online. Further development of guidelines and education of healthcare professionals about how to handle, prioritize, communicate, and facilitate patients online is required for future success of the introduction of patient-centered eHealth portals in a treatment program. Also, increased attention to organizational infrastructures and incentives for enabling and adapting such solutions in a healthcare context is required.

Considering the severe impacts that weight loss intervention has for this specific patient population, and the documented challenges they experience, novel solutions such as the eHealth solution in this study are necessary and can impose benefits for the individual but also for the society as a whole. The eHealth technology itself is not the solution, but use of the technology in healthcare service contexts and the outcomes of use might have a great importance and role in future weight loss treatment.

### **Further Research**

This study revealed that using human-centered methods with patients and providers can be beneficial in order to identify needs, requirements, tacit knowledge, use

contexts, aims, and desires that need to be considered when designing eHealth solutions for use in a clinical context. As pointed to in previous research, such activities are resource demanding and time consuming, and the need to identify which approaches that are the most efficacious and beneficial is still under demand.

Our findings imply that both patients and providers benefit from using an eHealth portal in bariatric surgery. However, as this research is limited to its qualitative approach, further studies are needed to explore this further and to verify the results. Studies of more quantitative characters are needed to evaluate cost-benefit, quality of life, and outcomes for the patients, and the impact on healthcare services are required for an increased body of knowledge concerning the use of eHealth portals in bariatric surgery treatment.

## **Concluding Remarks**

In this thesis, I have explored human-centered methodology in the design of a patient-centered eHealth solution, and identified factors that are important to consider when conducting design processes and HCD approaches with patients and healthcare professionals. Further I have characterized the experiences of patients and healthcare professionals using an eHealth portal in a bariatric surgery treatment program, and identified patients' motivating and restraining factors of using an online communication forum, and healthcare providers' perceived benefits and challenges of communicating with patients through such a portal. This research reveals implications to designers, policy makers, clinical practice, patient organizations, and research about designing and enabling a patient-centered eHealth solution in a healthcare context.

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## Part 2



# Paper I



# Management of Weight-Loss: Patients' and Healthcare Professionals' Requirements for an E-health System for Patients

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**Abstract.** An increasing number of patients with overweight undergo weight-reduction treatment. However, many people experience challenges with long-term maintenance and are in risk of weight-regain. Currently there is no unique solution that ensures long-term maintenance of lost weight. Several studies have explored the effectiveness of web-based and e-health interventions, on improving the outcomes of weight-management. The results are unclear. This paper describes requirements for e-health solutions for weight-loss patients. Our findings suggest that such solutions need to be developed in collaboration with both patients and healthcare professionals to ensure that they are in line with medical treatment in addition to taking consideration to the behavioral aspects of using such systems.

**Keywords:** Design, E-health, Healthcare, Obesity, User involvement.

## 1 Introduction

Involving multiple stakeholders in the design process is challenging due to the required time and investment. Within the healthcare domain, e-health systems typically have multiple end-user groups with widespread backgrounds and interests [1]. Patient-centered e-health solutions are patient focused, but are not always in conjunction with disease-management programs, in which healthcare professionals have a central role. For such systems it is therefore important to include the perspective of all stakeholders, both different patient groups and the relevant healthcare professionals.

Until lately, obesity have been managed within the primary care, but due to the increased prevalence of severe obesity, the demand for interventions such as surgical interventions and lifestyle programs offered by the specialist care is rising. People that undergo such treatment require lifelong lifestyle modification with focus on dietary habits and physical activity. With the treatments taking place within the specialist care, patients increasingly need to conduct self-monitoring activities in their home environment with little follow-up by healthcare professionals. E-health solutions hold

the potential to support patients after initial weight-loss, to help establish, support and maintain lifestyle changes. Successful long-term maintenance is associated with self-care management and self-monitoring [2]. However, conducting such activities are labor intensive, and compliance is often difficult [2]. Hence, we need a better understanding of the experienced challenges after treatment, about aspects influencing upon non-compliance, and how self-management can be promoted by the use of e-health systems in weight-loss patients. To be able to design a clinical e-health solution for this patient group, a first step is to gain knowledge and understanding of the challenges they experience, and further investigate how the behavior change process can be promoted by the use of e-health solutions. In this study we have involved patients and healthcare professionals in a participatory design process of a clinical e-health system, to elicit the multiple user groups' requirements and perspectives towards such a system.

## 2 Background

The prevalence of obesity in the western countries has increased the last decades [3]. Obesity is associated with increased morbidity and mortality, and is a risk factor for diabetes, cardiovascular problems, hypertension, cancer illnesses, osteoarthritis as well as other health problems of psychosocial characters [3]. Increasingly, obesity is being recognized as a chronic disease itself, requiring health interventions. Weight-loss has beneficial effects in co-morbidities and long-term survival, and can be achieved through lifestyle intervention, bariatric surgery or pharmacotherapy [4]. However, long-term maintenance of lost weight is difficult, and studies show that conventional treatment (incl. lifestyle modification programs and pharmaceutical agents) is relatively ineffective in a long-term perspective [5]. As for today, surgical interventions are shown to be the most effective, and produces substantial initial weight-loss in the great majority of patients [5]. However, studies imply that weight-loss of bariatric surgery is temporary, and that many patients regain weight after a while [5,6]. Long-term weight maintenance is therefore a challenge regardless of initial weight-reduction treatment, as many experience weight regain after a period of time.

Weight-reduction programs are resource demanding for the individual patient as well as for the healthcare services considering the time, economical costs and emotional investment it requires. Currently there is no unique solution that ensures long-term maintenance of lost weight [7]. Several studies has explored the effectiveness of web-based and e-health interventions, on improving the outcomes in the area of weight-management, physical activity and dietary intake with unclear results [7].

Since its infancy in the 1980s [8], the perspectives and techniques of Participatory Design (PD) have become part of the state-of-the-art in systems development. As exemplified by Druin's work with children [9], certain user groups require modification and adaptations to the existing PD methodologies. We will here report from a Participatory Design project with another non-standard user group: Obesity Patients.

### 3 Methods

During 2009 we conducted a qualitative study involving a series of four participatory design workshops including patients and healthcare professionals. The inclusion criteria for the patients were that they (a) had completed a weight-reduction program offered at the local hospital, (b) were age 18 or above, and (c) had basic proficiency in Norwegian language. The study got approval from the regional Ethics Committee (Central Norway, Trondheim), and all participants provided written consent when enrolling to the study.

#### 3.1 Workshops

We conducted separate workshops with the multiple groups, and two facilitators from the research team had the roles as moderators during each workshop. Healthcare professionals were included in the first workshop, followed by two workshops that included patients that had undergone weight loss treatment either through conventional treatment (lifestyle therapy) or bariatric surgery.

The workshops consisted of design tasks, semi-structured interviews and group discussion. In advance, we had clarified the topics that were to be discussed, and we used open-ended questions that were followed by probing questions that clarified the participant's responses. The objectives of the workshops were to systematically gather information, ideas and perspectives from the multiple user groups.

Finally, we conducted a last workshop where we included selected participants from the previous three workshops. The purpose of the last workshop was to present our results, and to validate the findings. Each workshop lasted for 3.5 hours, and the whole session was video-and audio recorded.

#### 3.2 Analysis

The recordings from the four workshops were transcribed verbatim. The data was analyzed qualitatively using a grounded theory approach [10]. The transcripts were coded before these were grouped together, and themes were identified.

### 4 Results

The aim of this study was to describe patients and healthcare professionals requirements of an e-health system to promote self-care management after weight-loss, to explore differences between these perspectives, and to assess the implications this may have for further e-health system development.

#### 4.1 Participants

In total 20 people participated in the workshops, 12 people that had undergone weight-loss treatment at the local hospital, whereas six people had gone through bariatric surgery, and six had attended conventional treatment. Eight healthcare professionals attended the workshops, and their professional background was from nursing, medicine and clinical nutrition. Demographics are presented in table 1. To validate our findings from the first three workshops, we invited all the participants to



**Table 1.** Demographics

Participants	Female	Male	Total
Professionals	6	2	8
Lifestyle group	5	1	6
Surgery group	4	2	6
Total	15	5	20

a final workshop. Not all were able to attend this workshop due to personal practicalities, and the last workshop consisted of 10 participants. Five were from the healthcare personnel group, two from the conventional therapy group, and three from the bariatric surgery group.

#### 4.2 User Requirements

All the groups suggested a secure-web-portal solution that would be accessible through the Internet. The benefit of gathering several features in one portal was the main reason. The possibility to send news feed and reminders from the web-portal to the users mobile telephone was proposed as an extra feature to motivate use of such a system. Ethical and privacy issues were discussed, and secure access that requires username and password for all users was pointed out to be important, as access to the system would only be give to patients treated at the hospital. Patients that had undergone weight reduction treatment would be the primary user, and healthcare professionals would have the role as moderators and facilitators.

The findings from the workshops identified that the multiple user groups have rather similar requirements when it comes to the features that they emphasize as important in a clinical e-health system for weight-loss patients. Table 2 gives an overview of the suggested features to be included in the system. However, the multiple groups have differing perspectives and rationales towards such a system.

**Table 2.** Required features in a clinical e-health system after weight-reduction treatment

Requirement	Healthcare Professionals	Patients
Information	X	X
Articles		X
Links	X	X
Discussion Forum	X	X
Private Communication	X	X
Buddy System		X
Self-management tools:	X	X
- Diary	X	X
- Notes		X
- Calendar	X	
- Diet plan	X	X
- Exercise plan	X	X
- Clinical Measures	X	
- Reminders on sms	X	X

Several broad themes were identified, and the participants emphasized patient education, communication and disease management as the most crucial ones. These issues will be further elaborated from the multiple perspectives.

#### 4.3 The Healthcare Professionals Perspective

Healthcare professionals have the responsibility to provide patient education. According to the healthcare personnel group they use much time on providing and repeating the same information to the same patients several times, but they experience that the patients claim not have received this information, and that they are non-compliant. As a result, the healthcare professionals had started documentation of provided information, and experienced that this was the reality. As one of the professionals expressed:

*“Not all, but let us say that 70% (of the patients) asks questions about things they already have received information about.”*

The professionals were particularly worried about the patients that undergo bariatric surgery, due to the nutritional and metabolic problems that these patients may experience if non-compliant to recommended post-surgery regime. Such surgery is an intervention to help patients loose weight and involves a decrease of the size of the stomach. The necessity of preventing undesirable repercussions of the treatment is crucial. The patients need to undergo major changes considering eating habits, and they are dependent on taking lifelong vitamin supplements daily to prevent developing nutritional deficiencies over time [5]. The surgery alone is not the solution to weight-loss, and they need to follow guidelines for diet, exercise and lifestyle changes to prevent long-term weight-regain.

The healthcare professional group suggested to provide more elaborate patient information in the e-health system, and had hopes that this could support patient education. Insecurity among the patients was another issue that was discussed in relation to patient education. Particularly this was observed among the bariatric surgery patients, where lack of information regarding food, diet and nutrition was a recurring topic. Positive patient outcomes, confidence and prevention of future malnutrition were the rationales that the professionals emphasized.

Enhanced communication between healthcare professionals and patients, but also among patients was highlighted as important issues that could be promoted in a future e-health system. To serve different communication purposes, an online discussion forum where the patients could discuss and share experiences was suggested, as well as private communication for one-to-one dialogues. The healthcare professionals experienced that patients seek contact with others in the same situation, and are positive towards that patients can learn from each other. However, they had experienced patients that had been misled due to wrong information they had found online and in chat-forums. If possible, they would like to be there for their patients, as one of the healthcare professionals put it:

*“The first thing is how important it can be if some of use are moderators (for the forum). There are enough online forums for these people, but these are not forums where experts (professionals) are present. That is where we can contribute - as a source to knowledge, as a source to correction.”*

The healthcare professionals were aware of the fact that some patients would like more frequent consultations, and professional guidance and advice in some periods after treatment. Particularly they experienced that during the first phase after treatment, the number of telephones to the clinic increased, and sometimes a simple question could turn out to become a long lasting telephone consultation. With the time pressure-and workload, some emphasized the potential of using electronic medias for information, and one-to-one communication channels, that could provide efficacy benefits for the clinic. As of today, electronic communication with the use of e-mail and chat rooms are established ways of communication. However, within the specialist healthcare in Norway this is not an established reality. The reasons are complex, and may be explained by the legal issues that limit healthcare professionals to use electronic communication channels due to the security aspects. Another factor is the economical model behind the financing of the healthcare system in Norway, where face-to-face consultations and telephone calls gives benefits, rather than electronic communication that still does not exist as an option within the billing system.

Patients self-care management and disease management was emphasized as crucial by the healthcare professionals. An e-health system that could promote self-care management activities, and where the patient can organize and structure their day were heavy arguments for implementing such a system closely connected to the clinic. The professionals experienced that several patients lacked structure regarding eating and exercise. They suggested that reminders about eating could be of help, and that the patients could receive these reminders on their mobile telephone, as most people carry their phone wherever they go. Such reminders were also proposed to apply to vitamin pills and doctors appointments. Another self-management activity they currently recommended for their patients was to write diaries. They observed that when patients wrote a diet record or diary, this raised awareness about diet and diet pattern. However, according to the healthcare professionals, many patients were non-complaint towards diary writing, but they would advocate implementing a diary feature in the system anyway. The possibility of for instance sharing the diet record with the dietitian (for feedback) could be a motivational factor for starting to use such a tool.

#### **4.4 The Patients Perspective**

The patient groups expressed that in contrast to the healthcare professionals, they experienced that their information needs were not addressed sufficiently in the current clinical practice. An e-health system could promote information access, providing patient information retrieval whenever they needed it. Tailored information according to the treatment was underlined as important. Patients that were operated emphasized the need for elaborated information regarding the postoperative phase, about expected side effects of the operation, and about food and nutrition, as many experience food intolerance due to the surgery. Some could tell that the information they had received on paper had been misplaced, and after that the information was gone. In lack of information from the hospital, some had searched for information online, with the result of becoming even more confused. The Internet provides amounts of information, and the overload makes it difficult for patients to filter what to trust, and what to ignore. A place with validated information that they knew was correct would make the information retrieval process easier. One of the patients that had undergone surgery searched online, and ended up in a obesity forum with the following experience:

*“That page... if you write something there, then you get an answer that belongs nowhere. Then you get a sensible answer, and then you have three others that criticize the sensible answer. And then you are back where you started, what is correct?”*

The patients in the conventional therapy group did not express the same need for information regarding food and nutrition as the other patient group. These participants had gone through a lifestyle therapy program involving a residential intermittent program at a Rehabilitation Centre. The basis for this treatment is dynamic group based psychotherapy, but in addition the patients take part in a structured Physical Activity (PA) program daily (2 sessions of group PA+ one individual/day), and in a nutritional education program (about estimation of energy-balance, food, healthy cooking and eating etc). The ultimate aim of the treatment is to empower the patients so they can be in charge of their own lifestyle change. However, these patients emphasized that they needed information that clearly stated guidelines for diet and physical activity according to their physical health. Several of these participants had knowledge about healthy food, but had difficulties estimating the amount of food to eat, and to establish healthy lifestyle habits. Further they emphasized communication with healthcare professionals and other patients, for both evidence-based information that professionals holds, in addition to the experiential knowledge that patients have. Several of the participants in the conventional therapy group had reduced significant amount of weight, but had regained weight after a while. Using food as coping mechanisms, and lack of structure in daily life were issues that were mentioned as the causative factors. A woman in this group put it as follows:

*“I eat because I like it, not because I necessarily am hungry. Food is, I probably eat in response to emotions – many people do that...So if I am happy - I eat, if I am bored - I eat, if I am exited - I eat.”*

Regarding Disease Management, suggested tools to support self-care management were reminders on sms, diary writing, meal plans, PA-plans and commitment to others. One of the patients experienced that commitment was a motivational factor to exercise:

*“For me, it helps with commitments, and for instance such as workout partners. And then it can be the fact that the exercise group has limited number of places. So when you get place, then you just have to show up.”*

Lack of structure was mentioned as a challenge in both patient groups. The majority of the patients described their daily life before treatment as unstructured regarding food, diet and exercise, and many described poor and inconsistent eating patterns. Changing their lifestyle was a challenge for many. As one woman said:

*“I am structured when I am at work, then everything goes according to the clock in my mind. It is during the weekends (the challenges come), because then I am free.”*

The patients believed that the disease management process could be facilitated by the use of a clinical e-health system. A system with several features gathered in one

portal was the main argument for wanting to use such a system. Validated information by professionals, and that professionals can act as moderators and correct invalid statements or misinformation, were highly rated requirements. In contrast to commercial web-portals and websites, the expertise that professionals hold about the treatment of severe obesity is invaluable for the patients going through such treatment. Several patients could tell about little understanding about their condition from their surroundings, and underlined that professionals' with knowledge about their particular condition was extremely important. General information about weight-loss and dieting becomes irrelevant, as these people experience their situation as more complex than only reducing weight.

#### 4.5 The Perspectives Compared

The main differences between the rationales of the patients and the healthcare professionals can be summed up as show in table 3.

**Table 3.** Multiple rationales

The Professionals' Rationales	Requirements	The Patients' Rationales
Patient education	Information	Self-care
Efficacy	Communication	Support, guidance
Prevent side-effects	Self-management tools	Social network
Patient self-care		Health outcomes

Our findings imply that a clinical e-health system can promote validated information delivery and retrieval, enhanced communication, and self-care management tools for the patients. Even though the multiple groups' requirements were similar, the rationales differ.

## 5 Discussion and Conclusion

Traditionally healthcare treatment has taken place in hospitals and healthcare institutions. Lately there has been a paradigm shift, where treatment also takes place in the home environment of the individual, particularly within chronic care. An understanding of this environment is crucial when implementing new technology. Patients hold on unique experiential knowledge, and they provide insight to their daily life, and about what their challenges and needs are.

Patients that have undergone weight-reduction treatment due to severe obesity need to implement lifelong lifestyle modification, and are dependent on implementing self-care and disease management. Our findings indicate that a clinical e-health system for this patients group would benefit from active involvement of healthcare professionals, even though the patients would be the primary users. Commercial e-health systems are probably more economical, but provide less professional contact [11]. The patients emphasize access to validated health information and communication with healthcare professionals. They require a social network with patients for social

support and experiential knowledge, and their main rationales are improved health outcomes and weight-management. The healthcare professionals emphasize patient education, prevention of side-effects of the treatment (bariatric surgery patients), and enhanced patient self-care management. Their rationales are efficiency of clinical practice, patient health outcomes, and improved quality of care.

In this project we also determined that we were dealing with two distinct user groups: Those undergoing surgery and those going through conventional lifestyle therapy. The difference was not mainly concerning medical or social characteristic, but simply the fact they had different needs. Having undergone weight-loss surgery leads to specific needs that are irrelevant for the other group. Mixing the two would only lead to confusion, and underlines the importance of involving multiple user groups during the development process. Professional knowledge and the experience that clinicians have gained over years are irreplaceable, as they have evidence-based knowledge about a whole group, and not only about one individual patient. That a clinical e-health system contain information that is in line with medical treatment is crucial. Our findings imply that when designing such a system, the perspectives of both healthcare professionals and patients need to be addressed, particularly when the system is to act in the continuation of the medical treatment offered by the specialist care.

Multiple stakeholders have different backgrounds, interests and expectations towards a system. In this study we found that the multiple groups' required features for a clinical e-health system for weight-loss patients are quite similar, but the multiple groups had different perspectives and rationales. These are important in a system development process, and imply that inclusion of multiple user groups may provide an added value when it comes to input about what to prioritize for implementation. The multiple user perspectives and requirements complement each other, and provide valuable input for system design. Our findings imply that development from only one perspective may contribute to a system that lacks important content and functionality.

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## Paper II







# Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment

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## ABSTRACT

**Background and objective:** Patients undergoing weight loss treatment require follow-up as part of the treatment process. E-health solutions may be used for this purpose. We have used an iterative design approach to develop a patient-centred e-health solution for patients undergoing weight loss treatment. Our objective is to describe and report on the design process and suggest implications for human-centred design of such systems.

**Methods:** Human-centred design methods were assessed as part of the design process. The process involved a field study to gain domain knowledge, followed by needs assessment through a series of participatory design workshops, and system evaluation through a workshop and a number of usability tests before system implementation.

**Results:** By using an iterative design approach and by involving patients and healthcare professionals throughout the process, letting them hold the roles as informants, design partners, testers and users, we could reveal important aspects throughout the design process that are crucial for system realization and user acceptance. We found that weight loss patients are vulnerable, requiring that designers take special care when involving them in the design process. Our findings imply that involving stakeholders separately during specific human-centred activities is important in order to capture subtle, but critical aspects of the users' requirements.

**Conclusion:** Applying human-centred methods in the design of e-health solutions requires that designers must take particular considerations when patients and healthcare professionals are involved in the design process.

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## 1. Introduction

An important part of e-health is the delivery of health information and services via the Internet and related technologies [1]. E-health solutions provide a variety of possibilities ranging from simple applications for smartphone to more complex online e-health systems with multiple features. The design of effective e-health solutions for patients is becoming

increasingly relevant as the number of people suffering from chronic diseases or long-lasting health conditions increases. Demiris et al. define patient-centred applications as e-health solutions that “enable a partnership among practitioners, patients, and their families (when appropriate) to ensure that procedures and decisions respect patients needs’ and preferences” (p. 8) [2]. A number of solutions have been developed, from areas of chronic conditions such as asthma, diabetes, chronic obstructive pulmonary disease (COPD) and cancer

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illnesses, to lifestyle solutions regarding diet, nutrition intake or smoking cessation [2–7]. Developers of such solutions face a number of challenges. The characteristics of the different illnesses and patient groups are diverse and therefore patient-centred solutions need to be developed with considerations to their particularities. It is often not sufficient for the solutions to be patient focused; they must also be in conjunction with the disease-management process in which healthcare professionals has a central role. As with all e-health solutions, the resulting system should be easy to use, engaging, adaptable, accessible and useful for the targeted end-users.

According to Kreps and Neuhauser, developers of e-health solutions have in many cases been more engaged with the technical elegance and innovation of new information technologies than with the utility of these tools for healthcare consumers and providers [8]. To remedy this, there is a need for design guidelines on how to conduct the design and development process for patient-centred solutions. Currently, few such guidelines exist.

In this paper we report from a case study where we have designed and developed a patient-centred e-health solution for weight loss patients undergoing treatment. Our objective is to infer methodological design implications for this patient group, and to reflect on the methodological aspects of conducting such a process with patients and healthcare professionals.

## 2. Background

### 2.1. The case of obesity and weight loss treatment

The number of people suffering from severe obesity and following diseases has increased globally the last couple of decades [9,10]. Weight loss has beneficial effects in comorbidities and long-term survival, resulting in a rising demand for weight loss interventions such as bariatric surgery and lifestyle therapy offered by specialist healthcare. The treatment process in the cases of obesity requires a two-pronged approach: treating the obese, followed by prevention of weight regain and secondary complications [11]. Studies show that successful long-term weight maintenance is associated with lifestyle changes related to dietary habits and physical activity in addition to conducting self-management activities [4,12–15]. However, conducting such activities are resource demanding, and long-term maintenance is difficult for many patients. Much effort is put into educational programmes as part of the treatment, but low literacy levels and non-compliance is a recurring challenge among this patient group [16–20]. Improving self-care management as part of the treatment process is therefore crucial for successful long-term health outcomes. There is a growing body of evidence that e-health behavioural interventions may be of significance for successful health outcomes, and a number of studies have explored the effectiveness of e-health interventions on improving the outcomes in the area of weight management, physical activity and dietary intake, but with unclear results [4,21,22]. Based on a meta-review of eighteen studies, Neve et al. [21] conclude that “Higher usage

of website features may be associated with positive weight change, but we do not know what features improve this effect or reduce attrition”: (p. 306). Most of the existing solutions are not tailored to the specific treatment processes of the patients. In another meta-review, Manzoni et al. [22] argue that “Future research should also develop and evaluate Internet-based weight loss interventions that are specifically tailored to the needs of the health-care delivery system” (p. 20). Patients undergoing such treatment could benefit from using an e-health solution with multiple features facilitating the behaviour change process and supporting communication between multiple actors, e.g. between patients and professionals, and among patients. The latter seem to be of great value for peer-to-peer support [23]. In the field of obesity, there is currently an expanding market for developing e-health solutions that aim to support, educate and facilitate the patients during the process of weight loss and maintenance. For the solutions to be useful and effective for the end-users, information about their needs, requirements and perspectives must be elicited through the design- and development process.

### 2.2. Human-centred design

Designing for specific user groups requires design processes that are informed by knowledge about the particular needs of these user groups; i.e. user-centred processes. Best practice in human/user centred design is summed up in ISO 9241-210 (2008) where human-centred design is defined as [24]:

“An approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques.”

The standard stresses that users should be included in all phases of the design and development process, and states in general that user characteristics such as knowledge, skill, experience, education, training, physical attributes, habits, preferences and capabilities should be identified [24].

The standard specifies that the design process should be iterative, but that the actual design processes can bypass one or more of the phases when appropriate (Fig. 1). The five main phases are defined as:

- I. Understand and specify the context of use
- II. Specify the user requirements
- III. Produce design solutions to meet the user requirements
- IV. Evaluate the designs against requirements
- V. Design solution meets user requirements

Systems design for or with patients involves specific considerations that go beyond what the standard describes. The patient population stands out from the average healthy technology users as they may be temporarily impaired due to their disease, they may have specific information and educational needs due to their condition, and they must be treated with particular considerations due to ethical and privacy reasons [25].

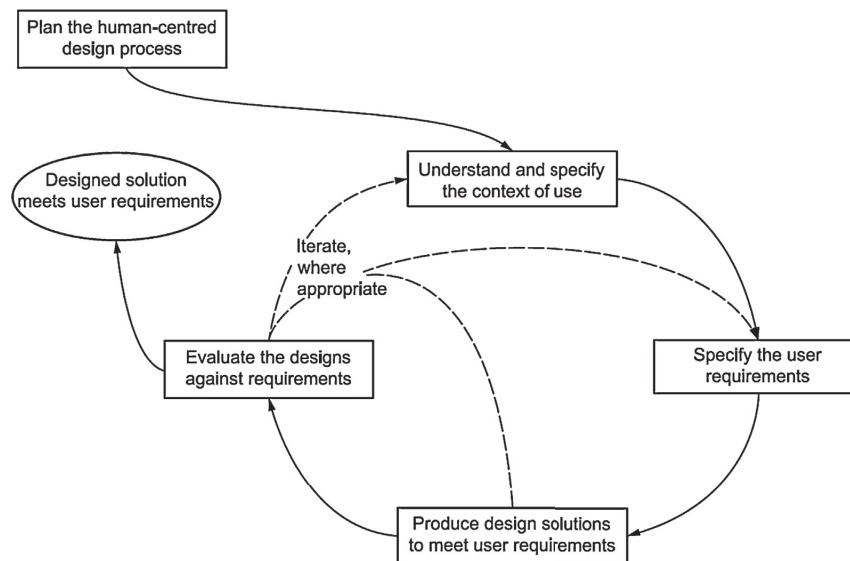


Fig. 1 – The phases of an iterative user-centred design process (from [24]).

End-users can have different roles in design projects. Based on experience from design projects with children, Druin makes a distinction and discusses four different roles: *user*, *tester*, *informant*, and *design partner* [26]. In the role of *user*, end-users contribute to the research and development process by using technology, while the researcher may observe, videotape or test for skills. This is done to try to understand the technologies' impact on the user with the aim that future technologies can be changed or future environments enhanced. In the role of *tester*, end-users test prototypes and are observed with the technology to capture their experiences, and the results are input for the development process. In the role of *informant*, end-users have an important part in the various stages of the design process, based on when the researcher believes that the participants can inform the process. This may involve observation of participants with existing technologies or they may be asked for input on design sketches or low-tech prototypes. In the role of *design partner*, end-users are considered to be equal stakeholders in the design of new technologies throughout the whole process [26].

Within user-centred design, Participatory Design (PD) refers to a set of theories, practices, and studies on how to include the end-users as active *design partners* in the design process [27]. The purpose of including the future users is to ensure that the final product is usable and meets the users' needs [28]. PD emerged in the mid 1970s, when computer-based systems were first introduced to the workplace, as a reaction to the ways this introduction was carried out and to the deleterious effects these systems were having on workers [29]. In PD, the research and design work is done *with* the users, while in related approaches within user-centred design, this work is done *on behalf* of the users [30]. PD's object of study is the tacit knowledge of the end-users, which is often difficult to formalize and describe [30].

User groups that have been included in PD-projects include pregnant women, people with aphasia, people suffering from amnesia, elderly undergoing stroke rehabilitation, and children [26,31–35].

PD techniques include (1) ethnographic approaches, (2) workshops, (3) stories and storytelling activities, (4) personas, (5) games and (6) constructions [27,30,36]. Current best practice in human-centred design has adopted many of these approaches and techniques. (1) Ethnographic approaches (field studies) involve observations, interviews, or questionnaires, where the aim is to learn and understand everyday life and practice. (2) Workshops are conducted to get multiple stakeholders together, to communicate and commit shared goals, strategies, and outcomes [27]. It is common to include various stakeholder groups together in the same workshop, and the most established structure is the "Future Workshops" which typically involves three stages. Critiquing the present, envisioning the future, and implementing – moving from the present to the future [27,37,38]. These stages allow the participants to develop new concepts and initiatives for future solutions. (3) Stories and storytelling activities (scenarios, dramas, photographs, storyboards) are used as triggers for conversation, analysis, or feedback, and may be used by the end-users as part of their contribution or by the design team to present their concept of what the designed solution will do, how to be used and outcomes of use [27]. (4) Personas are fictional people, and is a technique to enhance engagement and reality, often on which to build scenarios and data collection [36]. (5) The concept of games has had an important influence on PD, where the purpose is to facilitate groups of diverse participants to cohere together and communicate better [27]. (6) Constructions are commonly used as part of the PD-process, typically creating artefacts and prototypes. They are used to visualize or express ideas, enhance communication

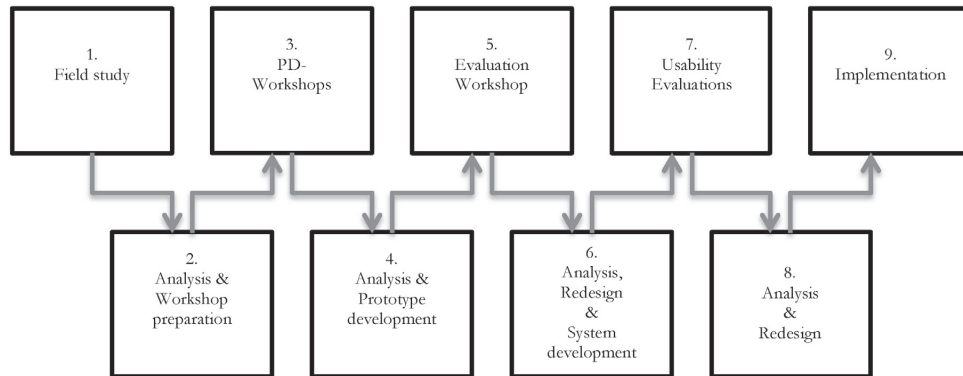


Fig. 2 – Overview of our methodological approach.

and understanding, and improve contextual grounding of the design [27].

### 2.3. The overall research approach – doing research on design methodology

The aim of doing research on systems design methodology is to improve the understanding of the pros and cons of different design techniques and approaches for different kinds of systems and user groups. Muller lists a number of techniques and approaches in PD [27]. Preece et al. describe and compare the design methods most common in user centred design [28]. ISO 9241-210 (2008), described in the previous section, sums up more than 25 years of research on human-centred design methodology [24].

The field of medical informatics has a number of examples of research on systems design methodology. Some authors propose new design methods and/or reflect on previous work. Searl et al. argue for a human-centred design process in the development of healthcare technology [39]. Peute et al. did a survey of the literature on usability studies in medical informatics from year 2002 to 2006, and conclude that there is an increase in the application of usability methods, although at a slow rate [40]. A number of studies have taken an experimental approach, such as Svanæs and Seland that report on the use of role play and low-fi prototyping in experimental PD-workshops with health workers [41]. Das et al. describe an experiment performed to give input to design guidelines for systems with cancer patients as users [25].

Some studies report from actual research and development projects, where the lessons learned concerning design processes are summed up. Teixeira et al. report from the development of a web-based system for managing clinical information in haemophilia care, and found that the user-centred approach is particularly valuable in the requirements engineering phase [42]. LeRouge et al. used personas and user profiles as part of a consumer health technology project, and state that this can be a valuable methodological approach in informing the design and development decisions of consumer health informatics [43]. Weng et al. describe the participatory design of a collaborative clinical trial protocol writing system

[44]. They contend that “quick and dirty” ethnography helped them to efficiently understand relevant work practice, and that participatory design helped them engage users into design and bring out their tacit work knowledge.

The present study is similar to the latter studies in that it reports on an actual research and development project. In this study we have designed and developed a patient centred e-health solution for weight loss patients. Our overall research approach is that of a qualitative and explorative case study. The resulting system requirements are reported and described elsewhere [45]. Best practice in user-centred design prescribes that the perspectives of the end-users need to be included to ensure user acceptance of the final product. In the present case this includes a necessary understanding of the patients' perceptions of obesity and its management. Our objective here is to report on the methodological implications for human-centred design for weight loss patients. This requires a documentation of the overall process of the project, and sufficient detail for each design activity to contextualize the results.

## 3. Methods

In the current study we have followed the phases of the ISO 9241-210 (2008) user-centred design methodology [24] for the design and development of an e-health solution for patients undergoing weight loss treatment. As illustrated in Fig. 2, we started with a field study (1). The data from the field study was analyzed (2) and used as input for participatory design workshops (3). Based on the requirements gathered in the workshops, a first version (prototype) of the solution was developed (4). The prototype was evaluated in a workshop with end-users (5), giving input to the design and development of the second version (6). The second version was evaluated in usability tests (7), the feedback from the tests led to redesign (8), before the final version was ready for implementation (9).

Table 1 shows how the nine phases of our design process map on to the iteration of phases prescribed in ISO 9241-210. As illustrated in Fig. 1, the ISO standard allows the actual design process to make “shortcuts” skipping some of the phases. In our case phase 5 to 8 iterate between the design

**Table 1 – Our methodological approach mapped to ISO 9241-210.**

	I. Understand and specify the context of use	II. Specify the user requirements	III. Produce design solution to meet the user requirements	IV. Evaluate the designs against requirements	V. Design solution meets user requirements
1. Field study	•				
2. Analysis & workshop preparation	•				
3. PD-workshops	•	•			
4. Analysis & prototype development		•	•		
5. Eval. workshop				•	
6. Analysis, redesign & syst. development			•		
7. Usability tests				•	
8. Analysis & redesign			•		
9. Implementation					•

**Table 2 – Summary of field observations.**

Field observation	Observation situations (n)	Duration (h)
Patient consultation with nurse	3	3
Patient consultation with dietician	3	3
Pretreatment education programme (2 days)	1	12
Pre-surgery group meeting (1-day)	1	6
Post surgery group meeting (1-day)	2	12
Total	10	36

phase (III) and the evaluation phase (IV) without reiterating the field studies (I) or doing more requirements gathering (II).

The study was conducted according to the guidelines of the Declaration of Helsinki [46]. Approval was obtained from the regional Ethics Committee (Central Norway, Trondheim), and from the Norwegian Social Science Data Services. Participants provided written consent when enrolling to the study. Inclusion criteria included age above 18 years and basic proficiency in Norwegian language. Specific inclusion criteria were set for the different workshops and usability evaluations and will be further elaborated in the following sections.

### 3.1. Phase 1 and 2: field study and analysis

The field study was conducted at the hospital and consisted of observations and interviews that were done over a time period of one month. As part of the weight reduction treatment programme, the patients are required to attend a number of lessons, meetings and consultations. Observations were done during day shifts and included observing patient consultations, a two-day pre-treatment educational programme, and two one-day group-based educational meetings, making a total of ten different observation situations (Table 2). The observed patient consultations were either with a nurse or a dietician. The observer took unstructured field notes, and semi-structured interviews were carried out with selected healthcare professionals to clarify observations and to get input about the patient trajectory. The field study notes were analyzed and triangulated with the interview material.

### 3.2. Phase 3: participatory design workshops

Next phase consisted of a series of PD-workshops that were set up as future workshops [27,37,38].

#### 3.2.1. Participants

Inclusion criteria for the workshops were the same as for the study as whole, but supplementing requirements were that the patients had to have completed a weight reduction programme at the hospital, and the healthcare professionals needed to have work experience in the field of obesity. Three researchers took part during each workshop, where two had the roles as facilitators, and one as an observer. To elicit the different involved groups' perspectives, needs and requirements, we conducted three separate PD-workshops with:

- (1) Healthcare professionals
- (2) Patients that had undergone lifestyle therapy
- (3) Patients that had undergone bariatric surgery

(1) The healthcare professionals were recruited through convenient sampling. Representatives from each healthcare professional group working with obesity treatment at the hospital were invited to participate, but not everybody could take part, stating shortage of time or other obligations. In total eight healthcare professionals participated, two men and six women, age 26–65 years. They had 6 months to 15 years of work experience in the field of obesity. The professionals represented included nursing (n=6), medicine (n=1) and clinical nutrition (n=1). The nurses were currently holding different positions: One department nurse, one lifestyle coach, one research nurse, one coordinator, and two of them worked with nursing at the ward. All the participants owned a mobile phone that they used daily, had an Internet-connected personal computer at home, and reported daily computer and Internet use.

(2) Six patients that had undergone lifestyle therapy (LT), five women and one man, age 45–60 years, took part in the second workshop. Four of them had completed high school, while two had higher education from university/college. All participants reported that they had a mobile phone, where two

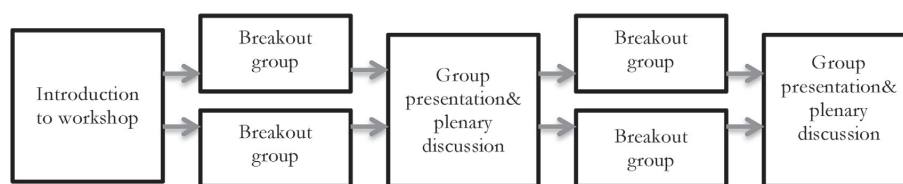


Fig. 3 – Workshop process (workshops 1–3).

used it on a weekly basis and the others daily. Everyone had a computer with Internet access at home. Three participants used the Internet daily, while the rest used it on a weekly basis. None of the participants were part of any online forum or used online social media regarding obesity, dieting or weight loss treatment.

(3) Patients that had undergone bariatric surgery (BS), four women and two men, age 31–60 years, took part in the last workshop. One had completed primary education, three had completed high school, and two had higher education. All of them reported to have a mobile phone and used it daily. All participants had a computer with Internet access at home, where one reported Internet use on a weekly basis, and the rest reported daily use. Two of the participants were part of an online forum or used online social media regarding obesity, dieting or weight loss treatment (Table 3).

### 3.2.2. Procedure and analysis

Each workshop lasted approximately 3h including a break where we served refreshments. Two facilitators moderated each workshop that involved a combination of semi-structured group interviews and design activities (Fig. 3). In parts of the workshops we created two breakout groups ( $n=3-4$ ), each group facilitated by one moderator. During the breakout group activities the participants did brainstorming activities where they used post-it notes, created sketches for ideas, and made illustrations that they used during the later presentations. This was followed by group

presentations, where each group presented their ideas and suggestions, which further formed the basis for the plenary discussions.

The overall structure and activities were similar for all three workshops and we used PD-methods such as creating personas, scenarios and envisioning future solutions. However, the specific tasks for the healthcare professionals were articulated differently and varied slightly from the tasks given to the patients (Table 4). In the breakout group activities with healthcare professionals, each group were to focus on one weight loss treatment: either patients undergoing lifestyle treatment or patients undergoing bariatric surgery. At the end of each workshop, all the participants were asked to evaluate the workshop process and tasks, and provided feedback during the plenary session. The workshop activities were audio and video recorded, and the recordings were transcribed verbatim before analysis, which was done using a grounded theory approach [47].

### 3.3. Phase 4: prototype development

A set of system requirements was formulated as an outcome of the PD-workshops. We ensured that all requirements were based on ideas and needs that emerged during the workshops, and this formed the basis for development of a prototype e-health solution. Furthermore, we searched for local vendors that might have a platform solution that we could use, and were able to get an agreement with a provider nearby.

Table 3 – Demographic data, workshop participants.

Demographics	Healthcare professionals ( $n=8$ )	Lifestyle therapy patients ( $n=6$ )	Bariatric surgery patients ( $n=6$ )
Age (range)	26–65	45–60	31–60
Gender			
Male	2	1	2
Female	6	5	4
Education			
Primary school	0	0	1
High school	0	4	3
University/college	8	2	2
Has a mobile phone	8	6	6
Frequency of use			
Daily	8	4	6
Weekly	0	2	0
PC with Internet access	8	6	6
Frequency of use			
Daily	8	3	5
Weekly	0	3	1

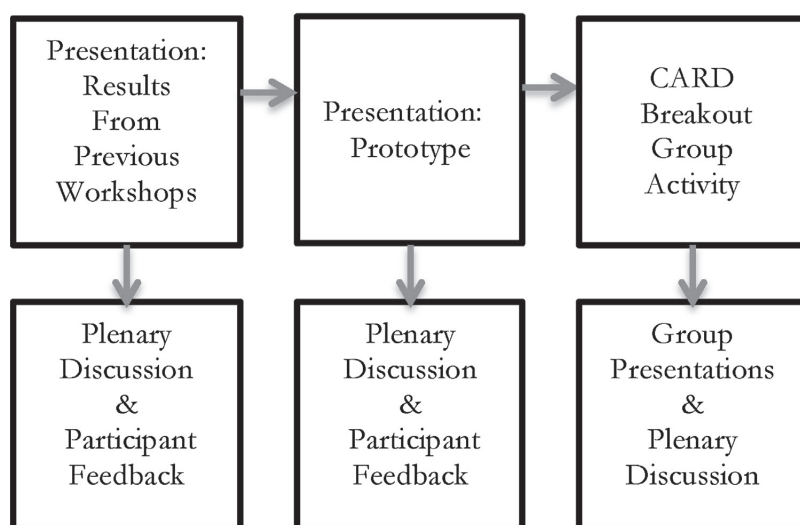


Fig. 4 – Workshop process (evaluation workshop).

### 3.4. Phase 5: evaluation workshop

Next phase involved evaluation of the prototype that was done in a workshop where the various stakeholder groups took part together.

#### 3.4.1. Participants

The participants that had attended the prior workshops were invited to take part, but of various reasons not everyone could attend. In total ten participants joined this workshop: Five healthcare professionals and five patients (BS patients  $n=2$ , and LT patients  $n=3$ ). In addition, three developers (of the prototype) and three researchers took part.

#### 3.4.2. Procedure

We had structured the workshop in two activity parts with a break in between. The first part involved presentations by the researchers and developers, while the second part consisted of PD-activities (Fig. 4). The researchers presented the findings from the previous workshops and the developers presented the prototype solution. Both presentations required feedback from the participants and resulted in plenary discussions. In the second part of the workshop, we grouped the participants in three separate breakout groups to conduct CARD-sorting (Collaborative Analysis of Requirements and Design) [27,48]. We formed one group with healthcare professionals, the second with bariatric surgery patients, and the third with lifestyle therapy patients. According to the CARD-sorting technique, the participants were given a set of cards, where some cards were illustrated with features from the future e-health solution while others were illustrated with perceived future outcomes. The participants were to create clusters and connections where they arranged system features with anticipated future outcomes, and further rank the most important features according to their

perspectives. Following the CARD-activity, the groups presented their reflections and outcomes, resulting in a plenary discussion with feedback and comments from the others. The workshop lasted 3.5 h and all activities were video and audio recorded.

### 3.5. Phase 6: system development

Based on the evaluation workshop outcomes, a redesign was done and the final e-health solution was developed. During this process the developers found that the initial platform (used for the prototype solution) was insufficient for further use in this project, as the vendors restricted additional changes and moderations. Therefore the final e-health solution was developed combining and tailoring a set of open-source web components.

### 3.6. Phase 7: usability tests

A number of usability evaluations were conducted as part of the system development process.

#### 3.6.1. Participants

In total 20 participants from three different user groups took part: (1) Healthy individuals, (2) Patients that had undergone weight reduction treatment, (3) Healthcare professionals.

(1) Eight healthy participants, three women and five men, age 18–55 years took part. Six of the participants were currently studying at the university, while two had higher education and were working full time. Regarding computer literacy, all participants reported to be experienced users, owned a computer with Internet access, and used it daily.

(2) Six patients, four women and two men, age 31–55 years, that had undergone weight loss treatment (bariatric



**Table 4 – Workshop activities.**

Activity/methods	Workshop 1 Healthcare professionals	Workshop 2 Lifestyle therapy patients	Workshop 3 Bariatric surgery patients
Brainstorming, creating and working with personas, scenario building (in breakout groups)	Breakout group with focus on LT-patients: (n = 4) Describe a typical patient that goes through LT/BS Describe a typical day in the patients life (LT/BS) Describe how the patient uses technology and self-management tools in daily life (LT/BS) Describe the patient trajectory (LT/BS)	Breakout group with focus on BS-patients: (n = 4) Describe a typical day for a LT patient before treatment Describe a typical day after treatment Describe what self-management tools you use/used in daily life after treatment	Breakout group: (n = 3) Describe a typical day for a BS patient before treatment Describe a typical day after treatment Describe what self-management tools you use/used in daily life after treatment
	Breakout group presentations	Breakout group presentations Plenary discussion (all participants) Break incl. refreshments	Breakout group: (n = 3) Describe a typical day for a BS patient before treatment Describe a typical day after treatment Describe what self-management tools you use/used in daily life after treatment
Break			
Envisioning the future (in breakout groups)		Technical solution - How can technology support the patients in their daily life? - Suggest technical solutions to support patients in their daily life - Describe outcomes of use (healthcare systems/professionals'/patients' perspectives)	
Breakout group presentations	Breakout group presentations Plenary discussion (all participants)	Breakout group presentations Plenary discussion (all participants)	

surgery/lifestyle therapy or both) took part. One of the patients had completed primary school, three had completed high school, two had completed higher education at the university or college, and all were either working full-or part time. All had a computer with Internet access at home and used it daily. Half of the participants reported to be experienced computer users, while the other half stated some experience. Four patients said that they were experienced Internet users, while two reported to have some experience. Four of the patients had participated in the previous workshops.

(3) The last group consisted of six healthcare professionals, three women and three men, age 31–65 years, and with higher education from college or university. Among these there were two medical doctors, one clinical nutritionist, and three nurses, all currently working with obesity treatment at the hospital. All owned a computer with Internet access, one reported weekly use, while the others reported daily use. Two participants stated some experience with computers and the Internet, while the rest reported to be experienced users. Four of the participants had taken part in the earlier workshops.

### 3.6.2. Procedure

The usability evaluations took place in a usability laboratory, and included testing of the online e-health portal, completing of questionnaires and a semi-structured post-test interview. The test planning was guided by the requirements of the ISO/CIF standard for reporting on usability tests, while the procedure followed the steps outlined by Tognazzini [49,50]. Subjects were tested individually under controlled settings, and a facilitator was present together with the participant during the session. The complete session lasted 45–60 minutes, and audio-and video recordings and a display capture of the computer used during test were made. The usability tests involved that the participants performed typical tasks interacting with the e-health portal solution. Tasks included secure log-on to the system, sending and receiving private messages, information retrieval, writing and posting on the discussion forum, and creating reminders to be sent to the participants' mobile phone. The participants were instructed to "think aloud" during the usability test, a technique developed by Erikson and Simon to examine peoples' problem solving strategies [28]. This required the subjects to verbalize everything they thought and tried to do to externalize the thought processes. If they forgot to "think aloud", they were prompted by the facilitator. The questionnaires included questions about demographics and computer literacy. A post-session semi-structured interview was conducted to elucidate the users' opinions and experiences of using the system, and we used the System Usability Scale (SUS) to evaluate subjective satisfaction [51].

### 3.7. Phase 8 and 9: redesign and implementation

The second version of the e-health solution was redesigned and improved based on the feedback from the usability tests. The final e-health solution was implemented at the obesity clinic at the hospital to be employed in a case study.

## 4. Results

We here report the results from the main phases described in the previous chapter, and reflect on the process for the various phases (Sections 4.3, 4.5, 4.8 and 4.11).

### 4.1. Phase 1: field study

The objectives of the field study were to understand this specific part of the healthcare domain and find out if the treatment process could be improved by the use of new technology. Through the field study we gathered domain knowledge, and we got an overview of the patient trajectory. We became aware of organizational aspects at the hospital and identified relevant stakeholders and got insight to the end-user groups' daily life and needs. Finally the field study informed the planning of the further design process.

#### 4.1.1. Domain knowledge

By conducting the field study at the hospital we gathered domain knowledge. By observing patient consultations we found that the patients' problems were related to difficulties with establishing and maintaining lifestyle changes. A number of patients felt that their daily life was stressful, lacked structure and regularity, leading to poor eating and dietary habits. Many experienced challenges with following the medical recommendations both pre- and post treatment. We identified that many patients had a rather complex medical history, with physical, psychological and psychosocial challenges, resulting in multifaceted needs. Through the interviews we got an overview of the patient trajectory, and were thereby able to identify in what point of the treatment process it might be appropriate to implement the new e-health solution.

When implementing new technology, awareness about organizational aspects is relevant. This initial phase provided us with insight to the healthcare professionals working day, workload and time pressure. The healthcare professionals had full schedules throughout their day, but we observed that the planned daily activities often were interrupted by patient phone calls or other unforeseen events leading to changes and delays. This was commented on by the professionals in the interviews, and elaborated with saying that this led to postponed paperwork and longer working days. They were also frustrated because they experienced that patients did not attend their scheduled appointments without giving notice, leading to a reduced production than predicted with economic consequences for the clinic. This was confirmed during the field study, where a number of patients did not come to their scheduled appointments.

In the field of obesity treatment (in specialist healthcare, Norway) a multidisciplinary team is involved, but the composition of the team depends on the resources and positions available. Identifying the stakeholders in obesity treatment is relevant for the further design process. Through the field study we identified the most central stakeholders to be: Patients, nurses, doctors (endocrinologists, surgeons), physiotherapists, psychologists, nutritionists, and administrative personnel (leader, secretary, coordinator).

### 4.2. Phase 2: preparation of participatory design workshops

Preparing PD-workshops requires thorough domain knowledge in order to create relevant workshop activities and design tasks. By conducting the field study, we had acquired domain knowledge relevant for this purpose. We found that our insights were particularly applicable for preparing the workshop structure, creating relevant tasks, and to know which stakeholders to include in the next stage of the design process. To ascertain different perspectives and needs, we anticipated it to be relevant to include representatives from the healthcare provider group and the patient groups. The traditional professional–patient relationship is characterized by interaction that is “professionally led”, which we had observed during the field study. We anticipated that this power balance could influence the PD-process. To prevent this we decided to conduct separate workshops with healthcare professionals and patients. We further considered it appropriate to conduct separate workshops with the patient groups (LT patients and BS patients) to get hold of the particularities they might have.

### 4.3. Reflections on process: Phase 1 and Phase 2

Through the first phase we identified the relevant stakeholders and got insight to organizational aspects such as work routines, interruptions, and efficiency issues. We obtained information about the medical treatment process and the patient trajectory. Finally we learned to know the patient population. Through the patient stories we got insight to their daily challenges and got detailed information about the multifaceted needs they had. The acquired domain knowledge was essential for planning the next stage in the design process, and provided input for preparing the PD-workshops: Organizing the workshop structure, making design activities and creating specific tasks, and finally which stakeholders to include.

### 4.4. Phase 3: participatory design workshops

Three separate workshops with different stakeholders were carried out as part of the design process. We aimed to get detailed insight to the different groups perspectives and requirements, and supplementary information about the patient population and context of use.

#### 4.4.1. PD-workshop with healthcare professionals

Through the PD-process the healthcare professionals identified the lifestyle therapy group to be slightly different from the bariatric surgery group. They considered that the patient characteristics influenced the patients' preferred choice of treatment, information needs during the process, and regarding patient education. According to the healthcare providers, social anxiety is more prevalent among those preferring bariatric surgery and thereby the choice of treatment and need for e-health technology.

The participants suggested a future e-health solution to promote patient self-care management where the potential of using it in a patient-educational context was emphasized. They highlighted the juridical aspects comprising in providing patient education, and emphasized the importance

of delivering better information. This was explained on the basis of the future complications and challenges that patients may experience after weight loss treatment, particularly for those undergoing bariatric surgery. The healthcare provider group proposed asynchronous online communication between patients and professionals that would let them answer the inquiries when they had the time. They believed that this could be a supplement or even a replacement to the current phone contact and envisioned potential benefits: Improved work situation with fewer interruptions and savings related to more efficient use of time. Finally they considered the possibility of e-health technology to support social interaction among patients, and suggested features for patient-to-patient (peers) communication. They alleged that patients searched for experiential knowledge that they as professionals could not provide. Potential outcomes were discussed, and peer-to-peer communication was presumed to lead to reduced inquiries to the clinic. The healthcare provider group suggested two different technical solutions, a mobile phone application and a secure online e-health portal.

The healthcare professionals described their patient personas in detail. The personas were given a name and personal characteristics, the work- and family situation and leisure time activities were described, and the location of residence defined. Even though the clinicians were successful in completing the task, they expressed that they found the persona-creating task as challenging, as this represented a contrast to how their professional approach normally would be. In this case, they were asked to find some average and representative characteristics for a patient group, while their professional norm required seeing the individual patient with their particular challenges and specific needs. They remarked that their work experience had taught them to see the patient group as heterogeneous. The participants actively used their created personas as part of the scenario building, and envisioned scenarios for current practice and future solutions. This task provided us with supplementary insight to situations where the patients could benefit from using new technology, and the impact this would have on clinical practice and working routines.

Most of the healthcare professionals knew each other in advance, as they were working at the same clinic. By creating breakout groups during the workshop, we experienced that the participants had to engage themselves in the design process. We observed that the participants presented different views and suggestions that led to lively discussions within the groups. A smaller group setting required that all participants had to contribute and participate more actively. This was observed as a contrast to the plenary settings, where we saw that those who were experienced/seniors at the clinic were the ones that contributed the most.

#### 4.4.2. PD-workshops with patients

We identified that the patient groups' requirements depended on weight loss treatment, and tailor-made solutions were required accordingly. This was particularly relevant concerning the patients' information needs. Patients that had undergone bariatric surgery experienced other challenges compared to those that had undergone lifestyle therapy, leading to rather differing needs and requirements throughout

the treatment process. The patient groups emphasized the need for better patient education and required self-help tools. Many patients also sought social interaction among patients, and suggested forum-like features, but where they wanted professionals to moderate the communication and correct misinformation. Further they required increased guidance and feedback from healthcare professionals than in current practice, and suggested more active involvement than the healthcare providers had assumed. Both patient groups advocated an online portal solution as the technical solution, where the rationale was easy access. They discussed a mobile phone application, but since this required a smartphone that a limited patient population had access to at the time of the study, they did not consider this as applicable.

The patient groups were to create patient personas based on their own experiences, something they perceived as challenging and difficult. The task suggested extracting personal experiences and finding common similarities that they could build the persona upon. We observed that instead of extracting personal experiences to a higher level, the participants tended to share their personal stories and in some cases very private narrations. Facilitation was therefore essential for the groups in order to conduct the given tasks. With some guidance, the patient groups were able to create personas, but ended up with several characters rather than one persona representing their user group. Scenario building was an approach that worked well with both patient groups. They were able to extract their needs to a meta-level, identifying situations and use cases, and further identify functionalities and goals. We observed that they used their personal experiences to identify use situations where it could be beneficial with future e-health solutions.

Since the patients did not know each other in advance we had to create a setting where they would feel comfortable, and actively take part and contribute to the design process. We observed that by creating smaller breakout groups within the workshop setting, it was easier to share personal experiences and stories. We noticed that the patients used the setting as an arena for sharing and listening to each other's personal experiences, resulting in that they sometimes needed facilitation to prevent the discussions to get far off track. Having a break in between the design activities was suitable to get a pause from the working process, but was also appropriate so that they could discuss issues of personal interest. During the plenary sessions we observed that some contributed less than within the breakout groups, implying that a bigger setting put some limitations to how much each was comfortable in sharing.

#### 4.5. Reflections on process: Phase 3

Letting healthcare professionals create personas was useful as it provided insights about the patient population as well as awareness about organizational aspects. Letting the patients conduct the same task based on their personal experiences, was a challenge, but provided valuable insights to the patients' personal stories, narrations and daily life. The field study and the PD-workshops had given us an understanding of the patients and we had learned that in addition to physical challenges, many felt ashamed and struggled with issues of

psychological and psychosocial character. We found that scenario building with patients was constructive and useful, as it provided first-hand information about the patients' daily life and challenges, and produced valued suggestions for future solutions. Healthcare providers contributed with second-hand information about the patient group, and first-hand information about the medical treatment process and aspects related to organizational issues and concerns. By creating smaller breakout groups within the workshop setting, we aimed to let the participants more freely take part and discuss perspectives and challenges concerning the current issues. We also had in mind that the participants might find it easier to discuss health related topics in such a setting. We found that working in breakout groups was appropriate as it allowed for creating more intimate and personal settings where the participants could share their experiences and narrations, and actively participate in the design process. We learned that active facilitation is important within a workshop setting, as the participants may perceive the activities as challenging and cumbersome. Particularly when involving patients and where sensitive issues may be discussed, facilitation is crucial to avoid inappropriate self-disclosure, but also to guide the participants within the scope of the workshop.

#### 4.6. Phase 4: prototype development

A system specification was made based on the three PD-workshops. This was further used for developing a system prototype on an already existing platform. All the groups discussed an e-health solution for mobile phones, but the professionals were the only group that actually proposed this as an option. Economic aspects, in addition to the technical requirements of having an advanced mobile phone were perceived as barriers for use by the patients. The fact that few patients had access to such at the time of the study, and thereby would limit the targeted end-user population, made us exclude this as an option for this study. All groups suggested an online e-health portal with multiple features. Internet access is highly available for most people in Norway, and most patients do have access to computers with Internet [52]. We therefore considered it appropriate to develop an online e-health portal for the purpose of this study.

The prototype e-health solution was developed by three computer science students as part of their masters degree projects at the university in Trondheim, Norway. A total of three person-months were used on the actual implementation of the prototype. The prototype portal did not include all suggested features that were proposed, due to lack of support in the e-health platform and limited time and resources. Included features were: An information module, a private communication module between healthcare professionals and patients, a personal self-management tool that included a calendar that could send sms-reminders (to the patients' mobile phone), and a discussion forum to be moderated by professionals. Features not implemented were: Personal diary, patient-to-patient messages, and patient control of the calendar. Overall, the fixed structure of the e-health platform made it very difficult to translate important aspects of the patients' and providers' needs into the solution.

#### 4.7. Phase 5: evaluation workshop

To validate our findings from the PD-workshop and to evaluate if the prototype solution was according to the participants requirements and needs, we conducted an evaluation workshop to get feedback and to assess the product. Not all suggested features were developed, but the workshop clarified that we had understood the participants' initial requirements correctly, and that the developed features matched these. Further, the patients emphasized to implement some of the features that were not developed, e.g. a communication module between patients, a diary feature and a place for personal notes. These features were anticipated to be important for self-management to get overview over food intake, diet, exercise and mental health. Finally, we got specific feedback about the graphical user interface, which the participants expressed needed further improvements and redesign.

The CARD-sorting session provided additional information about what features the multiple groups emphasized as important or less significant. Through this process we could identify the different groups' perspectives about which features they anticipated would have impact on the patients' health, daily life and medical treatment process. The results showed that the various groups had differing prioritization of features and outcomes.

#### 4.8. Reflections on process: Phase 4 and Phase 5

By conducting a workshop with the purpose of evaluating a first version of the prototype solution, we could validate the findings from the previous three workshops and get end-user feedback about needs and requirements. The CARD-sorting session provided information about further prioritizations for design modification and redesign. We could identify which system features to develop and implement in the final solution, which system features were less significant (and not prioritized for further development and implementation), and finally identify the relation between system features and possible future outcomes.

In this final workshop, we had included the different stakeholder groups together, as opposed to the previous ones with homogenous stakeholder groups. We observed that the participants were engaged and discussed actively within the breakout group activities, but during the plenary sessions only some participants contributed, while others tended to be passive. The power balance between patients and providers resulted in limited patient contributions during the plenary as we observed that some of the patients limited their own contributions, and did not embellish their statements to the same degree as we had observed during the workshop with patients only. Through the field study and the workshops we had learned that some of the weight loss patients were vulnerable, requiring considerations to psychological and psychosocial aspects during the workshop setting. In the plenary, we experienced that some patients used negative terms related to their previous lifestyle and about being obese, not considering the presence of other obese in the same room. In this mixed-group workshop, we did not have the same "control" as in the workshops with the homogenous user groups, and

**Table 5 – Outcomes of usability testing with multiple user groups.**

Outcome	Healthy users	Patients	Healthcare professionals
Feedback about the GUI	•	•	•
Feedback regarding domain specific features		•	•
Intention to use		•	•
Expectation of use		•	•
Context of use in home environment		•	
Organizational aspects and context of use in clinical practice			•
Security issues (log on procedures, etc.)		•	•

we thereby could not hinder statements that the participants might experience as upsetting.

#### 4.9. Phase 6: system development

The resulting outcomes of the workshop identified the need for redesign of the graphical user interface, in addition to implementation of some of the not yet developed features. As the prototype solution was developed on an existing platform and the vendors did not allow modification of their solution, the final e-health solution was developed by combining and tailoring a set of open-source web components. A total of approximately 12 person-months went into the implementation of the system, including improvements made after the usability tests. The medical content of the solution was provided by the obesity clinic at the hospital. The additional medical material that was demanded when running the solution was provided by the obesity clinic and our research team in close collaboration, making sure that all medical content was in line with the current obesity treatment process and medical recommendations. The online e-health portal solution included multiple features and was developed according to the guidelines of the Norwegian authorities concerning privacy and security. Since the scope of this study was to inform the design process and further use the e-health solution in a research project for a limited period of time, we did not follow any criteria for certification. If used in a different context, we would have quality controlled the e-health solution additionally, for example by the HON code of conduct [53].

#### 4.10. Phase 7: usability testing

As part of the iterative development process we conducted a number of usability tests to evaluate and improve the final e-health solution. The findings are summarised in Table 5.

We found that conducting usability tests with healthy, average users provided feedback about the GUI. However, this group did not provide feedback regarding domain specific aspects such as information structure and content, as they had limited knowledge about domain specific terms and issues relevant for the real end-users. Furthermore they could not provide information about the importance of such a system, about the context or use, or about the intention to use such an

e-health solution. Based on the results from the first phase of usability tests we could eliminate system bugs and improve the GUI before the real end-user groups were to evaluate the solution. In the next phases of usability evaluations we could focus on domain specific aspects relevant for user acceptance and system use.

Usability testing with patients and healthcare professionals provided feedback on domain specific issues, such as information content, -structure, -search and retrieval, and provided further insight into cognitive aspects related to doing these tasks. They provided feedback about experienced efficiency, satisfaction, and about intention and expectations of use. The post-test interview provided additional information. The professionals provided information about aspects that might influence system use in the context of clinical work, and underlined potential barriers for use: cumbersome log-on procedures and time restricted access. The patients provided information about the context of use in their home environment: About how and when they preferably would use the e-health solution, and if system use would fit into their daily routines and lifestyle. Some patients questioned the need for the log-on procedures, but did not predict these as barriers for use.

Including patients where some were severely obese required that we had to consider ergonomic aspects, making sure that we had adjustable facilities (chair/table/computer screen, etc.).

#### 4.11. Reflections on process: Phase 6 and Phase 7

We found that healthy users provided useful feedback on the GUI, resulting in improvements and redesign of the solution. They gave limited feedback on domain specific aspects and the usability tests were therefore not sufficient. However, if the targeted end-user population is difficult to include in usability testing, a first iteration test with healthy users can be productive. The real end-users, the patients and healthcare professionals, provided feedback on domain specific features, but in addition the patients gave supplementing information about the context of use in their home environment, while the healthcare professionals provided information about the context of use in clinical practice.

## 5. Discussion

In this paper we have reported on the design process of a patient centred e-health solution for weight loss patients. We have involved patients and healthcare professionals throughout the process, letting them hold the roles as informants, design partners, testers and users.

### 5.1. Implications for the design process

When a patient centred e-health solution is intended for use as part of the medical treatment process offered by specialist healthcare, there are several aspects that are important to consider during the system design and development process. The final e-health solution included features for patient education, self-management tools, communication features among patients and between patients and professionals. In

this case the patient is the primary end-user of the solution, but the healthcare professionals hold an important role as information disseminators, recipients of patient requests, and as moderators of the forum-based activities. Considering that both groups are important stakeholders of such an e-health solution, we found it crucial to include both perspectives in the process in order to get hold of the tacit knowledge of the end-users, their needs, perspectives and requirements. Our findings are in line of those of Ballegaard et al. who contend that it is important to acknowledge the knowledge and everyday life of the end-users, in the same way as the healthcare professionals' knowledge is crucial for proper treatment of a disease [31].

#### 5.1.1. Conducting separate workshops with various stakeholders

In this study we have involved patients undergoing weight loss treatment and healthcare professionals working in the field of obesity treatment. Initially the involved patients had the same diagnosis, but they underwent different treatments to achieve weight reduction. Within PD-projects it is common to include multiple stakeholders together in the same workshop to communicate and commit shared goals, strategies, and outcomes [27]. In this study we chose to conduct separate PD-workshops to assess needs and requirements with homogenous user groups, mainly to get hold of the particularities and tacit knowledge of the included group. Our findings showed that the two different weight reduction treatments resulted in that the patients had slightly differing requirements towards the e-health tool. As a consequence, the e-health solution had to be tailor made according to the particular treatment, entailing that the content and functionality needed to be customized accordingly, and thereby the need to develop separate portal solutions. If we had mixed the two patient groups together in the same workshop, we might not have been able to identify these differing needs, as some of them were subtle, yet important. By separating the healthcare workers from the patients, we got detailed insight to the healthcare practices, which is relevant for the success of a future e-health solution.

Obesity patients may be considered a vulnerable user group, as their condition have been associated with stigma and shame [54,55]. Through the initial phases of our study we had learned that some patients were sensitive and susceptible due to their personal experiences of being obese. During the last workshop we included participants from all the three user groups together. As weight loss interventions may result in different outcomes, where some achieve weight reduction while others do not, this entails a visibility about who has "succeeded" and who has not. The workshop setting made this visibly apparent, as some patients were normal weight while others severely obese. In the plenary sessions, some patients used negative terms related to their previous lifestyle and about being obese, without considerations to the presence of those still being obese. Such negative statements may be perceived as offending, and underlines the importance of separating different user groups in some workshop settings with vulnerable patient groups. This observation shows, however, that mixing the user groups together does not inhibit the discussion. Considering that some people may

experience such statements as upsetting or rude are aspects that designers/researchers need to take into account when planning the workshop structure, and if or when mixing different user groups together.

#### 5.1.2. Breakout groups

All patients have their personal story, experiences, and narrations. Sharing these with strangers can be challenging and some might have reservations about contributing to a setting such as the PD-workshop. Creating an environment where the participants feel that they can share their experiences and narrations is important to get hold of these stories, and we found it valuable to create smaller breakout groups within the workshop setting. We found this particularly relevant for the patients that did not know each other in advance, but the approach was also appropriate when working with the healthcare professionals, as a smaller environment required the participants to actively take part in the discussions and design activities. We observed that some patients talked freely and shared their personal experiences and stories, while others tended to be more reserved. This required the facilitator to balance the narrations and design activities, in order to create a setting where everybody could be engaged and actively take part. We learned that by creating smaller breakout groups, we could create a productive environment for discussing sensitive and personal issues, and where the facilitator could guide the process in a considerable and meaningful way. There is a fine tuned balance between getting the patients engaged and taking part, and at the same time limit too much self-disclosure. This is where the facilitator has an important role. These findings are in line with Seland's conclusion, who contend that the facilitator has an impact on group dynamics within role-play workshops [56]. We experienced that a workshop structure where the breakout group activities lead to a plenary group presentation, was something that was perceived as meaningful by the participants. This required them to work towards a goal, where they got feedback on their own work, and where the plenary session provided further insight to what the other groups had worked with, reflected on, and found to be relevant, giving different solutions to the same tasks.

#### 5.1.3. Personas and scenarios

Creating personas and scenarios are established methods within human-centred design [57,58]. We chose to include these techniques in order to engage the participants and let them more easily focus on the primary end-users of the future e-health solution. Traditionally the design team creates personas and scenarios that are used during human-centred processes, often based on real users that they have observed, interviewed or surveyed for each user group [36,43]. In the current project we let the participants create the personas and scenarios themselves, based on their own experiences as patients or their professional work experiences. The purpose was to get insight to the characteristics of the patient groups, and also so that the participants would get a shared understanding of whom the end-user of the future e-health solution would be. Surprisingly, it was easier for the healthcare professionals to create patient personas than for the patients to conduct the same task. The patients ended up with several characters rather than one persona representing

their user group, an outcome that we had not anticipated. Creating personas based on subjective experiences related to personal life and health condition might be more challenging. It might be easier describing others than describing oneself.

Scenarios can be created at multiple levels, from many perspectives, and for many purposes [58]. These are stories about people and their activities, and are less effective when not built on personas [36,58]. We purposely let the participants create personas before the scenarios, and observed that most of the groups used their personas as part of the scenario building tasks. However, the healthcare professionals worked more actively with their personas as part of the scenario building, compared to what we observed among the patients. This observation is not surprising, considering the patients' difficulties with creating personas. Moreover, since the e-health solution primarily would be used by the patients it was perhaps more applicable for the healthcare providers to use their created persona in order to envision scenarios. By letting the different stakeholders create the scenarios, we could triangulate the findings and experienced that we got a more comprehensive picture of how the future e-health solution might be used, in what context and for what purpose.

Allowing participants create personas and scenarios themselves may provide designers and researchers with new insight and other perspectives that are relevant for the system specifications. The healthcare professionals have several years of acquired knowledge after working with the specific patient groups. Patient group characteristics are difficult to get hold of, and by letting healthcare professionals work with personas and scenarios the design team got insight to the medical treatment process and patient characteristics that are difficult to capture in other ways. Letting the patients conduct the same tasks, but in a separate workshop setting, provided further understanding and first hand information from the primary end-users, including awareness about the patients daily life, particularities and challenges. We found that letting them create personas provided us with a very detailed and specific understanding of the end-user profiles. Similar methods have been used within other research projects [43]. By conducting separate workshops with the various user groups, the research team captured information from different perspectives that complemented each other, and thereby got a more comprehensive picture of the patients, the treatment process and needs related to weight loss treatment, and how an e-health solution could facilitate the process.

#### 5.1.4. Usability testing with multiple user groups

The purpose of conducting usability tests is to evaluate the product with specified users, and to find out how usable the product is by evaluating if they are able to achieve specified goals that are set in a specified context of use [59]. In our study we conducted usability evaluations with different user groups including healthy individuals, patients and healthcare professionals. Previous research has shown that healthcare professionals and patients can be difficult to get to participate in such projects [60]. The purpose of the initial usability evaluations was therefore to eliminate major difficulties and challenges in the graphical user interface (GUI), before the final end-users were exposed to the system. We

found that conducting usability tests with healthy individuals revealed technical bugs and major difficulties in the GUI, and we could redesign, eliminate and improve the GUI before the next phase of usability evaluations. Even though the first iteration of usability tests provided helpful information for improvements, the healthy users provided limited feedback regarding domain specific features and functionalities. E.g. it is customary to use domain specific concepts and terms within an IT-solution for patient use, but when the healthy users were to test information retrieval, they did not have the prerequisite to understand where to start searching and therefore provided little information in this aspect. If the end-users are a population group that is challenging to recruit and include in usability evaluations, a first iteration test to eliminate major difficulties might be efficient before the real end-users are exposed to the system. However, as they provide limited feedback, it is insufficient to conduct such with only this group of participants. Evaluation of patient centred e-health solutions requires domain knowledge in order to fully evaluate the solutions.

Conducting usability tests with patients provided additional information about the context of use in the home environment, which is crucial for patient centred e-health solutions. Learning about different use situations is valuable in order to adjust the solution in a best as possible way to fit into their daily routines and established habits. Information concerning context of use was also provided by the healthcare professionals, but then from the perspective of their daily clinical practice and current work routines. Acknowledging the end-users' perspectives is crucial for the system development process, as these may be critical for user acceptance, system use and adaptation.

#### 5.2. Recommendations

Based on the project we suggest an initial list of recommendations for human-centred design of e-health solutions for patients. These are particularly relevant for projects involving sensitive patient groups.

*Identify the stakeholders and context of use* of the future e-health solution. All stakeholders have different interests, and identifying their roles early in the design process creates an understanding of the future use and realization.

*Include the relevant stakeholders* throughout the design process, letting them hold the roles as informants, design partners, testers and users. This will reveal different aspects throughout the process that will provide invaluable contributions and increase user acceptance.

*Conduct separate workshops and design activities* with homogenous user groups to ensure that their particularities, their needs and tacit knowledge come to surface. Creating a setting where the participants can feel comfortable and feel trust is essential in order to get the participants take part and contribute. This is particularly relevant when discussing sensitive, health related and personal issues.

*Particular considerations and facilitation is required* when including vulnerable user groups in human-centred design activities.

*Conduct usability evaluations* as part of the system development process. If the end-users are difficult to include one may

conduct initial usability tests with healthy users in order to do improvements before the real end-users are exposed to the system in usability testing.

### 5.3. Limitations

Limitations of this study include the methodology used and researcher bias. As the field study was conducted at the hospital and not in the patients' homes, it did not provide detailed information about the patients' lives and context of use at home. The patient consultations and educational lessons that were observed provided a fragmented picture of the patients' daily life, depending on how much they shared during these sessions. However, patient characteristics and insight to the patients' daily life was something that was themed in our PD-workshops through the design tasks of creating personas and scenarios. This provided additional information and insight to the patients' daily life and preferences, and can to a limited extent compensate for our lacking field study in the patients' homes. A field study in the patients' homes would have required far more resources, time and personnel than the scope of this research project. Also ethical considerations of entering the patients' homes can be discussed, where a cost-benefit must be contemplated. However, a field study in the patients' homes such as described by Oudshoorn [61] and Grönvall and Kyng [62] might have informed the design process with richer information than we were able to get hold of in this study. Whether it would give a surplus value is difficult to say. A limitation of the study might be that the researchers served both as participators (facilitators/moderators) and evaluators of the processes, which might have influenced the process design. Ideally, dual roles should have been avoided, and someone standing outside the project might have had a different focus and captured other observations. Involving special user groups in research projects such as the current study may be challenging, as there is a limited population to recruit participants from. Since the participants were volunteers, they cannot be considered fully representative for either the professionals or the patients. The number of female participants was higher than the number of male participants that took part in this study, something that reflects the gender distribution for the population undergoing weight loss treatment. We might have got a biased population where the more affluent patients or the more computer literate might have taken part. It is an open question to what extent our findings can be generalized to other patient or healthcare professional groups. However, the methodological implications may be relevant to other e-health development projects.

## 6. Conclusion

In this study we propose some methodological implications when designing and developing patient centred e-health solutions for weight loss patients. By using an iterative approach and by deploying user-centred and PD-techniques, we could elicit various stakeholders' needs, requirements, and perspectives. Our findings imply that it is important to include multiple stakeholders throughout the design process, and that it is appropriate to involve the groups separately in some activities

### Summary points

What was known on the topic:

- Human-centred approaches are established methods within systems design.
- Such approaches are currently not established within e-health solution development, or within technology development in healthcare.
- Little is known about involving special user groups such as weight loss patients during e-health solution development.

What this study added to our knowledge:

- Human-centred approaches are useful for gaining insight to the healthcare domain, knowledge about various stakeholders perspectives and requirements, and finally about future possibilities which are relevant for patient centred e-health design.
- Separating different user groups in design activities and workshops is efficient to get insight to the unique needs, perspectives and requirements of the targeted user groups.
- Designers must take considerations to patient experiences and vulnerabilities when involving them in human-centred design activities.

in order to get hold of the subtle, but critical tacit knowledge of the specific user groups. Furthermore, we conclude that there are particular considerations when designing for and with patients due to health related and sensitivity issues.

### Authors' contribution

Anita Das contributed during the design and planning of the study. Performed data collection, processed, analyzed and interpreted the material. Wrote and revised the manuscript.

Dag Svanæs contributed during the design and planning of the study. Participated during parts of the data collection process, wrote and revised parts of the manuscript.

### Conflict of interest

None declared.

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# Paper III



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Original Paper

# What Influences Patient Participation in an Online Forum for Weight Loss Surgery? A Qualitative Case Study

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## Abstract

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**Background:** Many patients who undergo weight loss (bariatric) surgery seek information and social support in online discussion forums, but the vast amount of available information raises concerns about the impact of such information. A secure online discussion forum was developed and offered to bariatric surgery patients. The forum was moderated and allowed contact with peers and health care professionals.

**Objective:** The purposes of this study were to explore how individuals undergoing bariatric surgery used the moderated discussion forum and to better understand what influenced their participation in the forum.

**Methods:** The study was designed as an explorative case study. We conducted participant observation of the discussion forum over a time period of approximately six months. For further insight, we carried out in-depth semistructured interviews with seven patients who had access to the forum. We analyzed the material inductively, using content and thematic analysis.

**Results:** The patients used the forum as an arena in which to interact with peers and providers, as well as to provide and achieve informational and social support. The analysis suggests that there are three major themes that influenced participation in the online discussion forum: (1) the participant's motivation to seek information, advice, and guidance, (2) the need for social support and networking among peers, and (3) concerns regarding self-disclosure.

**Conclusions:** The findings of this study imply that a moderated discussion forum for bariatric surgery patients has potential for use in a therapeutic context. The discussion forum fulfilled the informational and support needs of the bariatric surgery patients and was particularly useful for those who excluded themselves from the traditional program and experienced barriers to expressing their own needs. Even though our findings imply that the patients benefitted from using the forum regardless of their active or passive participation, restraining factors, such as considerations regarding self-disclosure, must be further investigated to prevent certain users from being precluded from participation.

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**KEYWORDS**

obesity; eHealth; bariatric surgery; online forum; communication; social support

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## Introduction

### Bariatric Surgery Patients

The number of people suffering from obesity has risen globally in the last decade, and comorbidities such as metabolic syndromes, respiratory problems, coronary heart disease, cancer,

and psychosocial challenges are all closely associated with obesity [1-3]. Weight reduction has beneficial health effects on obesity-related comorbidities and mortality, and the demand for weight loss interventions has therefore risen [4,5]. Weight loss can be achieved through lifestyle interventions, pharmacotherapy, and/or surgery, but a number of people do not achieve the desired weight reduction [6,7]. Bariatric surgery

has been shown to be the most effective intervention and to produce significant initial weight reduction in the great majority of patients, but it is mainly reserved for the severely obese who fail to lose weight through conventional methods [8]. The purpose of the surgery is to restrict food intake, but it also contributes to reduced absorption, which leads to poor digestion and the reduced uptake of several nutrients. Thus, patients must take lifelong vitamin supplements [9,10]. Also, the surgery requires patients to undergo substantial lifestyle changes, including adjustments to eating behavior and physical activity. However, noncompliance with the postsurgery recommendations is pervasive, and a number of patients regain weight and experience nutritional deficiencies after some time has elapsed [11-17]. Providing support for bariatric surgery patients is an essential part of the treatment program because weight regain, nutritional problems, and metabolic problems can be prevented or treated [16,18].

### Online Support Forums

The Internet has become an important health care medium, giving people the opportunity to search for information, guidance, and social support. Online health resources are particularly relevant for patients who may encounter barriers to obtaining information on self-management and coping strategies [19,20]. In general, self-management activities are associated with successful long-term weight maintenance [14,21-25], and studies imply that social support may encourage compliance with postsurgery recommendations [26-28]. Studies on other patient groups show that online social support may include benefits such as enhanced health literacy, improved quality of life, and patient empowerment [29-32]. Some patients achieve considerable social support in their real-life environments, but a number of patients also participate in health-related forums on the Internet. Being aware of the lack of social support that some patients experience is important in providing complete health care service for these patients. Using health-related online forums has been shown to have an overall positive effect on the degree to which people are able to cope with the situations they are facing, both socially and as regards their conditions [20]. Hwang et al suggest that by addressing diet, physical activity, and motivation in a comprehensive approach, one can meet the needs of obese patients after surgery [33]. Using online forums to address these issues has the potential to support this patient group.

Most health-related online forums are dominated by peer-to-peer communication, without professional supervision or involvement [20]. In these forums, the quality and credibility of the available health information is mixed, which raises concerns about their impact and value [34]. Eysenbach et al reviewed publications on the effect of online peer support groups, but could not find any isolated outcomes of the peer support groups controlling for other interventions [35]. Research shows that patients want professionals to take an active role in such forums [36,37], and some studies indicate that facilitated or moderated communities are more beneficial [19,38]. Lindsay et al found that having a moderator in an online support group influences compliance in terms of maintaining healthy behaviors and reducing health care visits [19]. Klemm identified that the participants in moderated online support groups for breast cancer patients read and posted

significantly more than in peer-led groups [39]. Ryan performed a study on trust and participation in two online self-help communities, one moderated and one unmoderated, and his primary finding was that the moderation process prevented any communication from disruptive individuals [38]. The unmoderated community challenged disruptive and suspicious individuals, resulting in hostile discussions, while the moderated community encouraged social communication, experienced more participation, and facilitated the accumulation of a history-based trust [38].

We here report from a case study exploring how bariatric surgery patients used a moderated discussion forum in the context of bariatric surgery treatment. It is further intended to address the factors that influence their participation. By identifying these aspects, we aim to gain an improved knowledge of how such a solution can be used as part of a bariatric surgery program.

## Methods

### Study Setting

The online discussion forum under study was one of many features of a secure eHealth portal. The eHealth portal was developed for patients undergoing bariatric surgery and included health-related information, self-management tools, and communication features [37,40]. The portal was developed through a human-centered design process [41], and according to the security and privacy concerns that are required for such solutions in Norway [37,40]. To gain access to the portal, the user was required to be registered in the system and obtain a username and password. For authentication purposes, the user would receive a one-time pin code via text message that he or she would then enter during the log-on process.

The communication features of the portal included an online discussion forum and personal one-to-one communication (patient-to-patient and health care professional-to-patient or vice-versa). Posting on the forum required that the users appeared with their real names, which was necessary in order for it to be used in a medical context. One person from the research team had the role of moderator of the forum and could monitor the discussions and take action if inappropriate messages were posted, which was one of the requirements that was identified during the human-centered design process. The moderator was educated in nursing and could comment on the postings that were within her field of competence. She also had the responsibility of posting weekly topics that were relevant to the patient group. These topics were either initiated by the clinic or created after requests from the patients. There were five health care professionals (one psychiatric nurse, one head nurse, two nurses, and one dietician) at the clinic that had access to the eHealth portal and had the responsibility of facilitating the patients through the portal and answering their requests. Further, these five professionals could make contact with other professionals for additional counseling if necessary.

### Participant Inclusion

This study was designed as an explorative case study. The selection criteria for patient inclusion were as follows—18 years

or older, basic proficiency in the Norwegian language, and enrollment in a bariatric weight loss program at the hospital. Participants provided written consent when enrolling in the study. The study followed the guidelines of the Declaration of Helsinki and was approved by the regional Ethics Committee (Trondheim, Central Norway) and by the Norwegian Social Science Data Services. Participants were recruited at the bariatric surgery clinic, where the first author made contact with potential

participants, provided information about the study, and invited them to participate. The inclusion period lasted for one month, from the middle of May to the middle of June of 2011. Initially, 65 patients were asked to participate. There were 60 patients that agreed and obtained access from the time of recruitment until the middle of December of 2011. Demographic data were collected through questionnaires developed for this study (Tables 1 and 2).

**Table 1.** Demographic data of the patients who had access to the discussion forum through the eHealth portal.

Characteristic	Total n available	n (%) or mean (SD)
Age, mean (SD)	60	40 (SD 9.3)
Female, n (%)	60	45 (75)
<b>Highest education completed, n (%)</b>	57	
Primary school		4 (7)
High school		30 (53)
University/College		23 (40)
<b>Employment status, n (%)</b>	60	
Full/part time work		40 (66)
Student		3 (5)
On sick leave		4 (7)
Unable to work/disabled		9 (15)
Unemployed		3 (5)
Other		1 (2)
Have undergone surgery, n (%)	60	56 (94)

**Table 2.** Demographic data, interview participants.

Informant	Age	Gender	Highest education completed	Time of surgery
Anne	30-35	Female	University/College	Spring 2011
Kari	50-55	Female	University/College	Winter 2010/2011
Frank	45-49	Male	High school	Spring 2011
Linn	25-29	Female	High school	Waiting to undergo
Monica	30-35	Female	Primary school	Summer 2010
Nina	40-45	Female	High school	Spring 2011
Kristin	30-35	Female	High school	Autumn 2010

## Discussion Forum

Via the eHealth portal, the patients had access to the online discussion forum. We conducted participant observation of the forum during the access period, and when the period ended, we retrieved all postings to the online forum and analyzed the posts inductively using qualitative content analysis [42]. The analysis was performed in a stepwise process in which both authors reviewed and coded the transcripts individually before the findings were compared and refined in a consensus decision-making process. We used English terms and concepts during the analysis and used HyperResearch software to facilitate the process. The extracts from the discussion forum that are reported in this paper were translated from Norwegian

into English by the first author before the second author reviewed the translation.

## Interviews

To obtain a better understanding of the users' activities in the discussion forum, we conducted interviews with users who had access to the portal. Informants were recruited through the discussion forum, where the first author posted an invitation to take part in interviews. A stratified purposeful sampling was made in terms of the variables age, gender, and time of surgery in order to ensure variation among the participants. There were 8 patients that agreed to interviews, but one failed to show up. We carried out semistructured, in-depth interviews with seven informants at the university research center between September and December of 2011. The interviews were conducted in



Norwegian and lasted between 44-108 minutes, having a typical duration of 60 minutes. We used open-ended questions, for example, “How is your daily life (if operated on, after surgery)?” “What are your experiences with using the discussion forum?” “How do you experience the fact that your real name appears when you post to the forum?” “What are your feelings about the lack of anonymity?” The semistructured form of the interviews allowed the researcher to include questions related to emerging themes during the interview. All interviews were sound recorded and transcribed verbatim before analysis. When the last two interviews were analyzed, we did not identify new emerging themes and decided that we had reached saturation. HyperResearch software was used to facilitate the process of analysis, which was done inductively by using thematic analysis [43]. Both authors reviewed the interviews and analyzed the data. In the first stage of the thematic analysis, both authors made themselves familiar with the data and read through all the transcripts before they created initial codes of the data individually. In the next stage of the process, the codes were collated, and concepts were generated. These were then compared, contrasted, and discussed in light of the relevant literature and theory, and the final themes were achieved via consensus. This was done to ensure that our findings were coherent and increase the validity of the findings. The interview transcripts were in Norwegian, but the process of analysis was performed in English, using English codes and concepts. The quotes in this paper were translated from Norwegian into English by the first author before the second author reviewed the translation. The names reported in this paper are pseudonyms and not the real names of the participants.

## Results

### The Three Themes

Through the analysis, we identified three major themes that influenced participation in the online discussion forum: (1) the participant’s motivation to seek information, advice, and guidance; (2) the need for social support and networking among peers; and (3) concerns regarding self-disclosure.

### Informational Support, Guidance, and Advice

By observing the discussion forum, we identified the fact that the patients used the forum as an arena in which to provide and obtain informational support. Patients that undergo bariatric surgery must perform a number of self-management activities in order to achieve and maintain weight loss. Also, they must adjust their dietary habits to avoid malnutrition and other negative repercussions of the surgery. The informants who had undergone surgery mentioned that these considerations made them feel insecure. Therefore, they began to search for information and guidance regarding how to manage their “new lives.” Frank had undergone surgery six months before the interview and found himself continually searching for information.

*You are afraid about what you can eat. It says that you should be aware of rice and such, but you haven’t got any information about whether you can eat it now, after so long a time. You don’t know anything about that. It is the first phase that is*

*[described]...and then you have to try things yourself.*  
[Frank]

Insecurity related to coping with their new lives was a recurring topic, and the possibility of contacting health care professionals through the forum was highly appreciated by all the informants. Kristin remarked that she found it “brilliant” to have this opportunity. Anne described the professional guidance one could obtain as “the advantage of this forum as compared to the other ones.” Forum observations revealed that some patients approached the health care professionals directly with specific questions, for example, “How often are we supposed to take blood tests at our primary care doctor to determine whether we are taking the correct dose of vitamins?” Others simply reported their general experiences, for example, “When the weather is hot, I experience dumping (repercussion of the operation, experienced as uneasiness) more quickly, and it is caused by foods and drinks that I normally tolerate,” to which the professionals could then respond. The moderation process involved health care workers understanding patient challenges and taking actions accordingly, such as assigning the patient to a regular consultation for further investigation if necessary. We observed that in some cases the patients required informational and instrumental support, while in other instances the needs were of a more emotional or social character. Every week the moderator published a relevant topic on the discussion forum, and the participants would receive a reminder about it on email. The topics related to food, diet, nutrition, exercise, and practical information. We observed that these postings triggered further comments and questions from the patients, and those interviewed commented that these weekly topics motivated them to continue using the forum—“I like that I get that email about the weekly topic because then, I get a reminder to go in” (Kristin).

Some informants reported that they experienced difficulties in making direct contact with the professionals due to personal barriers. When they began using the forum they discovered the benefit of connecting with professionals via the forum, rather than waiting for an appointment or making contact via phone, as Monica expressed.

*I think it is very positive that you can ask questions that are conveyed to a dietician or a doctor because I must admit that picking up the phone and asking someone is very challenging. That barrier—I think it is difficult. What if it’s only me? How ridiculous! You get that feeling. Then, it is easier to write online.*  
[Monica]

This was supported by the other informants, and the convenience of the asynchronous aspects of such communications were also seen to be beneficial—“It’s easier to go in here, ask questions, and get answers, rather than calling around and stuff” (Anne). Kristin underlined the advantage of connecting with both peers and professionals through the forum.

*The fact that you have others who have gone through it themselves to talk to and that you can ask health care workers about things you wonder about makes participating in the forum easier than persuading oneself to make a phone call...so this is good...one has complete health care service.* [Kristin]

Thus, the possibility of making contact with both professionals and peers through the same forum was an advantage that they had not experienced before.

### Social Support and Networking Among Peers

Some patients experienced the first period after surgery as particularly difficult because it was characterized by uncertainty and a lack of information.

*It is undoubtedly the first period, the first three weeks [after surgery], when you have the most questions. Can I eat this? What can I do now? Because clearly, it is mentally tough too.* [Kari]

The emotional and psychological factors related to surgery were recurring topics among the patients, and the need for social and emotional support was clear. The online forum became an arena in which they could introduce and discuss sensitive matters that they would not have discussed in another setting. As Anne said, "I think it is easier to talk about them (sensitive issues) in a place like this than face-to-face." Kristin remarked that one could have different attributes online than in real life, enabling the discussion of problems that one otherwise would have kept to oneself.

*You can be much tougher on the Net, write things that you might not want to say to people because they are difficult to talk about. This becomes easier when you have a screen you can hide behind.* [Kristin]

Many of them experienced challenges in their daily lives related to the weight loss treatment, many of which were of a motivational or psychosocial character. In some cases, the value of peer support and understanding was extremely important in order to maintain inner motivation, as Linn revealed.

*So you go into a downturn just by talking to a person that doesn't know what you are talking about. Then, it is more important to talk to a person who has been there, who knows what you have been through, who can encourage you to continue.* [Linn]

Sharing personal stories and narratives was an important part of the forum, and the topics covered related to the challenges of losing weight, motivational difficulties, and the everyday experiences of the patients. When asked about the motivation behind this, they reported that the aim was to promote acknowledgement, emotional support, and approval. Anne explained this as follows—"It is actually the support and the approval regarding what you are doing, feedback regarding whether it is right, and feedback regarding insecurities." A few patients created "threads" in the discussion forum that they named "diaries," where they wrote their personal diary notes with details about their daily life experiences and challenges. The following excerpt is from the initial post written by one of the diary writers.

*I think it is more enjoyable to write a "diary" that everyone can read and comment on. I like to get feedback on how I do things, what I eat, and thoughts that I have about the surgery and about life after the operation, so here comes a little of everything...Hope you will read and comment.* [Diary writer]

The excerpt shows that the diary writer was aware and honest about her own intentions to share her personal experiences from the beginning. We observed that the diary writers received feedback and comments on their writings from other patients, as well as from the health care professionals. The replies were often of a supportive and motivational nature and were regularly offered when the narrator expressed the need for emotional and social support. Even though the diary writers wrote to achieve something in return, their postings also had value for the other readers.

*I think they are really brave. I like to read in other peoples' diaries [laughs]. I can recognize myself [in their writings] and see how other people cope.* [Kristin]

Some preferred not to write anything on the forum themselves, they accessed the online forum solely to read others' stories and contributions, and quite a few reported that they learned from reading other patients' tips and advice. Kristin felt that she had difficulties in expressing herself in writing, but she said that she found great value in recognizing herself in other patients' stories.

*I am not any good at writing myself, so I haven't. It holds me back. I am not any good at formulating myself. When I read others' postings, yeah, that is actually how I feel myself. To put things into words is not something I am good at.* [Kristin]

By reading other peoples' articulations, we observed that some patients found that their experiences were similar, providing a kind of relief and support because these experiences were seen as being within the "scope of normality." Some patients accessed the online forum to achieve contact with other peers. In some cases, this was articulated directly as presentation rounds, while others were more indirect in their appearances. The possibility of peer communication was more greatly appreciated in some cases than others. Monica, for example, described the fact that her daily life limited her ability to meet others face-to-face.

*I think it is alright. I don't have the physical ability to go out several times a week to meet people. The computer has become my second home [laughs]. Yeah, so I have much contact with others, and my social life is through the computer. Therefore, I have this idea about getting to know people in the same situation.* [Monica]

The need to come in contact with other patients became evident through the forum observations, and the patients experienced benefits from having access to it, regardless of whether they were active contributors or passive participants.

### Concerns Regarding Self-Disclosure

Observations indicated that some patients were active contributors to the forum, others posted little, and certain patients did not post at all, but followed the discussions. They could therefore be described as lurkers. Linn, who at the time of the interviews was waiting for her operation, expressed that she would very much like to post questions on the forum.

*I was really looking forwards to ask about the experiences of the others who are operated. To get some of their experiences, "harvest" of their knowledge, right? That would have been extremely valuable. But then, I think it is really scary to ask the questions, you know?* [Linn]

She explained that she perceived her literacy abilities as what precluded her from writing on the forum.

*I have reading and writing difficulties as well, so when I start writing, it comes out weird. Then, I become even more reserved regarding writing.* [Linn]

The fear of disclosing her own writing disabilities turned her into a lurker. Observations revealed that a minority of those who had access to the forum were active contributors, and some informants revealed that they often followed the discussion without disclosing their own presence. Some said that they considered their own experiences to be insignificant and therefore did not write anything themselves. However, they reported appreciating reading other peoples' stories despite the fact that these were without particular highlights or events. Reading these narrations was mentioned as one of the main reasons they accessed the forum. The process of moving from passive participant to active contributor was suggested to be a result of experience. Anne described herself as a "forum person" because she was an experienced and active participant, but she recalled that she had only become this way through a slow transformation.

*I was like that in the beginning. I read a lot before I took the step and started writing myself.* [Anne]

The fear of disclosing more than one might be comfortable with can be a barrier to actively contributing to such a forum. Hence, Anne's strategy was to gain confidence by reading forum posts in order to feel eligible to post.

Unlike many online forums, the discussion forum under study did not allow the participants to use nicknames, and the users appeared with their real names when posting. Most said that they did not mind posting to the forum despite the absence of anonymity, but Kristin expressed her view that she would prefer to be anonymous because this would make it easier to introduce sensitive issues and ask difficult questions. Using nicknames provides some degree of anonymity, but there are always certain degrees of self-disclosure related to posting online, as Anne expressed.

*It does not bother me. On other forums, even though you don't have your name, with a nickname, you can find out who the person is anyway. You have to be very careful if you want to be anonymous.* [Anne]

Even though most did not perceive the lack of anonymity as a personal barrier, some questioned whether this might influence other patients' contributions, as Frank suggested.

*For me, it doesn't matter, because I don't write anything I don't want people to know about. So, for my own sake, it doesn't have any influence, but perhaps, there could be an added feature via which you could post anonymously? There might be those*

*who... not everybody is as open about everything.*

[Frank]

Also, the fact that posting to the forum would reveal that they were part of a bariatric surgery community could be perceived as a barrier to active participation, which is something Kari had thought about—"I think it could be a limitation for others, and many wouldn't like the fact that other people could know about what they have gone through." Hence, being open about the surgery is not something everyone likes. Nina mentioned that the fact that only bariatric surgery patients had access made it easier to use the forum. However, she knew several others who had undergone surgery, but preferred to keep it a secret.

*I don't have any problems with it, but others do because I see that among those I have contact with who have had the operation, I know two principals who have undergone surgery. They don't want to be open and talk about it. They want it to be kept secret... Thus, I think it can be a challenge for some.*

[Nina]

Monica believed that the fact that the forum was moderated meant that it was perceived as more serious than other online health forums, and she held that this prevented people from harassing each other, as she had experienced in other forums—"I believe that when you know that this is more serious, when there are doctors and others (from the clinic) that go through (the postings), then I don't think people become that childish, letting themselves sink that low..." Forum observations did not identify any form for bullying, harassment, or other negative comments among the participants, and the peer interactions we identified were of a purely supportive character. Everyone has his or her personal limits regarding what he or she is comfortable sharing with others. Because the discussion forum under study was moderated and posting to it did not entail full anonymity, some expressed the feeling that this might increase the participants' consciousness of what they shared. Kari felt that the demarcation between personal to private sometimes disappeared when people posted online.

*I can be personal, but I don't want to be private... Because there are many things that I think are too private to talk about. People reveal too much. I do not want all that information. Some people need to be protected against themselves. That is just something one has to realize. Some people have no boundaries. You see that on Facebook as well.* [Kari]

The various degrees of self-disclosure seemed to influence whether the participants felt eligible to actively participate or not. Also, the fact that the forum was moderated appeared to influence how the participants used the forum.

## Discussion

### A Moderated Forum

This study shows that patients who undergo bariatric surgery can obtain information and social support through a moderated online forum and that making such a forum available creates various practices among the patients. The patients were motivated to use the forum by the fact that they must undergo

major lifestyle changes that affect both their physical and emotional health. Thus, there is a need for informational and social support. This finding is consistent with previous research that suggests that the desire for both information and social support is a prominent reason for online interaction [26]. The fact that the forum was moderated, and the patients could make contact with health care professionals, meant that the participants experienced the forum under study as being reliable and trustworthy. The participants provided emotional and social support to one another, and we did not identify any communication that was of a disruptive character. This was suggested to be a result of the moderation process, which is in accordance with the findings of Ryan [38].

### The Digital Divide

The digital divide refers to a gap in the access and use of information and communication technology [44,45], and has been a threat to access for poor, minority, and older patients [46-49]. In a recent study that examined underserved patients' readiness towards patient portal use, Sanders et al found that the majority of the patients did have Internet access and were interested in using a patient portal as a way to manage their care [50]. However, they identified that among those who reported barriers to using the Internet, these were due to interests, know-how, and costs [50]. Because most people have access to computers and the Internet, the challenge of adopting and using these technologies becomes more prevalent, as illustrated in our study. Our findings indicate that some patients experience barriers in participating actively in the forum, implying that there might be a digital divide in this patient population that must be considered when introducing such a solution. Sarkar et al did a study on Internet patient portals in diabetes, and concluded that with the health systems increasingly relying on the Internet, those who are at most risk of poor health outcomes might fall further behind, underpinning that the digital divide extends beyond access [49].

### Lurking

The discussion forum served as a source for information and advice, a place for mutual social support and networking with peers. The existence of online forums and communities is dependent on active participation and contributions, but many prefer not to participate publicly [51]. Based on our observations, we found that most were passive participants, who did not reveal their presence in the forum. This behavior can be defined as lurking, which involves seeking answers to questions and viewing and browsing others' postings, but not actually contributing [51-53]. Participation was uneven in that a minority of the patients contributed to most of the patient-generated content. This is in line with the description of lurkers and posters reported by numerous others [51-54]. There are many reasons for lurking, ranging from the personal to the work-related [51]. In our study, the consideration of self-disclosure, for example, where to draw the boundary between what to share in an online space and what not to, was identified as a factor that restrained active participation. The patients who contributed little or nothing still benefitted from having access to the contributions of other patients because the experiences of these closely resembled their own experiences.

This finding is consistent with past studies showing that reading in itself benefit those who lurk in online support groups [30,32,55,56]. Despite their lack of participation, lurkers have the potential for enhanced health promotion through observing or by listening in on others conversations [55]. The fact that the users did not have the opportunity to be anonymous influenced participation. Even though some patients were reluctant to actively participate due to personal barriers, it appears that for others obtaining social support and guidance was of more importance than the issue of self-disclosure. That some patients shared their personal stories shows that the personal benefits of revealing such information are, in some cases, greater than the disadvantages. The fact that patients discussed personal problems online regardless of full anonymity indicates that not being face-to-face with the other participants made it easier to reveal such information. These findings are opposed to those of Kummervold et al, who studied mental health forums in Norway [36]. In their study, the majority of the respondents reported that they would not have participated had they not had the opportunity to use a pseudonym, thus providing full anonymity [36]. However, their respondents also found it easier to discuss personal problems online rather than face-to-face, a finding that is supported by our study [36].

### Study Limitations and Implications

Our study was limited to a qualitative case study, and the findings therefore cannot be generalized. One subject of limitation was the method of recruitment to the interviews, which was done by posting an invitation on the discussion forum. This involved that only those who accessed the discussion forum would see this invitation. One might have achieved contact with other participants if one had used other recruitment methods, such as approaching them by phone. However, this would have involved far more resources than we had available at the time of the study. This study was limited to one discussion forum for bariatric surgery patients, and the results cannot be transferred to other patient populations or other health forums.

There are factors that influence forum participation, thus, determining the degree of engagement and activity. In our study, the mean age of the forum participants was 40 years, indicating that the users were not in the young segment of the population, which uses online communities as an integral part of their daily lives. However, the individuals who obtained access represent a cohort within the population of bariatric surgery patients and therefore provide some implications for future directions. Our findings imply that previous forum experience may influence participation, in that those familiar with online forums may be the individuals who contribute the most. In the literature, a phenomenon called "de-lurking" is described-unfamiliar users begin with reading and getting to know the community to educate and prepare themselves for a more active participation, and eventually write and post themselves [57,58]. It is reasonable to believe that with time, the number of people familiar with such forms of communication will increase and that those who were lurkers in the current study may "de-lurk" with time.

Our findings have some practical implications regarding how such a solution can be used in the context of a bariatric surgery program. First, the patients are unambiguous regarding the value and usefulness of such a moderated discussion forum. Through the forum, the providers have the ability to reach out to those patients that exclude themselves from traditional programs—those who do not show up for traditional consultations, those who experience difficulties in expressing their problems in a face-to-face situation, and those who experience barriers to making contact through conventional methods. Considering the severe outcomes that patients may experience as a result of bariatric surgery, reaching out to those who are in need of informational and social support is crucial. Second, the fact that the users access the forum to read about “new” topics, for example, the weekly topic of relevance, and to read new postings from their peers implies that the forum must be dynamic. This requires the continuous facilitation of the forum, a responsibility of the relevant health care clinic. Third, the fact that the users experience the forum as trustworthy compared to other online forums indicates a great potential for the health care providers to use this channel to deliver the validated health information that the patients need. Thus, one may prevent misinformation and hopefully support the patients’ coping strategies and self-management activities.

In summary, benefits such as social support obtained through interactions with peers and providers motivate patients to actively contribute in an online eHealth forum. However, issues concerning self-disclosure influence whether the patients are comfortable participating actively in the forum or prefer to lurk. Our findings indicate that previous experience with using online forums seems to have an impact because those familiar with the technology may be the individuals who contribute the most. The patients reported benefits from using an online discussion forum, regardless of their active or passive participation, even though active members obtained the greatest advantages in regard to social support and approval.

### Conclusions

The findings of this study imply that a moderated discussion forum for bariatric surgery patients has potential for use in a therapeutic context. The discussion forum fulfills some of the informational and supportive needs of the patients and is particularly useful for those who exclude themselves from traditional programs or experience barriers to making contact with professionals. Even though our findings imply that the patients benefit from using the forum regardless of their active or passive participation, restraining factors, such as considerations regarding self-disclosure, must be further investigated to prevent certain users from being precluded from using such forums in the future.

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### Conflicts of Interest

None declared.

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# Paper IV



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Original Paper

# The Impact of an eHealth Portal on Health Care Professionals' Interaction with Patients: Qualitative Study

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## Abstract

**Background:** People who undergo weight loss surgery require a comprehensive treatment program to achieve successful outcomes. eHealth solutions, such as secure online portals, create new opportunities for improved health care delivery and care, but depend on the organizational delivery systems and on the health care professionals providing it. So far, these have received limited attention and the overall adoption of eHealth solutions remains low. In this study, a secure eHealth portal was implemented in a bariatric surgery clinic and offered to their patients. During the study period of 6 months, 60 patients and 5 health care professionals had access. The portal included patient information, self-management tools, and communication features for online dialog with peers and health care providers at the bariatric surgery clinic.

**Objective:** The aim of this study was to characterize and assess the impact of an eHealth portal on health care professionals' interaction with patients in bariatric surgery.

**Methods:** This qualitative case study involved a field study consisting of contextual interviews at the clinic involving observing and speaking with personnel in their actual work environment. Semi-structured in-depth interviews were conducted with health care professionals who interacted with patients through the portal. Analysis of the collected material was done inductively using thematic analysis.

**Results:** The analysis revealed two main dimensions of using an eHealth portal in bariatric surgery: the transparency it represents and the responsibility that follows by providing it. The professionals reported the eHealth portal as (1) a source of information, (2) a gateway to approach and facilitate the patients, (3) a medium for irrevocable postings, (4) a channel that exposes responsibility and competence, and (5) a tool in the clinic.

**Conclusions:** By providing an eHealth portal to patients in a bariatric surgery program, health care professionals can observe patients' writings and revelations thereby capturing patient challenges and acting and implementing measures. Interacting with patients through the portal can prevent dropouts and deterioration of patients' health. However, professionals report on organizational challenges and personal constraints related to communicating with patients in writing online. Further development of guidelines and education of health care professionals about how to handle, prioritize, communicate, and facilitate patients online is required in addition to increased attention to the organizational infrastructures and incentives for enabling such solutions in health care.

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**KEYWORDS**

bariatric surgery; online communication; eHealth; patient; health care; Web 2.0

## Introduction

Given the limited time for face-to-face consultations, health care professionals and patients experience considerable challenges in setting priorities to address clinical concerns. New approaches to organize and deliver health services are being explored and eHealth technologies are one of the key elements to address this. Promises about improved cost-effectiveness by the use of such may reduce the pressure on the health care system and improve the quality of care for the recipients [1-3].

### Weight Loss Surgery

The number of people suffering from obesity and obesity-related comorbidities has increased significantly the last couple of decades [4,5] entailing enormous economic and health costs [6]. The effects of obesity are reversible and have led to a rising demand for weight loss interventions [4,7-9]. Bariatric surgery (weight loss surgery) is currently one of the most effective interventions to produce initial weight reduction [7,10] and the number of performed surgeries has increased dramatically over the past decade [7,8]. Most surgeries nowadays are performed with short hospital stays. A number of aspects prove that this is both cost-effective and considered beneficial for the individual [9,11,12]. Bariatric surgery procedures are no exception because patients are procedurally discharged a couple of days after surgery if no complications have incurred [11]. Accordingly, the outcomes depend on the patients' adherence to recommended treatment regimens and on their abilities for self-care management.

### Challenges Related to Bariatric Surgery

Even though bariatric surgery is one of the most effective interventions to produce initial weight reduction, there are many challenges related to the treatment. Patients commonly experience difficulties, particularly the first period after surgery because of the immediate impact of the surgical procedure on their physical well-being. The purpose of the surgery is to restrict food intake and involves removing and bypassing parts of the intestine. The operation contributes to reduced absorption, leading to poor digestion and reduced nutritional uptake. As a consequence, the patients must follow a particular dietary regimen and, in some cases, are required to take lifelong vitamin supplements to prevent nutritional deficiencies with severe outcomes [13-16].

The surgery alone does not suffice to achieve successful outcomes; the patients need to change their lifestyle, addressing dietary habits and physical activity in order to accomplish results [17,18]. Research shows that bariatric surgery patients experience challenges after some time because the recommended lifestyle and behavior changes are difficult to maintain [19,20] and many patients regain weight [20-24]. The underlying reasons for weight regain are multifactorial: the causative factors are patient-related (mental health and behavior) and surgery-related (anatomical alterations and complications) [25]. Weight regain is an important public health issue with significant consequences to the patient as to the recurrence of obesity-related comorbidities and to the health care system due to the economic costs of obesity and societal impacts of recalcitrant obesity. In

an effort to manage and prevent weight regain, an organized and systematic approach is essential [25].

Most bariatric surgery clinics offer some kind of follow-up to their patients; these are typically telephone conversations, individual face-to-face consultations, or group-based meetings. However, this group of patients commonly experience stigma and shame [26,27], and restrain from making contact with health care professionals through traditional means, such as by telephone or meeting in person [28]. In worst-case scenarios, this might result in fatal consequences because complications or other challenges might not be acknowledged and adequately handled. Therefore, the need to facilitate bariatric surgery patients in connection to their treatment program is critical to provide sufficient health care delivery and clinical care to this patient group. Toussi et al [20] pointed out that having more contact with patients and requiring adherence to behavioral changes, especially with respect to exercise and dietary restrictions, may improve the long-term outcomes for bariatric procedures.

### eHealth Portals in Health Care

eHealth solutions, such as secure online portals, hold great potential if offered to patients in conjunction with their treatment program because they create new opportunities for improving health care delivery and follow-up of clinical care [1,29]. eHealth portals offer a number of potential benefits to providers, including administrative efficiencies, improved responsiveness to patients' needs, decreased utilization of health services, more effective care, and cost savings [30]. Despite the potential advantages, the adoption of eHealth solutions and portals has been low [30,31]. The success depends on the degree of acceptance by its users, where health care professionals are key stakeholders to adoption and use [32,33]. A number of barriers to adoption have been identified, such as concerns about costs, added workload and workflow demands, technology literacy, liability issues, and confidentiality and privacy risks [30,34,35]. To our knowledge, few studies have explored Internet-based tools such as eHealth portals in bariatric surgery. A number of studies have been done in other areas of chronic disease management, such as in diabetes care, chronic obstructive pulmonary disease (COPD), and asthma [36-41]. eHealth portals in diabetes and COPD show that access to information and support via online patient-centered tools improves patient engagement and health outcomes, but there are unclear results when it comes to the effectiveness of follow-up [37,38]. In diabetes care, studies show that providers often are reluctant to adopt these technologies due to lack of knowledge about the Internet or information technology systems [40,42]. There are few, if any, studies exploring health care providers' perspectives on the use of eHealth portals in bariatric surgery. Because the impact and success of such solutions depends on the organizational delivery systems and the professionals' acceptance and adaptation of the solutions, the need to explore their views is important.

### Objective

The objective of this study was to characterize and assess the impact of an eHealth portal on health care professionals' interaction with bariatric surgery patients. The aim was to develop a better understanding and insights relevant for using

such solutions for health care delivery and care in bariatric surgery programs.

## Methods

### Study Setting

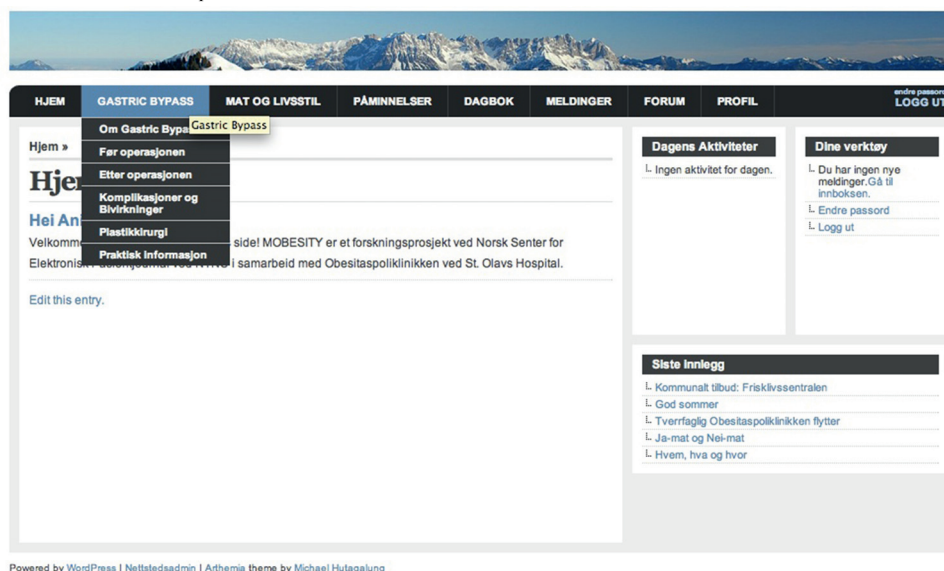
In this research project, an eHealth portal for bariatric surgery patients was established in 2011 in collaboration with a bariatric surgery clinic in Norway. The portal was developed through a human-centered development process [43] and according to the security and privacy concerns that are required for such solutions in Norway. Access to the portal required log-on procedures with username, password, and entering of a one-time personal identification number (PIN) sent to the user's mobile phone. The features of the eHealth portal included:

1. Patient information (eg, validated information about the surgery, pre- and postsurgical recommendations, food and diet, nutritional facts, lifestyle recommendations, physical activity)
2. Self-management tools (eg, personal diary, calendar, reminders via short message service [SMS] text messaging)

3. Communication features (for dialog with peers and providers)
4. Online discussion forum
5. Personal messaging

The eHealth portal (Figure 1) was implemented in the bariatric surgery clinic, where 5 health care professionals (all women; 2 nurses, 1 clinical dietician, 1 psychiatric nurse, and 1 administrative leader) at the clinic received access to facilitate the patients and respond to their requests. In addition, one person from the research team, educated in nursing, had the overall responsibility to moderate the forum and could comment on postings that were within her field of competence. The patients received access to the eHealth portal for approximately 6 months. In total, 60 bariatric surgery patients (75%, 45/60 women and 25%, 15/60 men) received access and 80% (48/60) of them logged on to the system one time or more. The study was approved by the Regional Ethics Committee [44] and by the Norwegian Social Science Data Service [45]. All participants provided written informed consent when included to the study.

Figure 1. Screenshot of the eHealth portal.



### Data Collection and Analysis

Data collection involved a field study and in-depth interviews with health care professionals. The field study was conducted at the clinic, consisting of contextual interviews with professionals at the clinic during the 6-month study period. Such interviews involve observing the people in their actual work environment and speaking with them about their work and actions [46]. The contextual interviews typically lasted 20 to 60 minutes, were informal, and notes were taken. At the end of the study period, the 5 health care professionals were requested to give in-depth interviews [47], but not all could participate. Semi-structured in-depth interviews were conducted with 3

health care professionals. The interviews were conducted in Norwegian, lasted 1 hour each, were sound recorded, and transcribed verbatim before analysis. The two first authors conducted the analysis, which was done inductively using thematic analysis, and used English terms and concepts. HyperRESEARCH software was used to facilitate the process, involving a stepwise process in which both researchers reviewed the material and created codes individually. Next, the codes were collated and concepts were generated in a mutual process. These were compared, contrasted, and discussed in light of relevant literature and theory, and the final themes were achieved via consensus. The quotes in this paper are translated

from Norwegian to English and the names reported are pseudonyms.

## Results

The analysis revealed two main dimensions of using an eHealth portal in bariatric surgery: the transparency it represented and the responsibility that followed by providing it. The personnel reported the eHealth portal as (1) a source of information, (2) a gateway to approach and facilitate the patients, (3) a medium for irrevocable postings, (4) a channel to expose responsibility and competence, and (5) a tool in the clinic.

### The eHealth Portal as a Source of Information

The health care professionals reported the eHealth portal to be a source of information in regards to gaining awareness about the unique challenges of the individual patients and as a learning source about the group of bariatric surgery patients. With access to the portal, the patients could write and post whatever they wanted, whenever they wanted. Most of their postings were stories and narrations about personal experiences; they shared thoughts about daily ups-and-downs, often without specific questions requiring attention. Some patients used the online forum as an arena to post their “personal diaries.” The professionals reported that the length of the postings and/or the number of threads related to a particular topic could signify a problem that needed attention; therefore, they read most postings even though they were not addressed to them in particular. “Linda” described “reading between the lines” to identify if anything was out of the ordinary: “Even though it’s there as part of a diary, and there is not a single [direct] question there, you understand that something isn’t how it should be.” During the field study, we observed how she handled such postings: if she considered that the patient needed facilitation by the clinic, she would approach the patient by sending a personal message through the portal to identify if there were issues that needed further investigation. All professionals who had access to the portal reported that they were surprised about the vast and rich amount of information about the patients that became available through the portal. Some issues and themes were recurring, posted by several patients, signifying what information this group of patients searched for and needed:

*We have learned a lot as well. So we need this type of patient contact. [Linda]*

The patients posted a great number of questions; some were meant for their peers, others were addressed to the health care professionals. The professionals reported becoming aware of issues they previously had not considered significant. They knew that the patients experienced challenges in adjusting their lifestyle, but they were not aware of how complicated this turned out to be. The insights that became evident by reading the postings concerned the patients’ unique experiences postsurgery, the psychosocial aspects that came to pass, and the enormous challenges they experienced related to the new lifestyle and diet. These understandings benefited the patient group:

*We can capture the information they write. In addition, we can learn a bit more about how to facilitate the patients. [Bente]*

The information they attained was important for their occupational behavior, knowing what to emphasize in contact with the patients:

*In relation to the need of feeling cared for as patients, it is probably useful. And it’s educational for us as well. Because learning goes both ways. [Fride]*

The knowledge gained was further enabled to customize the patient information and contents in their patient education program.

### The eHealth Portal as a Gateway to Approach and Facilitate the Patients

The eHealth portal worked as a lowered threshold solution for the patients to seek advice, guidance, and help, and as a gateway for the health care professionals to approach and facilitate the patients.

#### Lowered Threshold Solution

By following the patients’ writings, the professionals got an overall impression about the patients’ daily lives as opposed to the selected issues they were presented during time-limited face-to-face consultations:

*But it’s obvious that one can capture things in the portal that I cannot capture during a consultation. [Fride]*

In the patients’ online writing, their information was described in greater detail compared to oral contexts:

*You get more information about them here [online] than on the phone. [Bente]*

This was considered to be relevant in order to identify patient symptoms and needs: “...because, in the portal they are more laid back and at home...and they are closer to what is relevant for them there and then.”

They found that some patients had difficulties in revealing their actual problems in face-to-face settings:

*Those who come for consultation and sit in that chair and talk to the person in white coat, I don’t think it’s always that easy for the patient to come with his or her request to me. [Fride]*

In the field study, we observed that the patient consultations often ran overtime and other patients were kept waiting. The professionals described that some patients’ required significant time during the consultations because they needed time to feel confident and had complex needs. However, because other patients were waiting for their turn, the personnel had to end the consultations even though they knew that the patients had more on their mind. The professionals reported that factors such as time constraints, shame, and fear of stigma could influence the oral dialog and thereby restrict what the patients were comfortable in sharing in face-to-face settings. These issues were not as prevalent for the patients when communicating online. The personnel quickly learned that some patients found it easier to take contact with the clinic through the eHealth portal: “Yes...they give their notice here instead of calling...” Also, they observed that some preferred to express themselves in writing via the portal and, therefore, it became a lowered

threshold solution: "...they are at home, it's easier to send a message online than to call, and that's why we get so many questions."

### Dropouts

When undergoing bariatric surgery, the patients were offered a 5-year follow-up program at the clinic consisting of a combination of group-based and individual outpatient consultations. These consultations occur at specific intervals after surgery: at 3 months, 6 months, and 12 months after surgery, and at yearly intervals for the following 4 years. The health care professionals reported that a number of patients failed to show up to these scheduled (face-to-face) consultations, something we also observed in the field. Even though they rescheduled the appointments, sent letters, and tried to achieve contact by phone, some patients still did not show up, thereby dropping out of the follow-up program. This represented a challenge for the clinic because they were left with no data about the cause or how these patients coped after the surgery. "Linda" observed patients having difficulties in achieving their expected outcomes:

*The operation, it is kind of their last chance. And if they don't succeed with that either...they say that they think, "Oh my God, now I got this operation costing 100,000 NOK, and all that help and follow-up, and still it doesn't work".*

The personnel stated that several patients refrained from taking contact with the clinic by traditional means when necessary because of shame:

*If this can be that place where those who struggle and who do not want to show up in person because of shame...because it is shameful not to be able to make it [lose weight], right? One had great expectations and then it did not go as planned...If we can get hold of them through this, then it's really good. Because we want everyone to succeed. [Fride]*

As a consequence, the clinic could not follow up and provide health care to patients they perceived needed it:

*In reality, I think that there are more people that struggle than those who say they do. Who need help, and yes...they are ashamed. [Linda]*

They detected that some of those who excluded themselves from the traditional follow-up program were active on the website:

*And not everybody who are in here [the portal] makes contact with us by phone...because not everybody, I don't think that everyone that are in here would take contact with us otherwise. [Bente]*

"Linda" discovered that one of their patients failed to show up to her scheduled consultations, but posted considerably on the forum. By following her postings, she understood that the patient needed help and initiated contact through the portal. They communicated in private messaging and identified that she needed additional medical investigations and scheduled her for further follow-up to the endocrinologist at the clinic. Later, this patient expressed gratitude about receiving the care she needed

due to the portal because she would not have taken contact with the clinic directly. The portal became an important asset as it represented an additional approach for the professionals to reach out to the patients:

*I think that this can be, if we are going to [continue] using it, then this might be a place where we can get hold of them. The people who do not dare to take contact...yes, or who are to shameful to show up at the traditional programs we offer, to meet in person. [Fride]*

### The eHealth Portal as a Medium for Irrevocable Postings

Interacting with patients in writing online was a new way of communicating and represented other aspects than in an oral dialog. "Fride" reported that this signified uncertainty about how to deal with this new kind of interaction:

*I have chosen to read what I have found to be related to my area of competence, and I think that has been okay. Occasionally I have felt that some have disclosed themselves. And I don't know if that is okay.*

"Bente" expressed concerns about the degree of self-disclosure she observed: "They expose themselves too much for the others that are in and have access to read..." The personnel were concerned about what the patients exposed online and were equally apprehensive about their own postings:

*It's just that you have to consider that this can be used against you later in some way, it remains there. [Linda]*

This was a shared understanding among all the professionals. The awareness about how to communicate online became particularly significant when their posting would be available to many people:

*It is about practice—to practice to write short and concise, and dare to be...not vague. At least I am very afraid of writing to concluding, particularly when I am in such a forum, when it will be standing there written. It gets a lot of readers and you try to ensure that what you write is correct. [Fride]*

When online, nonverbal cues, such as body language, tone of voice, and gaze, that were present in face-to-face conversations disappeared. "Fride" contrasted online communication with a face-to-face dialog, where she continuously would assess whether the patient actually understood what she said and the information she provided. When communicating in writing she had to be particularly aware in order to avoid misinterpretations: "And what I said before, that you have to be sure about that what you say is correct, and that it cannot be understood differently."

"Linda" shared this understanding:

*It's okay, but you have to consider what you say, when it's written...I have to be aware about how I articulate myself. It's almost like when you get an SMS from someone, and "What!? Bad mood today, or what is it?" If I talk to them (patients) on the phone for*



*instance, I hear if someone misunderstands something. Yes, and that you don't here...have to think carefully, can't just [write].*

She had become used to communicating with family and friends in writing by using SMS text messaging and social media forums, and stated that this transition needed to be undertaken in the professional sphere as well: "Thus, there is something about getting used to communicate this way, and you are in your personal life." All assumed that with time and practice the clinic would adapt to communicating online with their patients.

### **The eHealth Portal as a Channel to Expose Responsibility and Competence**

According to the professionals, the questions they received online differed from the ones they traditionally received in oral contexts: "Maybe more specific in the portal. And maybe it is those who are interested, or who try [who ask]." The patients' access to other information sources seemed to have an impact:

*But then the questions here, it's clearly that the questions that have been posted, those are from patients that have read all the information that is available here [in the portal], and they have also talked to others that have undergone surgery.*

Also, the patients' context when articulating the questions influenced the topics:

*Because here they are at home in peace and quiet, and can use – can get information from other arenas as well obviously...The questions have not only been experiential. [Linda]*

The personnel reported being unprepared for the advanced level of questions they would receive: "Thus, the questions have been really good, often so advanced that we have been required to speak with a specialist." This represented a challenge for the level of expertise required to provide an appropriate response: "...so there have been many questions that I have not been able to answer, have needed to talk to the specialist." They could not refer the patient to another professional through the portal because not everyone at the clinic had access. Neither could they ignore the patients' requests because the presence of unanswered questions could create an impression about not doing their job. As a result, it became necessary to provide high quality answers to the patients' posts. In cases when the personnel having portal access could not respond themselves, they made contact with other professionals at the clinic, such as the physician, physiotherapist, pharmacologist, surgeon, and endocrinologist, to get quality assured information for redistribution to the patients. The fact that they needed to make contact with other professionals became more obvious when using the portal compared to an oral context:

*Now we get quite some calls about that they have pain or...We can't give the diagnosis [stating her profession] over the phone. And I couldn't have done that here either. [Bente]*

When delivering the response in writing, the caregivers felt obliged to take contact with others to ensure a qualified response:

*Like "why can't they take NSAIDs?" That resulted in that our pharmacologist didn't want to answer, needed a statement from the chief over there. [Linda]*

"Linda" explained that the activities triggered by this one question required considerable efforts: the process required resources in regards to have expertise in knowing the right addressee, time effort to contact them, have them write a statement, and get the information validated before they could finally post the statement online. In the field study, we observed that the process could take quite some time and effort, which verified the personnel's experiences. Even though the patients' requests were specific, the answers from the professionals would not necessarily correspond in level of detail because they delivered an answer based on the information they had available there and then:

*When you are in a face-to-face consultation, you have access to much more medical information and about the patients' history, and you aren't supposed to give advice without knowing, without knowing the underlying cause. So it's, call it whatever you want to, but it's a weakness as well, and then you have to give more general advice, less specific advice, because you don't know. [Fride]*

In the field study, we observed that some of the professionals would search the electronic patient record and look up test results if necessary to answer the patients' requests as best as possible. But the professionals experienced that the online communication had its limitation in cases where they found it necessary to go deeper into the matters to provide sufficient help:

*Particularly those who have posted a lot, then it's preferable that you have read what they have posted before, and not only answer the question. Like the one I just answered, I think it's a lot, and then there is no use to just answer the last one there, then it's better to get them to come to a consultation when [you understand] it's complex. [Linda]*

Therefore, in some instances, the patients' postings worked as triggers for further communication, occasionally leading to face-to-face consultations.

### **The eHealth Portal as a Tool in the Clinic**

In the beginning, when introducing the portal in the clinic, the professionals expected that it would become an integrated tool in their daily occupational practice. They talked about their intentions for using the portal in peace and quiet, focusing on the patients' posts, and responding to their requests. They assumed that the opportunity to communicate with the patients in an asynchronous manner would give them more flexibility in when to do the work, but the reality turned out to be different from expected and factors such as normal work routines, time constraints, and prioritizations became evident in the daily clinical practice:

*Then I can sit down whenever I have time, but on the other hand, I probably have shown that I don't have the time, or do other stuff, right? So you need to get accustomed to use it. [Bente]*

The professionals described their work routines to be hasted, characterized by fully booked calendars with appointments and patient consultations, and often interrupted by unexpected telephone calls and other emergent tasks. Thus, their intentions failed to materialize:

*It is just that the days are filled with patient lists, and suddenly it is 4 o'clock, and then you are off to home. We haven't organized the time for it, and we should have. It hasn't been a priority because when a patient is physically here, then you have to attend to him. If the phone rings, you have to pick up. And then this is what we postpone to use. Unfortunately.* [Linda]

Enabling a tool that the personnel were unfamiliar with proved to be a restraining factor in getting it integrated into their daily work routines. Using the portal became an extra task in addition to their current duties, which we observed that they prioritized to complete:

*It is the time pressure we have at work, we don't have time for anything. I have to put everything aside, and when I get time I have to catch up [the other work]. So one can say that it has to do with priorities.* [Bente]

The lack of incentives became prevalent when using the eHealth portal:

*It does not give us any incomes because we got feedback about that from our boss that if it does not give us any incomes...we have to register it some way. Because our leader go in and check how many patients we have every day. And then surely you get feedback if you haven't reported any patients, then you would have gotten some questions.* [Bente]

It was difficult to justify using the portal when they knew that their work was evaluated based on other criteria:

*To be honest, this has not been something I could prioritize. You prioritize those that are on your patient list. Those are the ones you are counted for...how many notes [in the electronic patient record] that are in progress and incomplete and so on. That is something my leaders go in and check. So that is what you are counted for.* [Fride]

The organizational infrastructures and economic incomes that the professionals perceived to be important for getting such a tool integrated into their current work routines were nonexistent at the time of this study. These were reported by the personnel to limit portal use and redeem the opportunities it presented.

## Discussion

### Principal Findings

The findings suggest that health care professionals experience a number of benefits from interacting with bariatric surgery patients through a secure eHealth portal while it also poses a distinct set of challenges. The two dimensions of transparency and responsibility that follows by providing an eHealth portal to this patient group became decisive for how the professionals enabled the portal. The transparency to both the patients' lives and the professionals' online actions influenced the

professionals' roles and responsibilities toward the patients. The success of implementing such a portal into bariatric surgery care appears to depend on how confident the professionals are in communicating in writing and using online tools as well as organizational infrastructures and incentives. Yet, such online communication portals may place greater demands on the caregivers because it appears to be a solution that the patients both prefer and benefit from using. Traditional communication arenas between bariatric surgery patients and their health care providers seem to have their shortcomings. Thus, professionals must learn how to communicate online and enable eHealth tools as a complement to traditional care for this patient group in order to follow up and facilitate patients in need and consequently enhance patients' outcomes after treatment.

### Transparency

The eHealth portal provides transparency to the patients' daily life, their challenges, and their needs, and it became an information source about the patient group. The narratives that patients create and share outside the constraints of time-limited consultations can help professionals develop a more comprehensive view of the situation of their patients, thereby enabling them to individualize the care to the patient's particular needs. But the transparency goes both ways: an eHealth portal that make the patients' requests and the health care professionals' postings available for all to read makes professionals spend more time in preparing comprehensive, thought-through answers compared to communicating in oral contexts. This is a fact that is important to consider when introducing additional tasks for the personnel. Given the fact that their postings would remain online and the fear of publishing information that can be perceived as incorrect, results in the professionals acting carefully and deliberately in their online acts and written communication. Also, each health care professional's competence becomes evident when using a written communication form, resulting in that they become particularly aware about what they are eligible and comfortable on posting.

### Responsibility

The online portal represents responsibility to follow up and provide high quality health care to the patients. This become particularly evident for following up the patients' postings because these signalize the professionals' work; if they do not respond, this can signify poor quality and work. The responsibility can be seen at two levels: with the competence and skills to identify the patients' challenges and needs, the professionals are obliged to act and implement measures accordingly. On the second level, the responsibility to provide correct and quality assured information becomes evident when communicating online in writing; it becomes an absolute of no discussion when it stands in text. The fact that the professionals "monitor" the patients by accessing their writings and narrations means that they can identify if and when patients experience signs and symptoms of health deterioration that need professional follow-up and care. Given that the professionals, based on their clinical expertise, can identify patient symptoms and needs at an early stage, makes them responsible to act and implement measures accordingly. The prevention of health

deterioration can have great impact on both the patients' health status and quality of life, and to society as a whole considering the health care expenses of treatment costs and hospitalizations.

### Implications

Bariatric surgery is often a "last chance" solution to patients who have tried and failed various approaches to achieve weight reduction, which leaves them with unrealistic expectations toward the outcomes of surgery [48,49]. The informants report that patients' inadequate adherence to the follow-up program were due to unsuccessful outcomes and shame, resulting in restraints in making contact with the clinic when in need and dropouts. These findings correspond with earlier research that show that inadequate adherence to follow-up programs in bariatric surgery is associated with poor weight loss and maintenance, poorer control of obesity-related comorbidities, and the development of postoperative complications [50]. Attrition to bariatric surgery aftercare and weight loss intervention programs is associated with greater presurgical weight, psychological and behavioral patient factors, processes associated with the treatment, and greater travel distance to the follow-up center [50,51]. The portal proves to be a possible gateway for the professionals to communicate and interact with patients, particularly as a channel to a subgroup of patients who for various reasons do not use traditional communication forms currently in use at the clinic and would have been lost to follow-up. Bariatric surgery patients report that they experience difficulties in communicating with professionals in face-to-face meetings [28]. This underlines the need to offer new solutions. The personnel report that some patients prefer to communicate online rather than face-to-face, which implies that they experienced a benefit of using such an eHealth portal. For those who reject participation in the traditional aftercare program, eHealth portals for online communication can be a substitute and be valuable for addressing clinical needs and care. Adherence to scheduled visits (and compliance to recommended rules) predicts success of bariatric surgery [52], where health care professionals can use eHealth portals in communicating and promoting recommended postsurgical regimens. This might be an additional approach or even a substitute for face-to-face visits to selected patients. Better contact between health care providers and patients may improve the long-term outcomes for bariatric procedures [20]; this study has shown that an eHealth portal can be one approach to achieve this.

Despite the potential advantages of using the eHealth portal, the professionals report a number of organizational challenges, such as time constraints, busy working hours, and lack of incentives as underpinnings for their work. These findings are similar to the ones of Hanberger et al [53] who found that practitioners in diabetes care had a hard time starting to make use of an eHealth portal in their practice due to obstacles such as deep-rooted working habits and too many working tasks. Enabling and using the portal was more time consuming than anticipated, a finding that is opposed to previous envisions about more efficient use of clinical time by the use of Web-based tools [54]. The professionals had difficulties in justifying the use of a work tool that did not give the clinic income because, in the end, their occupational behavior depends on giving the clinic sufficient earnings. The lack of incentives drives the

prioritization of the personnel's activities and, for increased adoption and use of technology, incentives at both the individual level and organizational level should be considered. At the individual level, remuneration for work efforts can be either financial (eg, reimbursement for activity) or nonfinancial (eg, workload credit for activity) [55]. When introducing a personal health record at the Department of Veterans Affairs, a workload code for secure messaging was implemented to enable workload credit for secure messaging activity, providing incentives at the individual level to foster increased adoption and use of the technology [55].

### Implications for Practice

The findings of this study have demonstrated the feasibility of an eHealth portal for patient care and communication in bariatric surgery, which provides both clinical benefits and challenges. The health care professionals imply that an eHealth portal has great potential and impact in bariatric surgery, but that there are a number of aspects that need to be addressed in order to take full advantage of the benefits. A portal for communicating and interacting with bariatric surgery patients can be a useful complement for most patients, but for selected patients it might be a substitute to traditional postsurgery care. Even though the practitioners are motivated to use the new solution, the fact that they are evaluated by their economic income to the clinic makes them prioritize their work accordingly and the necessity to implement incentives is therefore crucial.

Based on these findings, we present some practical implications that need to be considered when introducing and implementing eHealth portals into clinical practice:

1. Establishment of clinical rationale. Define why and for what purpose the eHealth portal is implemented. What are the major motivations and how should these be communicated to the personnel?
2. Clinical skills and competences. Identify if the personnel have sufficient competencies to identify patients' symptoms and needs. Are other competencies or skills than those currently available required?
3. Decision support and multidisciplinary team. Assess whether the personnel who will facilitate the patients have sufficient decision support. Do they have a multidisciplinary team available for questions?
4. Individual motivation. Explore the personnel's individual motivation. Are the personnel motivated to use the eHealth tools? Are they satisfied with the information, training, etc, they have received in order to enable the solution in an efficient manner?
5. Communication skills. Identify the personnel's competences and experiences with communicating in writing/online. Are the personnel comfortable in communicating in writing? If not, do they need practice or education?
6. Organizational infrastructures. Identify barriers to enable the technology. Do the personnel have time and resources to use the technology? Do they have access to sufficient infrastructures (eg, computers, Internet) and dedicated time when they can use the technology?
7. Clinical workflow. Identify how enabling of the new technology corresponds with the established workflow at

- the clinic. Which adjustments are required for satisfying integration between current and new tasks?
8. Incentives. Identify which incentives are required for enabling the technology. Is it necessary with economic incentives? Does it require incentives at the individual or organizational level, or both?

### Study Limitations and Future Work

This study is limited due to its qualitative approach, restricted to a case study, and the results cannot be generalized. The results might be different if other informants were involved, a different patient population, another Web portal, or setting was studied.

In this project, the patients had no restrictions about length, topic, or timing for their postings. Because our findings show that the professionals experienced that the time and competence required for handling the postings were significant, this suggests that more structured forms of communication should be investigated in future projects: patients can fill-in predefined categories or answer a particular set of questions. The need to investigate which categories and contents these should include are subject for future investigations. Also, further studies considering quantitative measures and cost-efficiency studies are required when it comes to eHealth portals in bariatric surgery. Our study reveals that communicating with patients and facilitating them online requires certain clinical skills and competences to capture their symptoms and needs. This underlines that not just anyone can be a moderator and recipient to patient requests, but that it requires particular health education in order for the patients' to be adequately handled. Also, skills in communicating in writing with patients are required when providing such eHealth solutions. The need to acknowledge

that these are required competences and educate professionals about how to communicate and interact with patients online is an underestimated issue that needs further attention.

This study revealed a number of aspects that are not directly evident when introducing eHealth portals, but that are extremely important for the tools to be appropriately implemented and adopted in bariatric surgery practices. When considering the use of an eHealth portal in clinical care, the motivation and clinical rationale for the implementation should be established. Our findings imply that the integration of technology into busy working hours requires alignment with clinical workflow, incentives to justify the work, and organizational infrastructures, all crucial and underpinning factors for successful implementation and adaptation of eHealth portals in clinical care.

### Conclusion

The findings of this study show that by providing an eHealth portal to patients in a bariatric surgery program, health care professionals can observe patients' writings and revelations, thereby capturing patient challenges and acting and implementing measures. Interacting with patients through the portal can prevent dropouts and patients' health deterioration, factors that predict the success of the surgery. However, professionals report on organizational challenges and personal constraints related to communicating in writing with patients online. Further guidelines and education of professionals about how to handle, prioritize, communicate, and facilitate patients online is required, in addition to increased attention to organizational infrastructures, incentives, and rationales for enabling eHealth solutions in health care.

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### Authors' Contributions

AD, DS, AF contributed in designing the study and preparing the manuscript. AD planned and performed data collection and analysis, and wrote and revised the manuscript. AF performed analysis of collected material and contributed in writing and revising the manuscript. DS critically reviewed the manuscript. All authors approved the final manuscript.

### Conflicts of Interest

None declared.

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**Abbreviations**

**COPD:** chronic obstructive pulmonary disease

**PIN:** personal identification number

**SMS:** short message service

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