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Patient involvement and service innovation in healthcare

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In loving memory of my mother

Heléne Engström

ABSTRACT

This thesis adds to a stream of research suggesting that healthcare can be more patient centered and efficient by redefining the role of the patient from a passive receiver to a more active and collaborative participant. This may relate to healthcare provision (Anderson and Funnell, 2005; Berry and Bendapudi, 2007; Bitner and Brown, 2008; McColl-Kennedy et al., 2012; Nordgren, 2008) and innovation (Bate and Robert, 2006; Groene et al., 2009; Longtin et al., 2010). Through research initiative containing four healthcare units and 68 patients, the present thesis combines healthcare research (e.g., Anderson and Funnell, 2005; Nelson et al., 2002) with service research (e.g., Grönroos, 2006; Vargo and Lusch, 2008, 2004) to explore three aspects of patient involvement and service innovation.

Firstly, the concept of patient involvement itself is investigated through an extensive literature review of empirical research on patient involvement. A model describing the antecedents, forms and consequences of patient involvement is proposed. What value is, and how patients can co-create value is discussed from the perspectives of healthcare research and service management thought.

Secondly, the thesis proposes a diary-based methodology for involving patients in service innovation. My colleagues and I developed the methodology in collaboration with the participating care providers and applied it in practice. We used the experiences we gained from the project and the contributions from the patients to examine the opportunities for user involvement in service innovation. The participants contributed with ideas and insights stemming from their experiences in their contact with healthcare and other resources. We suggest the following three ways of learning from the collected data: As ideas for improvements; through summary reports to illustrate other quantitative data; and as narratives to promote change.

Thirdly, the thesis explores patients' motivations to participate in service innovation, a hitherto unexplored field. Through an analysis of patients' contributions and interviews with participants we found that there are a number of factors that motivate patients to participate and that participation is perceived as a social- and meaning-laden event. Patients derive psychological well-being and support from participation, but disease was sometimes a barrier to participation. This thesis elaborates on how the most motivated users can be involved in service innovation, applying thinking from the lead-user methodology to a healthcare setting.

Overall, the thesis explores patient involvement from new perspectives and, by doing so, adds to our collective efforts to improve healthcare.

Key words: Patient Involvement, participation, co-creation, patient empowerment, user involvement, patient centered care, motivation, user experiences, co-creation, service development, service innovation, service design, health care, lead users, diary, value

SAMMANFATTNING

Denna avhandling syftar till en mer patientcentrerad och effektiv sjukvård. Den bidrar till en strömning inom forskningen som menar att sjukvården kan förbättras genom en omdefiniering av patientrollen – från en roll som passiv mottagare till aktiv, samskapande aktör. Patienten kan ses som en resurs både i utförande av vården (Anderson and Funnell, 2005; Berry and Bendapudi, 2007; Bitner and Brown, 2008; McColl-Kennedy et al., 2012; Nordgren, 2008) och inom utveckling och innovation (Bate and Robert, 2006; Groene et al., 2009; Longtin et al., 2010). Avhandlingen kombinerar sjukvårdsforskning (Anderson and Funnell, 2005; Nelson et al., 2002) med tjänsteforskning (Grönroos, 2006; Vargo and Lusch, 2008, 2004) i en forskningsansats som innefattar fyra vårdenheter och 68 patienter. Den utforskar tre aspekter av patientinvolvering och tjänsteinnovation.

För det första undersöks konceptet patientinvolvering genom en omfattande litteraturöversikt av den empiriska forskningen på området. Översikten leder till en konceptuell modell för att beskriva patientinvolvering: vad dess förutsättningar är, vilka former av patientinvolvering som finns och vad patientinvolvering leder till. Avhandlingen diskuterar även begreppet värde och hur patienter kan samskapa värde, utifrån perspektiv inom vårdforskning och tjänsteforskning.

För det andra föreslår avhandlingen en dagboksbaserad metod för att involvera patienter i tjänsteinnovation. Deltagande patienter skriver i denna metod ner sina ner sina idéer och upplevelser varje dag under två veckors tid. Mina kollegor och jag utvecklade metoden i samarbete med personal från de deltagande vårdenheterna och applicerade den på praktiken. Erfarenheterna från projektet och de deltagande patienternas bidrag användes för att utforska möjligheterna med patientinvolvering i utvecklingen av vården. Vi föreslår tre sätt att lära sig från det insamlade materialet: som direkta idéer till förbättringar; summerat till rapporter för att ge kvalitativ förståelse av andra kvantitativa mätningar; och enskilda patienters berättelser kan användas för att förmedla patientperspektivet i organisationen och mana till förändring.

För det tredje undersöker avhandlingen patienters motivation att bidra till tjänsteinnovation, ett hittills outforskat område. Genom en analys av patienters bidrag och genom intervjuer med deltagare finner vi att patienter motiveras att delta av en rad olika anledningar, från ett behov av upprättelse till en glädje av att utföra aktiviteten. Deltagandet uppfattas som en social och meningsfull händelse. Patienter upplever psykiskt välbefinnande och stöd genom att delta, även om sjukdom kan vara ett hinder i deltagandet. Avhandlingen undersöker även hur de allra mest motiverade patienterna kan identifieras och

inkluderas i tjänsteinnovation, detta inspirerat av lead user-metoden (von Hippel, 1986).

Sammantaget utforskar avhandlingen patientinvolvering och tjänsteinnovation från nya perspektiv och bidrar därmed till våra gemensamma ansträngningar för att förbättra vården och patienters välbefinnande.

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First of all, I wish to thank my advisors, Mattias Elg and Lars Witell. I realize how lucky I am to have had two highly engaged and supportive advisors. You have been able to transmit curiosity and a joy in research.

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I also wish to thank my other colleagues and friends at the division – Elisabeth, Erik, Jostein, Martina, Margo, Lilian, Peter, and Promporn – for your support and company.

A special thanks to Mary-Jo Bitner at Arizona State University, who hosted me during a most rewarding semester, and to Michael Hutt and Naomi Mandel, my teachers in Tempe. You have really inspired me.

Jörg Pareigis helped me develop the manuscript. Thank you.

The thesis builds on a collaboration with healthcare units of the county councils of Jönköping County and Dalarna. I am grateful to them for their collaboration. I aslo wish to thank the patients who shared their thoughts and feelings most openly. I interviewed some of them in their homes – a warming experience.

A big thanks to my many friends who have supported me, especially Johan Sigfridsson, for keeping me on track during the last year, and for all the pasta.

My dad spent much time reading to me as a kid and helping me with my writing assignments. That has come in handy lately – thank you. The thesis would not have happened without you.

Thanks also to the rest of my large and growing family for being there.

The thesis is dedicated to my mum. She passed away a few months before I started working on this thesis, following a difficult battle with cancer. It is my hope that some of all the love, compassion and wisdom she showed me in her life will shine through in the following pages. She made me who I am. My gratitude to her is beyond words.

Jon Engström,
Linköping, April 2014

PREFACE

With this thesis, I wish to help develop better, patient-centered healthcare, in which the patient's abilities are acknowledged. While we face challenges in today's healthcare, with an aging population and increased medication costs, we need to remember that modern healthcare is young. The year 2014 marks the centennial anniversary of the beginning of World War I and a 30-year period following that would shape our healthcare, all of which directly relates to challenges our healthcare systems face today.

In 1914, modern medicine was just established. Louis Pasteur had made important contributions to our understanding of germs. The invention of anesthesia and antiseptics revolutionized surgery. Researchers found vaccines for cholera, rabies, typhoid fever, and bubonic plague. Thanks to these advances, along with industrialization, Swedish life expectancy increased from 39 years in 1814 to 58 years in 1914 (see gapminder.org). Sixteen million people died in World War I, and another 20 million were wounded. This was more than a decade prior to the invention of penicillin. In 1918, when the war ended, the Spanish flu infected more than 500 million people around the world, killing more than 50 million people from January 1918 to December 1919 (Bynum, 2006). Twenty years of relative peaceful, but economically troubled, times, followed. Backlashes for democracy, German hyperinflation, and unemployment led to World War II. In this war, 50 million to 80 million people were killed, and typhus would kill the same number of people. Blood transfusions were commonplace, and penicillin production was industrialized (ibid). Life expectancy rose. Today, life expectancy is more than 80 years in industrialized countries. This is a tremendous success.

However, the baby-boomer generation, created in the wake of World War II, produced many of the current challenges to healthcare. Once the war was over, a large generation was born. The size and longevity of this aging baby-boomer generation is causing strains on current healthcare. When people live longer, they also have more diseases associated with old age, such as diabetes, cancer, osteoporosis, and arthritis. Until now, we increased longevity for young people. In the future, we must make elders live longer to continue this positive longevity trend.

The current roles of patient and doctor were established during this turbulent first half of the 20th century. Doctors could cure patients in a way that they could not before, and enjoyed prestige and trust. Surgeons performed an increasing number of operations, and patients needed to have faith in their doctors (Shorter, 1985). Doctors were affected by the military organization and had gotten accustomed to thinking of patients in the aggregate (Bynum, 2006).

After the war, comprehensive healthcare systems were created, which were inspired by the production industry to construct large hospitals. These healthcare systems hoped to achieve the same effects of scale as in the production industry. In this production model, the doctor is the engineer, the nurses are blue-collar workers, and the patient is the product. Today, this rigid model seems ill-suited to handle many current challenges, which often relate to chronic diseases and hinge on patient activity.

The tone in the current discourse on healthcare is rather pessimistic. There seems to be no end to the difficulties, and the outlook is gloomy. The fact is that we are better equipped today than ever before to meet challenges. Our production systems are more efficient, our communication is faster, and our understanding of human biology is much more advanced than just a decade ago. Most of the benefits from these advances have not yet been harnessed. A century ago, some of the best researchers discussed the different forms of leeches and their applications in healthcare (Figure 1).

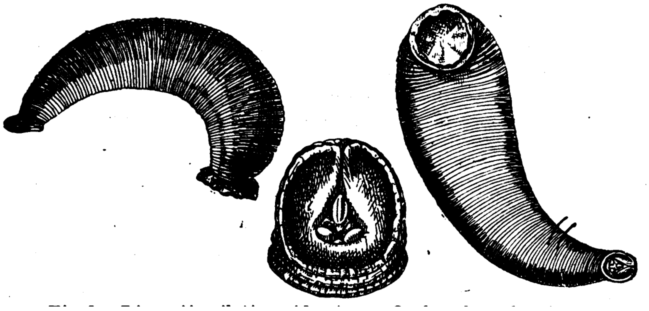

Figure 1 Asiatic leeches. (British Medical Journal, 1914)

Today, doctors use surgical robots, diabetic patients continuously monitor their own blood sugar levels, and the Newton supercomputer will begin supporting doctors in Africa. What a difference a century makes! What will be discussed a century from now?

To live longer, cope with chronic diseases, and harness the potential of new technology, we must understand how individuals can be involved in the healthcare system. We need a foundation of knowledge in how healthcare services develop and function that is rooted in the needs of individuals and societies. At the same time as we change, we must protect what we already have. The Swedish healthcare system already has much to be proud of. According to OECD healthcare data, we have some of the best outcomes in the world and the lowest costs. Sweden spends 9.5 percent of its GDP on healthcare costs, compared to 11 percent to 12 percent in Germany and France, and 17.7 percent in the United States (www.stats.oecd.org). This is possible thanks to a public healthcare system that, compared to other healthcare systems, efficiently allocates resources; in other words, the proper care to the proper patients.

In this context of patient equity and evidence-based care, we should see more patient involvement. This involvement is a way to engage patients to improve their health and the healthcare system. This requires a deep understanding of both the possibilities and limitations of patient involvement in developing and delivering healthcare. This thesis aims to contribute to that understanding.

LIST OF ARTICLES

1. Snyder, H., Engström, J. (2014). The Antecedents and Consequences of Patient Involvement – A Systematic Review and Thematic Analysis. Presented at the international HELIX conference, Linköping 2013. Submitted to journal
2. Elg, M., Witell, L., Poksinska, B., Engström, J., Dahlgaard-Park, S., Kammerlind, P., (2010). Solicited diaries as a means for involving patients in development of healthcare services. International Journal of Quality and Service Sciences, 3(2), 128–145.
3. Elg, M., Engström, J., Witell, L., Poksinska, P. (2012) Co-creation and learning in healthcare service development. Journal of Service Management, 23 (3).
4. Poksinska, B., Witell, L., Engström, J., Elg, M., Snyder, H. (2013). The influence of disease and context on patient participation in healthcare service development. Accepted for presentation at Frontiers in Service conference, 2014, Miami. Will be published as a book chapter in 2015 (Edward Elgar).
5. Engström. J., Snyder, H. (2014). Patient involvement in healthcare service development – who to involve and why. Presented at the 13th Symposium on Service in Management (QUIS), Karlstad, 2013. Submitted to journal.
6. Engström, J., Elg M., (2014). Innovating service while fighting cancer? User involvement, motivation, and patient well-being. Working paper.

MY CONTRIBUTIONS

Below I have noted my contributions in the articles with regard to research idea, research design, empirical work, analysis, and writing. As a general principle, the work in the articles has been conducted through a close collaboration between authors. I have been deeply involved in all articles except Article 2 that was written in the beginning of my PhD studies.

1. Research idea, research design, empirical work, analysis and writing.
2. Data analysis and writing.
3. Research idea, research design, empirical work, analysis and writing.
4. Research idea, empirical work, analysis and writing.
5. Research idea, research design, empirical work, analysis and writing.
6. Research idea, research design, empirical work, analysis and writing.

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1 INTRODUCTION

In 2005, Christian's life took a turn for the worse. He was a young man full of energy for work, friends, and sports, when he had kidney failure. His doctors informed him that he needed a new kidney and that he must receive dialysis several days a week. When in treatment, he soon realized that he no longer had the energy he once did. Not content with the situation, Christian began to scan the Internet on how kidneys and dialysis worked, and even contacted a professor in the US who was a dialysis specialist. He discovered that although the dialysis he received was enough to maximize his longevity, he would probably need dialysis more frequently than what his healthcare center offered, in order to get back his energy levels.

He contacted one of his nurses to ask if she would teach him to perform the dialysis by himself. She was positive to his suggestion, and they formulated a training program to operate the machines and manage his condition. Within weeks of hard work, Christian could perform the dialysis by himself. As a result, his kidney values improved, and he regained much of his lost energy. The care center also quickly realized the benefits. Not only would this give patients better quality of life, but it could save money since less staff was needed. Nine years later, the care center has a teaching process for self-dialysis, developed with patients who have free access to the dialysis room. Christian decided to study nursing and is active at the care center, teaching other patients about their illness and treatment. He shows them not only how to manage their dialysis, but also the possibilities for a good life despite the disease.

Leading scholars propose a paradigmatic shift, signified by redefining the patient role from passive recipient to a more autonomous, active, collaborative participant in healthcare delivery (Anderson and Funnell, 2005; Berry and Bendapudi, 2007; Bitner and Brown, 2008; Nordgren, 2008) and development (Bate and Robert, 2006; Groene et al., 2009; Longtin et al., 2010). The example of Christian demonstrates that when healthcare is developed in collaboration with patients, innovations of significance can be achieved. Patients' value-creating potential can also be acknowledged, and care providers can be more effective. A report from the British Department of Health (2001) promotes the concept of *expert patients*, based on the notion that they often understand their disease and situation better than do their doctors and nurses. Therefore, they can be involved in different aspects of their own care. This thesis broadly defines *patient involvement* as the deliberate activation of the patient in relation to many aspects of healthcare. These aspects can include self-care, patient education, decision-making, and development. Patient involvement is an important component to patient-centered medicine, which is founded on the principle of autonomy (Sacristán, 2013; Stewart, 2003). Patient involvement is also central to concepts such as *shared decision-making* (Makoul and Clayman, 2006; Wills and Holmes-Rovner, 2003), *empowerment* (Brennan, 1999; Salmon and Hall, 2003), and *self-management* (Bodenheimer et al., 2002a; Soto et al., 2007). The microsystem approach to healthcare, which is an important paradigm for improving healthcare, is based on the premise that value is created in contact with the patient, on a microsystem-level (Nelson et al., 2002).

There are several reasons why patient involvement currently receives significant attention. First, although providers strive for good care, healthcare systems are challenged with an aging population and unhealthy lifestyles that drive steadily increasing rates of chronic diseases. The need to activate chronic-disease patients is one important driver for increased interest in patient involvement. New costly treatments and medications create further pressure for innovative ways of meeting demand (EIU, 2011). One way this can be achieved is by increasing patient participation, which can increase the overall capacity of the healthcare system.

Second, developing information technologies opens up new ways in which patients could take over tasks, such as Christian's self-dialysis. The Internet is one such technological advancement. With a seemingly endless amount of medical information available online, patients inform and engage themselves more than ever (Orizio et al., 2010).

Third, the change in the view of the patient follows a larger trend of marketization, in which patients are viewed, and often view themselves, as value-creating actors, rather than patients in the traditional sense. This is a transformation with practical implications that can sometimes be problematic (Nordgren 2008, 2009). While patients see themselves as more competent, active and able, they also perceive themselves as patients, rather than customers. They only want to be involved when they are able to do so.

As the notion of patient involvement gains acceptance, a growing concern emerges for practitioners about how to operationalize it into practice. Research shows that cases such as Christian's are unusual. In practice, patients are scarcely a source of innovation, and their involvement often symbolic (Groene et al., 2009).

In parallel to increased focus on patients in healthcare, the service-management field developed toward an emphasis on customer actions. This concerns both direct value creation (Grönroos, 2000; Normann and Ramírez, 1993; Vargo and Lusch, 2004) and how users can be engaged in service innovation (Edvardsson et al., 2000; Witell et al., 2011). The service perspective can help improve our understanding of healthcare (Berry and Bendapudi, 2007; Bitner and Brown, 2008; Hardyman et al., 2014; Snyder, 2014). A new field, called *transformative service research* (TSR), has emerged (Anderson et al., 2013; Ostrom et al., 2010; Rosenbaum et al., 2011). TSR centers on creating improvements in well-being (Anderson et al., 2013). It encourages service researchers to understand the role of services and how individuals themselves can improve their well-being (Rosenbaum et al., 2011).

This thesis belongs to the TSR paradigm, and uses service theory to investigate three aspects of patient involvement: How patient involvement and value creation can be understood from a service perspective; how patients can be involved in service innovation; and what motivates patients to participate and how participation influences them. I will elaborate on these aspects in the following.

Patient involvement and value co-creation in healthcare

While the term *patient involvement* is commonly used, its meaning and benefits are unclear to both the public and the medical profession. A report on patient involvement (European Commission, 2012) found that "for both practitioners and patients [patient involvement is] often simply equated with medical compliance and following doctors' orders." Patient involvement is complex, and the example of the dialysis center contains some of the challenges for care providers: How can patients be involved, what is required of patients, care providers and organizational systems, and what are the effects of patient involvement?

When healthcare providers start to see patients as active partners in the care process, they will adopt a view on value creation that is different from the traditional, paternalistic view. According to service-management thought, the role of the firm is to engage customers in value creation (Normann and Ramírez, 1993). The term *value co-creation* is part of a larger theoretical framework based on the understanding that value emerges in context when resources are integrated. Changing the view of the patient from passive to active is a shift from goods-dominant logic toward service-dominant logic (Vargo and Lusch, 2004; 2008). In goods-dominant logic, the producer creates value, and consumers use it. In service-dominant logic, the customer and the organization co-create value in use.

However, healthcare has several unique features. An important difference between healthcare research and service research is how value is conceptualized. While the perception of value in healthcare is multidimensional, containing subjective and objective dimensions (Nelson et al., 1996), value in the service perspective is conceptualized as experiential and idiosyncratic (Vargo and Lusch, 2008). There is information asymmetry between physician and patient (a relationship that builds on trust), in which decisions are made in collaboration (Arrow, 1963). In relation to service theory, the consequences of these salient differences have not been sufficiently discussed. I will argue that the service perspective provides a framework for understanding value creation in healthcare, but idiosyncrasies need to be acknowledged.

According to the service perspective, the patient is the primary resource integrator, who draws from healthcare providers' competencies and skills, but also those of other actors, family and friends. Patients also draw resources in contexts not accessible to healthcare (McColl-Kennedy et al., 2012). Patient involvement in service innovation offers opportunities to better understand these contexts and interactions, and for innovations rooted in individuals' needs.

Patient involvement in service innovation

Based on a service perspective, Michel et al. (2008) suggest that innovation is increasingly created not by the firm-customer dyad, but rather through multiple sources that form innovative value constellations. Organizations must understand customers' multi-faceted roles, to improve value-co creation.

In other domains, user involvement is a strategy to better understand customers and develop new, innovative products and services that are attentive to user needs. Gustafsson and Johnson (2003) argue that service innovation is carried out from either an inside-out or outside-in perspective. The former stresses the organization's service efficacy, while the latter focuses on the organization's ability to identify with, and provide, value-adding activities for the customer. Organizations can significantly benefit from users' creative capabilities by involving them (Hippel, 2005). Thanks to users' previous service experiences, coupled with a naivety about possibilities (Wiley, 1998), they can provide new insights and more creative ideas than expert developers (Kristensson et al., 2004).

The development of Volvo's SUV model XC90 is a successful industrial example of user involvement in innovation. A group of professionally successful women was invited to give ideas on the car's features (Dahlsten, 2004). The XC90 won North American Truck of the Year in 2003, thanks to its ability to combine traditional SUV qualities with the aesthetics and practical needs of luxury-brand consumers (Volvo, 2003). There is an emerging field of research that suggests that greater user involvement in innovation is also possible for healthcare and emerging good examples (Bate and Robert, 2006). However, overall, there is a lack of established methods and knowledge for care providers to involve patients and know which patients to involve at what time (Grol, 2001). Given that these users often are vulnerable, it is necessary to understand the effects not only on the service, but also on participating patients.

Patient involvement in service innovation from a patient's point of view

While there is reason to believe that patient involvement in innovation can lead to better services in healthcare, little is known about how individual patients are affected, and what drives them to participate. Studies in industrial settings show that a number of reasons drive users to participate in service innovation: Peer approval, gaining information, or intrinsic motivation (Brockhoff, 2003). The lead-user methodology for innovation builds on the observation that a subset of users are more motivated and prone to address their needs by coming up with their own solutions (von Hippel, 1986).

Previous research on user involvement in healthcare settings has primarily concerned attitudes. Involving patients in healthcare evaluation has patient support, preferably via ongoing initiatives rather than passive methods such as surveys (Gagliardi et al., 2008; Kielmann et al., 2011). However, the preconception among patients and staff is that patients are relatively passive when it comes to involvement initiatives (Forbat et al., 2009).

Understanding these users motivation and experience from participation is important. Patients are sick, often reluctant, and must relinquish their privacy (Berry and Bendapudi, 2007).

In the above, I presented three aspects of patient involvement in healthcare, containing challenges and opportunities that lead to the purpose and research questions of the thesis.

1.1 Purpose and research questions

This thesis' purpose is to explore patient involvement in healthcare delivery and service innovation. The thesis considers three aspects of patient involvement: How patient involvement and value co-creation can be understood in healthcare; how patients can be involved in service innovation; and participation in service innovation from a patient's point of view. The specific questions that guide the research are:

Concerning patient involvement and value co-creation in healthcare:

1. What are the current forms, antecedents, and consequences of patient involvement?
2. How can value and patient value creation in healthcare be understood?

Concerning patient involvement in service innovation:

3. How can patients be involved in service innovation?
4. What may care providers learn from involving patients in service innovation?

Concerning patient involvement in service innovation from a patient's point of view:

5. What motivates patients to participate in service innovation?
6. How does patient participation in service innovation influence patients' well-being?

To answer the research questions, the thesis uses a mixed-method strategy together with a careful examination of the literature. It contains an extensive review of patient involvement. The concept of value co-creation is discussed in relation to healthcare. It also contains a methodology for involving patients in service innovation through diaries, as one example on how patients may be involved. My colleagues and I developed the methodology with four healthcare units in an action-research approach. The methodology draws on the use of diaries in research methodologies (Alaszewski, 2006; Burgess, 1984; Hammersley and Atkinson, 1995). The diary was also effective in capturing innovative ideas for service development (Kristensson et al., 2004; Magnusson et al., 2003). Contributions in the diaries and interviews explored potential patient involvement in service innovation, from a care provider and a patient perspective.

1.2 Some definitions

In the thesis, I draw on theory from primarily healthcare and service research. These traditions may refer to the same, or similar, phenomena using different terminology. I will try to clarify my usage of some key concepts.

Healthcare. In this thesis, I see healthcare as a service. I do not discriminate between, healthcare or healthcare services. Healthcare fits well into Vargo and Lusch's (2004) definition of service as: “the application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself.” However, healthcare has several idiosyncrasies compared to other services, such as patients’ vulnerable position, which must be considered (Berry and Bendapudi, 2007).

Patient. In service research, the intended beneficiary of a service is most often referred to as the *customer* or *consumer*. In some cases, the term *user* is given. In healthcare, the intended beneficiary is typically referred to as the patient. I use the same words as the original authors in the theoretical framework. In my own usage, I typically use the word *patient* to avoid unwanted connotations. In all cases, I refer to the *intended beneficiary*.

Service innovation in healthcare. The dictionary definition of *innovation* is the process of innovating: “to make changes in something established, especially by introducing new methods, ideas, or products,” from Latin *innovare*: to change (Oxford Dictionary, 2013). The research literature contains multiple views on innovation in general, and in relation to service and healthcare. I will present some of these in the theoretical chapter. The thesis primarily discusses innovation of disease prevention and provision of healthcare in line with Djellal and Gallouj (2007). This excludes innovation in areas such as medications and medical technology. In the literature, service innovation and service development is often used interchangeably. When used in this thesis *service development* refers to planned service innovation processes.

Value. There are different views on the definition of *value* in relation to healthcare. A common conceptualization of value on an individual patient level is the clinical value compass (Nelson et al., 2002). This describes value in healthcare as a multi-dimensional construct that contains health status, functional status (including well-being and risk), satisfaction, and cost. In service research, value is defined implicitly as *value-in-use*, which the beneficiary defines and determines (Grönroos and Voima, 2013; Vargo and Lusch, 2004). The theoretical framework presents different views on value, which are then elaborated in the Discussion section.

Value co-creation. A central concept is *value co-creation*. McColl-Kennedy et al., (2012) define it as “benefit realized from integration of resources through activities and interactions with collaborators in the customer’s service network.” In the healthcare literature, the term *co-production* is sometimes used with similar meaning. In the service literature, co-production means involvement in the creation of the offering itself (Lusch and Vargo, 2006). I avoid the term co-production not to cause confusion.

Patient involvement. Value co-creation is used in service research, and highlights the customers’ role in value creation. A related term in healthcare research is *patient involvement*, which I define as the deliberate activation of the patient in relation to multiple aspects of healthcare. The term is discusses in Discussion.

1.3 Organization of the thesis

This thesis is a compilation thesis that is built on a compilation summary (chapters 1 to 6) and six appended articles. The compilation summary serves several purposes. Most importantly, it binds together the articles. The articles build and extend on each other, and the discussion is based on findings across articles. Furthermore, the compilation summary provides more depth. It contains a reflection of the research methodology and the theoretical chapter is more extensive. I also use the added space to show somewhat more text from the patient diaries (in the summaries of Articles 2 and 3) to provide an understanding of the empirical material. Finally, the concept of patient involvement and the findings in the review are related to theory in the Discussion, which is not the case in the review, Article 1.

The thesis is organized as follows:

- Chapter 1: Introduction, topic of study, and research purpose and questions
- Chapter 2: Theoretical framework, literature review to provide a background of the thesis and the analytical framework
- Chapter 3: Research method to describe and reflect on the research design, methodologies, and methods
- Chapter 4: Summary of appended articles, findings and contributions of the individual studies
- Chapter 5, Discussion of the research with research questions as starting points
- Chapter 6, Conclusions, contributions and further research

2 THEORETICAL FRAMEWORK

This chapter reviews relevant literature pertaining to the thesis aim. It has five sections. The first two sections presents views on value and value creation from a healthcare and service perspective. The third section presents different perspectives on service innovation and methods for involving users in service innovation. The fourth section concerns service innovation and patient involvement in healthcare specifically. Finally, the fitfth and final section concerns motivation theory, which is used to analyze patients' possible motivations for participation.

2.1 Value in healthcare and the patient role in value creation

2.1.1 Value in healthcare

There is no ubiquitous definition of value in healthcare. The term *value* may itself be foreign to healthcare organizations, which typically use a different terminology to describe benefits of healthcare, such as *health outcomes* and *efficiency*. Value, however, is often described as quality in relation to costs, and sometimes volume (Nelson et al., 1996). Focus in the debate is often costs; Lee (2010, p. 2481) notes: "*Value* is a word that has long aroused skepticism among physicians, who suspect it of being code for *cost reduction*." The high healthcare costs in the US has led to a discussion on *high value healthcare* (see Curfman et al., 2013). One of the contributors to this debate is Michael Porter, who define value in health care in line with micro-economic thought (and in line with the idea of efficiency, later described): "health outcome per dollar spent" (Porter, 2010, p. 2477). Porter suggests that value should be measured for patient groups with similar needs. A challenge with this approach is that neither health outcomes nor costs are easily defined or measured. Blumenthal and Stremikis (2013) note that outcomes are subtle and multidimensional, involving not only physiological and functional results, but also patients' perceptions and valuations of their care and health status. A fundamental question is why value needs to be defined as something other than supply and demand on a market (Blumenthal and Sremikis, 2013):

> *We need to define the value of healthcare, however, for a simple but profound reason explained in 1963 by Nobel-prize-winning economist Kenneth Arrow. Arrow showed that healthcare markets don't work as others do, because consumers lack the information to make good purchasing decisions. Healthcare is simply too complex for most people to understand. And healthcare decisions can be enormously consequential, with irre-*

> *versible effects that make them qualitatively different from bad purchases in other markets.*

On an individual patient level, the question is what we wish to obtain from healthcare. Studies show that patients want many things – both in terms of end results, where restored health is central, and in the process of how results are achieved, with effective treatment and other elements such as emotional support and easy access (Coulter, 2005; Detsky, 2011). The clinical value compass (Figure 2) is a tool to illustrate the multidimensionality of value to help assess value in terms of outcomes (Nelson et al., 2007). The clinical value compass has four cardinal directions or dimensions. First: Clinical outcomes, measured as mortality, morbidity and complications. Second: Functional health status , risk status and well-being. Third: Satisfaction and perceived health benefits from care. Fourth: Costs, measured as the direct costs of care and other costs. It can be used at multiple levels in healthcare adapted for individual diseases (ibid). Applied on an individual patient, outcomes and costs that refer to benefits and costs for the patient.

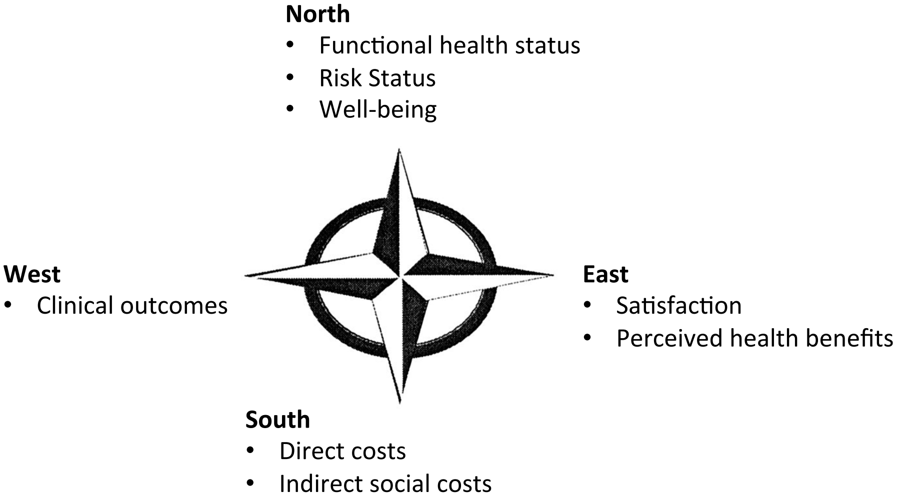


Figure 2. The clinical value compass. Adapted from Nelson et al. (1996)

Because of the challenges of measuring outcomes and costs over time, an alternate approach is to focus on the process. The Institute of Medicine (IoM) defines *quality in healthcare* (medicine) as the extent to which healthcare increase the likelihood of desired health outcomes consistent with current professional knowledge for individuals and citizens (Sorian, 2006). The patients' role in creating these outcomes is increasingly acknowledged in healthcare research. In the following, I present different views on value-creation in healthcare, starting with a brief look back.

2.1.2 The shifting view of value creation in healthcare

Historically, the view on how value, or health benefits, is created has shifted. Early medicine, from the ancient Greeks until the establishment of modern medicine, was humble and passive, based on the "healing power of nature" (Bynum, 2006). Although elements of interventions through medication and surgery were present, the place of the doctor was at the bedside of the patient, tending to the patient's own healing from a holistic perspective (Shorter, 1985). Nature itself healed the patient, with the doctor as a facilitator. Patients would frequently produce their own remedies. As professional healthcare was accessible only to the rich and influential, and doctors relied on patients' accounts of their own feelings and symptoms to make their diagnoses, historians describe patients as dominating these encounters (ibid).

A number of discoveries were made at the end of the 19th century that increased the status of the doctor. Germs were discovered, plasters invented, epidemiology was founded as a field, and the first versions of hospitals were established (Bynum, 2006). As physicians could cure an increasing number of diseases, and surgeons performed more advanced operations, their status improved. Specialization in healthcare also meant that a paternalistic doctor who focused on different diseases and procedures replaced the bedside doctor. The paternalistic doctor "is more interested in the disease than in the patient" (Shorter, 1985). By the middle of the 20th century, the patient had full faith in the doctor, who was the primary actor and value creator in providing healthcare.

Toward the end of the 20th century, the authority of healthcare would weaken (Shorter, 1985). Patients' sensitivity to symptoms and the tendency to seek help from healthcare increased. At the same time, patients felt alienated from a medical profession that focused on the disease rather than them (ibid). Patients diagnosed, and sought to cure, diseases outside healthcare, just as patients had done prior to modern medicine (ibid). Today, despite unproven efficacy, complementary medicine is a global business worth billions of dollars and one of the fastest growing fields in healthcare (Sherpman, 2008).

Recently, attempts have tried to break patients' feelings of alienation. Healthcare increasingly sees patients as active participants and the importance of holistically viewing the patient.

2.1.3 Patient involvement

Multiple concepts in contemporary healthcare management build on actively involving patients: Patient-centered care, patient empowerment, shared decision-making and self-management. These concepts have different origins, but are related and overlap.

Patient-centered care

Patient-centered care is a move away from disease-oriented care by incorporating the patient's experience of illness, the psychosocial context, and shared decision-making (Epstein, 2000). Stewart (2001) suggests that patient-centered care should be defined by the patients' wishes. An empirical examination of patients' wishes resulted in five features of patient-centered care (Little et al., 2001): Explores the patient's main reason for the medical visit, concerns, and need for information; holistically understands the patient, including emotional needs and life issues; finds common ground about the medical problem and how to manage it; enhances prevention and health promotion; enhances the relationship between patient and doctor.

An important expected outcome of patient-centered care is increased adherence to treatment (Robinson et al., 2008). To this end, patients' participation in the decision-making process is central.

Shared decision-making

Shared decision-making is an important component in patient-centered care, which is extensively treated in the literature. Terms such as *informed consent*, *informed decision-making*, *shared decision-making*, and *patient choice* describe situations in which the patient is involved in the decision-making process (Dolan, 2008; Moumjid et al., 2007). Patients' preferences and values are most important in cases where the course of action is uncertain. However, patients can be an important resource in all decisions (Dolan, 2008). The extent to which the provider takes part in the decision-making process makes healthcare unique. It is a collaborative process, built on trust between patient and provider (Arrow, 1963).

Patient empowerment

Patient empowerment is described as a state of mind in which individuals or groups gain control over certain aspects of their lives by initiating an active, participatory role (Bodenheimer et al., 2002; Bulsara et al., 2004). It is also a shift in healthcare professionals' attitude from feeling responsible for the patient to feeling responsible to the patient. This entails collaborating with patients and providing them with expertise, information, and support (Anderson and Funnell, 2005). For example, chronic disease patients must take action and be responsible for their own care. A large part of disease management extends beyond the healthcare sector into individuals' daily lives (McWilliam, 2009; Badcott, 2005).

Self-management

Self-management typically refers to patients' management of their treatments, such as controlling asthma or sugar levels (in the case of diabetes) (Barlow et al., 2002). Self-management is enhanced by productive interactions in partnerships between a practice team and informed and active patients (Bodenheimer et al., 2002). Partnerships are relationships between patients and healthcare providers that develop over time to support patients to become actively involved in their care (Hook, 2006). Self-care is a related term. Chambers et al. (2006) note: "Self-care is about people's attitudes and lifestyle, as well as what they can do to take care of themselves when they have a health problem."

The self-management literature highlights the need to view the healthcare as a system. Together with increasing focus on the patient as an actor, it is part of a second shift in healthcare away from the patient-physician dyad toward a system view on healthcare.

2.1.4 A systems perspective on healthcare

A 1999 IoM report, *To Err is Human: Building a Safer Health System* concluded that mortality and morbidity numbers were unnecessarily high due to preventable mistakes. This report was followed by another report from the IoM (Baker, 2001) that calls for improvements in six dimensions of healthcare performance (Berwick, 2002):

- Safety – avoiding injuries to patients from the care.
- Effectiveness - providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit.
- Patient-centeredness - providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
- Timeliness - reducing waits and harmful delays for both those who receive and those who give care.
- Efficiency - avoiding waste, including waste of equipment, supplies, ideas.
- Equity - providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

The ensuing work resulted in the microsystems approach to healthcare, which today is an important paradigm for improvement at an operational level (Andersson, 2013). The fundamental idea is that healthcare systems are composed of many micro-, meso-, and macrosystems.

Healthcare has contact with the patient in the microsystem (Nelson et al., 2007). These form mesosystems, which consist of administrations or clinical departments. The macrosystem is the organization-wide apex with strategic responsibilities. Nelson et al. (2007, p. 3) state: "The quality and value of care produced by a large health system can be no better than the services generated by the small systems of which it is composed." The microsystems approach is built on a resources-based view, in which staff, healthcare teams, equipment, support staff, and the environment in which care providers and patients meet all constitute resources (Nelson et al., 2007). A multitude of management practices are used within the framework, including human resources, process management and lean production. Traditionally, only physicians and their behaviors were mentioned in terms of improving healthcare. Other medical and care providing/nursing staff and organizational processes were rarely mentioned at all (Laffel and Blumenthal, 1989).

The patient in the microsystems approach

Patient-centered care is central in the microsystems approach and understands patients and their process through the healthcare system (Nelson et al., 2007). This may include several micro- and mesosystems. The role of the patient is that of a traveler who moves through different microsystems and mesosystems. Healthcare providers should understand their patients and which microsystems support these patients. Patients are also involved in self-management activities (Nelson et al., 2007).

2.1.5 Value creation and evidence

An important concept in current healthcare practice is *evidence-based medicine* (EBM) (Sackett et al., 1996). This creates value by applying the best evidence. EBM relates to effectiveness, which is one of the goals in the microsystems approach. It is often viewed more widely as a new paradigm built on use of clinical evidence (Montori and Guyatt, 2008). While the microsystems approach greatly relies on internal process data for improvement, the EBM approach emphasizes scientific studies as a basis for knowledge, and the approach is concerned with the dissemination of evidence. Sackett et al. (1996, p. 71) suggest: “Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.” This is the first and fundamental principle of EBM.

The patient in EBM

A second principle in EBM, added in 2000, is that patient preferences should be integrated in every clinical decision (Montori and Guyatt, 2008). The EBM literature stresses skills such as understanding biology, demonstrating empathy, new skills of formulating questions, information searching and appraising (Montori and Guyatt, 2008). Although EBM highlight the importance of patient preferences, it has been criticized for not sufficiently taking them into account in practice (Spring, 2008).

2.1.6 Summary of the healthcare perspective on value and the patient’s role in value creation

Healthcare is moving from a paternalistic view on value creation toward one where the patient plays a more important role in decisions and delivery of care. Researchers see healthcare from a systems perspective, containing macro-, meso- and micro-levels. The microsystems produce value by interactions with patients. Self-management in patients' home is also increasingly important, with the increase in chronic patients. It requires patients to be active in their own care. Challenges for practitioners lie in understanding how individual patients pass through multiple microsystems and mesosystems and self-management activities can be supported.

Current concepts in healthcare suggest that patients and physicians work together in shared decision-making. Estimations of value are important in these decisions, which often have long-term effects. Value is a multi-dimensional construct that contains subjective and objective dimensions of health, and costs.

The next section also concerns value and how it is created, but from a service perspective. The healthcare and service perspectives have several similarities, such as an increased focus on the patient, or customer, and systems thinking, but also differences, such as in how value is defined.

2.2 The service perspective on value and value creation

While service research primarily concerns non-healthcare settings, it faces many of the same challenges that healthcare is facing in terms of defining value and understanding the customers' role in creating value.

I will describe the service perspective on value and value creation, and highlight some existing work on healthcare from a service perspective. This also introduces the last section in the theoretical framework, which discusses service innovation and user involvement and is based on the service perspective. The next section will make a distinction between value-in-use and value-in-exchange, which is central to this article's discourse.

2.2.1 From value-in-exchange to value-in-use

Aristotle drew a distinction between value-in-use and value-in-exchange: "Of everything which we possess, there are two uses. For example, a shoe is used for wear and it is used for exchange." (Aristotle, reprint 2004). Through history, the analytical focus has shifted between the two uses.

Value-in-use refers to user benefits of a product or service when using it (Ekelund and Hébert, 2013). This concept has received less attention than *value-in-exchange* in economics, but was discussed by classical economists. Adam Smith refers to *real value*, meaning that the value of an item was created through labor (ibid). Skills were put in the product, which would emerge during use. Marx suggests that all value-in-exchange is derived from its value-in-use, and that *use values* constitute all substance of wealth (ibid).

Although value-in-use is important to customers, its experiential and individual nature makes it hard to quantify. Value-in-exchange has dominated theoretical development from Smith and onwards, and is the basis for micro-economic models. Supply-and-demand models, developed by economists in the 19th century (notably by Jevons and Ravnas), simultaneously account for value relating to production costs, scarcity, and the utility to the customer. In an open market, value-in-exchange, expressed as price, is determined by these factors (Ekelund and Hébert, 2013).

The models for value-in-exchange have influenced the thinking in other domains and have resulted in an emphasis on the company itself and the product to be exchanged, rather than its usage by individual customers (Lusch and Vargo, 2014). According to Srivastava et al. (1998), the traditional goal in marketing is to create value *for* the customer to and win the product marketplace. The marketing-mix approach (McCarthy, 1960) is the core of this marketing thought. In this view, the customer is the object of marketing's actions. Marketing services give physical clues to the offering, to productify them. Services are developed, packaged, and priced in the same manor as products (Edvardsson et al., 2006). The value-in-exchange perspective also influences healthcare. Supply and demand models also analyze patients' behavior in relation to healthcare, but also by management used in healthcare. The influence of the value-in-exchange perspective can also be traced to healthcare language, in which healthcare is demanded and delivered, and management models from production industry are applied.

When the importance of services in the economy increased, some scholars began specifically studying the marketing of services. Initially, services were seen as a subset of products. This perspective was limiting, so service marketing as a field of its own was born in the 1980s (Brown et al., 1994). Important contributions concerned service quality. Grönroos (1982) suggests that service quality can be understood based on outcomes and how those outcomes are achieved. Service quality includes two parts: Technical quality, which is the outcome; and functional quality, which is how the technical quality is transferred to the customer. The interactions between customers and firms are highlighted in the conceptualization of quality based on the fact that services are simultaneously produced and consumed (Parasuraman et al., 1985).

By the middle of the 1990s, some felt that the exchange-based paradigm in marketing was not only unable to explain services, but a new world where physical products, IT systems, and services were deeply intertwined. A new perspective in service research emerged that did not separate services and products, but instead used service as a perspective based on value-in-use (Edvardsson et al., 2006).

2.2.2 Service as a perspective on value creation

Normann and Ramirez (1993) argue that the primary challenge for companies is engaging customers' activities and illustrated their case with how IKEA engages its customers to create value.

Companies should study value constellations rather than value chains:

Increasingly companies do no longer add value, they reinvent it. Their focus of strategic analysis is not the company or even the industry, but the value creating system itself, within which different economic actors – suppliers, business partners, allies, customers – work together to coproduce value. Their key strategic task is the reconfiguration of roles and constellations of roles and relationships among this constellation of actors in order to mobilize the creation of value in new forms and by new players. (Normann and Ramírez, 1993, p. 65)

The need to engage customers and the social aspect of marketing is highlighted in relationship marketing (Grönroos, 2000; Gummesson, 1996). This research draws from marketing and quality management to study the relationships between firms and customers. Quality management subjectively defines quality as emerging during use, based on Juran's definition of "fitness for use" (Juran, 1992). While it is more difficult in the short term to observe and measure value-in-use than value-in-exchange, value-in-use is the more important concept for suppliers (Grönroos, 2008). Firms that understand how value is created for customers will be more able to compete than companies who focus on the short-term exchange. Vargo and Lusch (2004, 2008) describe this as a change in logic from a transaction-based, goods-dominant logic to a value-in-use, service-dominant logic (SDL).

2.2.3 Service as a logic

A *dominant logic* refers to mental maps developed by experience in a business (Prahalad and Bettis, 1986). Vargo and Lusch (2004) use the term *goods-dominant logic* to describe the traditional perspective, in which the producer creates value, and consumers use it. Vargo and Lusch use the term *service-dominant logic* to describe the service perspective in which value-in-use is co-created by the customer and the firm. The terms *operand resources* and *operant resources* articulate these different perspectives. An operand resource is that upon which an operation or act is performed to produce a primarily physical effect (Vargo and Lusch, 2004). In goods-dominant logic, the customer is the operand resource to be acted upon. In service-dominant logic, customers are operant resources that can act and create value.

Service-dominant logic is based upon 10 foundational premises (FP1-10; Vargo and Lusch, 2008) (See Table 1). Four of these are core foundational, or axiomal, premises, which I will describe in the following. The remaining six are derived from the other four. The first core foundational premise is FP1:

"Service is always the foundational basis of exchange." When we buy things and services, we buy them for the service or the service they render, not because of the item per se. The second core foundational premise is FP6: "The customer is always a co-creator of value." Therefore, value is interactional. Importantly, this means that the firm cannot deliver value, but only offer value propositions – invite the customer. The third core foundational premise is FP9: "All economic and social actors are resource integrators." Actors have their own network, and value is created in groups of networks. The last foundational premise (FP10) states that "Value is always uniquely and phenomenological determined by the beneficiary." While the word *phenomenological* is used, the authors sometimes also use the term *experiential*. The authors argue that when many people encounter the term *experience*, it often invokes connotations of something like a "Disneyworld event" (Vargo and Lusch, 2008, p. 9).

Table 1 The 10 foundational premises of SDL (Vargo and Lusch 2008)

Foundational premises of Service-Dominant Logic
FP1. Service is the fundamental basis of exchange
FP2. Indirect exchange masks the fundamental basis of exchange
FP3. Goods are a distribution mechanism for service provision
FP4. Operant resources are the fundamental source of competitive advantage
FP5. All economies are service economies
FP6. The customer is always a co-creator of value
FP7. The enterprise cannot deliver value, but only offer value propositions
FP8. A service-centered view is inherently customer oriented and relational
FP9. All social and economic actors are resource integrators
FP10. Value is always uniquely and phenomenologically determined by the beneficiary

Grönroos and colleagues have been a major influence to SDL, but have presented a somewhat different conceptualization, they call *service-logic*, which aims to be more operational than SDL, which they describe as metaphorical (Grönroos and Gummerus, 2014). Grönroos (2008) emphasizes that customers and firm have different roles and processes. If there is no interaction, just the customer creates value. The primary role of the firm is to facilitate value by providing customers with resources (goods and information services). If there is interaction, the firm can directly co-create value if invited by the customer (Grönroos, 2008). Grönroos and Ravald (2011) build on this view by proposing a model that divides the customers' value-creating process into two parts. In the open part, the customer creates value by interacting with the supplier. In the closed part, the customer creates value alone. Similarly, the supplier's production part of its operations is closed to the customer, but the customer and supplier can meet in the interaction part of its operations (see Figure 3).

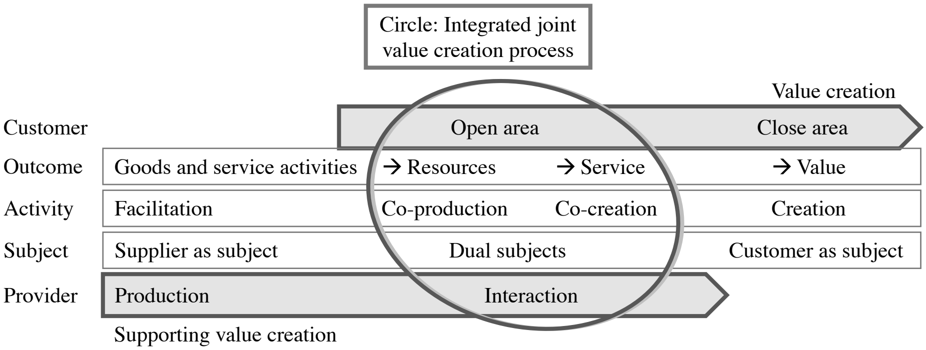


Figure 3. Value creation and co-creation in supplier-customer relationships. Grönroos and Ravald (2011). Emerald Group Publishing © 2011

According to Ravald (2010) the consequence of this customer-centric perspective is that companies must form business models that successfully integrate the service provider's processes with the customer's process of value creation, rather than the opposite. Heinonen et al. (2010) suggest that companies must understand customers to fit into their lives, and how customers integrate service into their own activity systems.

Service systems

In the same way as the system perspective influences healthcare thinking, it also influences service research. Vargo and Lusch (2014, p. 161) define a service ecosystem as "a relatively self-contained, self-adjusting system of resource integrating actors that are connected by shared institutional logics and mutual value creation through service exchange." Service ecosystems should be comprehended at several levels. A mesosystem emerges from the microsystem, and a macrosystem emerges from the mesosystem. The macrosystem filters its way down to meso- and microsystems and influences the actors.

Because value-in-use inherently follows a goods-centered thinking (where *usage* originally refers to usage of an item) Vargo and Chandler propose a reformulation from value-in-use to value-in-context, which fits into systems thinking, where value is created in the context of service systems (Chandler and Vargo, 2011). Figure 4 depicts the service in a service system, where service is exchange for service (or "service rights", money).

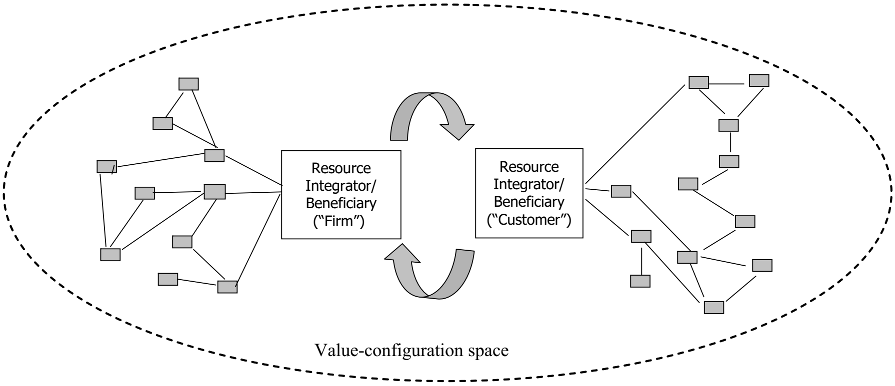


Figure 4 An illustration of value co-creation in a service system. Vargo (2008). Reprint with permission. © SAGE Publications 2008

2.2.4 Definitions of value-in-service research

Value in the service research perspective is idiosyncratic and subjectively experienced as value-in-use. Vargo and Lusch define value as "benefit, an increase in the well-being of a particular actor" (Lusch and Vargo, 2014, p. 57). They stress that value is actor-specific, contextually distinct, and unique in every occurrence. Helkkula et al. (2012) have explored how this experiential value can be described using phenomenology. Grönroos and Gummerus (2014) state: "Value is defined as value-in-use. Value-in-use is the value for customers, created by them during their usage of resources. Value is created and determined by customers." Other previous definitions of value in service research highlighted the cost, or effort, in the definition, such as "the consumer's overall assessment of the utility of a product based on perceptions of what is received and what is given" (Zeithamel, 1988, 14).

The above presented service perspective can also describe how healthcare functions. Next I will present some work to examine these possibilities, starting with a description of important differences between healthcare and other services.

2.2.5 Service research in a healthcare context

Berry and Bendapudi's (2007) article entitled "Health Care: A Fertile Field for Service Research" represents an important starting point for much of service research in healthcare.They concluded that: "Health care needs the expertise, objective point of view, and fresh ideas of service scholars in operations, management, and marketing" (Berry and Bendapudi, 2007, p. 121). That article concerned the differences between healthcare and other services to consider and extended the work by economist Arrow (1963) to describe differences between healthcare and other sectors.

Arrow pointed to physicians’ behaviors, which are different from other business employees, and are based on ethical behavior (Kenneth Arrow, 1963). Self-interest behaviors are not acceptable in relation to medical services. This role is needed, as there is high degree of product uncertainty and information asymmetry. In most other products and services, customers learn from experience, but this is often not the case for healthcare. The patient generally has much less information than the physician regarding the potential outcomes.

Berry and Bendapudi (2007) used the patient as the starting point in their discussion. The fact that these customers are sick has certain implications; for example, it may make them more sensitive, emotional, demanding, or dependent and these emotions may influence their ability to make choices (ibid). Further, patients are often reluctant. In healthcare, customer wants and needs frequently conflict. Other differences are that patients relinquish privacy and psycho-social issues often emerge in healthcare encounters, and patients must discuss highly personal matters. There is a stronger need to customize services and view patients holistically than for other customers. This means considering the patients’ medical condition, age, mental condition, personal traits, family, and more (ibid).

Possibilities and pitfalls of the service perspective

The possibilities for a service perspective on healthcare were explored by Nordgren (2008), who suggest a redefinition of the concept of productivity in healthcare to include the contribution of the patient in value creation. He pointed to Foucault's observiation in 1973 (reprint 2003) that the patient has been previously described as weak, exposed, and dependent object in the healthcare discourse. However, Nordgren (2008) also suggested caution in the use of a business-oriented discourse in healthcare. When patients are seen as active, value-creating customers, this must consider the individual’s ability to mobilize strength, and the actual will and possibilities of the individual. When healthcare managers use a business terminology and perceive patients as customers, the moral appeal in terms such *patient vulnerability* and *patient exposure* might become lost.

An increasing number of empirical healthcare studies have adopted a service perspective. Rosenbaum and Smallwood investigated third places in relation to health (2013). A third place is a commercial service establishment beyond the home and work (the first and second places, respectively) (ibid). This study examines how patients can improve well-being by using cancer resource centers, which are intended to support cancer patients. The authors found that it is primarily through the contact with the resource centers employees, not other patients at the center, that patients can enhance their feelings of support.

McColl-Kennedy et al. (2012) examined what patients actually do when they co-create value in healthcare, thereby showing how value is created in service systems. They found that the level of activity and number of contacts varies substantially among patients, who adopt different styles in value co-creation.

Some patients see their role as one of assembling and managing a team around them, while at the other end of the spectrum are patients who find it in their role to comply, with little activity or interactions. By understanding the different ways in which patients co-create value, care providers can design their services to accommodate different behaviors (ibid).

2.2.6 Summary of the service perspective on value and the customer's role in value creation

In the same way that the focus in healthcare is shifting from a paternalistic view solely of the healthcare staff and not the patient, service research builds on the notion of the value-creating customer. Value in this view is co-created in the customer's service system, including with multiple actors. This view builds on the value-in-use perspective, where value is individual, experiential and contingent on contexts. The service perspective is increasingly used to study healthcare, with emphasis in patient behaviors and well-being.

A challenge for providers is to understand the customer's service system, and how customers perceive value. Given the customer's central position, a natural consequence is to involve customers in service innovation.

2.3 User involvement and service innovation

This section describes different views and models of service innovation and the service innovation process. It also describes the rationale for involving users in service innovation, and presents methodologies for involving users. The purpose is to put the developed method for involving patients in healthcare service innovation through diaries into context, with regard to its logic foundations and where it fits into the service-development process.

2.3.1 Service Innovation

The dictionary definition of *innovation* is "to innovate," or "make changes in something established, especially by introducing new methods, ideas, or products," from Latin *innovare*: to change (Oxford Dictionary, 2013). The importance of innovation and innovators was a centerpiece in Schumpeter's work, which introduced the topic into economic studies (Sundbo, 1998). It defined *innovations* as new ways of doing things, or more unique combinations of production factors (Toivonen and Tuominen, 2009). This was the basis for more recent definitions of innovations (ibid). Innovations should not be confused with inventions, which are novel devices that are not necessarily implemented or create improvement (ibid). Innovations can be incremental or radical (Ettlie et al., 1984). The magnitude of change, in terms of technology, process, product or costs, may determine whether an innovation is the former or the latter (ibid). This means that innovations are not just an outcome of assigned innovation projects, but stem from processes in the organization, such as quality, marketing, and human resources management. Organizations must be configured for both types of innovations (Ottenbacher and Harrington, 2010).

With the increased importance of the service sector in the economy, considerable attention has been given to service innovation. Ostrom et al. (2010, p. 15) state: "For the past decade, many product-centric organizations have focused on traditional product innovation to address the challenges of globalization and economic transformation."

Approaches to service innovation

Because there are different views on what defines service (add-ons to products; a unique set of category of offerings; or value creation), there are also different views on definitions of service innovation and how service innovation should take place. Coombs and Miles (2000) name three corresponding approaches to service innovation: Assimilation, demarcation, and synthesis. In the assimilation approach, services are a subset of products, implying that services can develop in the same way as products. In a demarcation approach, services are different from products, and service innovation needs its own theories and methods. The synthesis approach views service as a perspective on value creation. In this view, service innovation concerns new ways of creating value.

Ostrom et al. (2010, p. 5) aims to define innovation in a way that is acceptable independent on view on service: "Service innovation creates value for customers, employees, business owners, alliance partners, and communities through new and/or improved service offerings, service processes, and service business models." Ostrom et al. point out a number of challenges regarding service innovation: how to stimulate service innovation, how to think about design; and how to improve service networks. It is vital to identify and manage customers' roles throughout the service-innovation process and find ways for staff and customers to collaborate (ibid).

Michel et al. (2008) use service as a perspective to understand radical innovation. Innovation research has traditionally followed goods-dominant logic and failed to explain innovations that change how customers co-create value that may lead to major market impacts. Michel et al. propose that how value is created may be innovated by a change of the customers' roles (as buyers, payers, and users) and in how the firm creates value (its embedded operant resources, resource integration, and value constellations). An innovation may concern one or more of these dimensions. For example, diabetic patients can now measure and adjust their own glucose levels. This changes the customers' role and the firms' embedded operant resources (competencies, knowledge, and skills embedded in the glucose-measuring device).

Innovation is increasingly created not by the firm-customer dyad, but by multiple sources that form innovative value constellations (Michel et al. 2008).

Consequently, organizations need to understand customers' multi-faceted roles to improve their value co-creation.

2.3.2 The rationale for user involvement in service innovation

Although user involvement in development is traditionally limited and largely passive (Nambisan, 2002), there is evidence for its benefits. One study shows that user involvement in service development positively affects new service performance (Carbonell et al., 2009). A study in the hospitality industry shows that collaborating with users leads to increased innovations, but not mainly radical ones (Ordanini and Parasuraman, 2011).

The benefits for involving users in service development can be divided into (at least) four categories: Advantages of obtaining the user perspective; understanding latent needs; increased innovative capacity; and the fact that users may already have implemented or considered solutions.

Involving users to obtain their perspective

Involving users in service innovation allows organizations to view themselves from customers' perspectives (Gustafsson and Johnson 2003). Bitner and Brow (2008, p. 43) argue: "No matter what the service innovation, and whether or not service R&D is formalized, the customer's viewpoint and value to the end customer must be considered throughout the innovation process." In service-dominant logic (Vargo and Lusch, 2004), customers are value-creating actors who integrate recourses from various sources, such as service providers and private resources (family, friends, or other customers) (McColl-Kennedy et al., 2012).

Involving users to understand their latent needs

The next motivation for involving users is based on the problem of expressing their needs. There are expressed and latent customer needs and solutions (Narver et al., 2004). An expressed need or solution is one of which customers are aware. Latent needs and solutions are those of which customers are not aware. Customary involvement techniques, such as interviews or focus groups, may reveal expressed needs. However, methods built on user involvement are preferable for understanding latent needs (Witell et al., 2011).

Involving users to be more creative

A third argument for involving users in service development is that users bring additional creativity to the table. A study that compares users with professional developers shows that users submitted ideas with greater user relevance that were more original and easier to implement than those of telecom product-development experts (Kristensson et al., 2004; Magnusson, et al., 2003; Matthing, et al., 2004). This may be explained by an experiment showing that domain knowledge which experts typically possess can be an obstacle to problem-solving, as it confines experts to a search space where the solution may not be found (Wiley, 1998).

Involving users to find out about their innovations

A final reason for involving users is that they may already have innovated solutions to their needs, or thought of solutions (von Hippel, 2005). In an investigation of how innovations actually came about, von Hippel (1986) suggests that lead users are an important source of innovations. These users experience needs ahead of the general market and are especially motivated to find solutions. Since these users benefit from fulfilling these needs, they will also put forth greater effort to obtain the solutions than will less-motivated users (ibid). (The lead user methodology will later be further described.)

Given these benefits for user involvement, the question is how to achieve it. The next section discusses processes and methodologies for service innovation that integrates users.

2.3.3 Processes and methodologies

If service organizations want to achieve incremental or radical innovations, they must manage both types of service development. Incremental innovation greatly depends on engaging employees in continuous development work. Radical innovations require greater attention to strategic direction and activities other than those undertaken for continuous service (Ottenbacher and Harrington, 2010).

User involvement in incremental service innovation

Gustafsson and Johnson (2003) propose a model for service development that builds on three processes: Service maintenance (removing things done incorrectly); improving service performance (adding things done correctly); and service innovation (developing innovative solutions to customer problems). The first two typically concern incremental innovations.

To remove things done incorrectly, it is necessary to systematically identify problems, which can be done by collecting user complaints. Since most users do not complain even if dissatisfied, other methods are needed, such as comment cards, focus groups, interviews, or the critical-incident technique (Gremler, 2004). In the critical-incident technique, users are asked to describe their experiences and emotions concerning a specific positive or negative situation. On the other hand, improving service performance involves improving the service, within its framework. To do so, the service provider must use qualitative and quantitative methods to learn how customers view the service, and how well the firm performs on important service aspects. Based on that information, the service provider can identify service aspects that will benefit the most from improvements so that customers will benefit more.

Radical service innovation requires concerted effort. In the following, I present three approaches for this kind of service development.

User involvement in radical service innovation

Some organizations with dedicated processes for service innovation use models inspired by stage-gate systems (Cooper, 1990, 1983). Each stage contains a number of process steps that depend on the project's complexity and goals. To pass to the next stage, the project must pass a gate, or a number of predefined criteria (Cooper, 1990). Edvardsson et al. (2000) provide an example model for service development in line with this sequential thinking, which draws from previous service-development models (Table 2). There are four stages;

1. *Service-idea generation* builds on the observation that successful organizations typically have established systems and procedures to generate ideas (Robinson and Stern, 1998). Employees, competitors, and customers are important sources for these ideas (Edvardsson et al., 2000).
2. The *service strategy and culture gate* step concerns formalizing the development process and forming a project team. Edvardsson et al. suggest building multiple teams with organizational resources, customers, and other external actors, such as researchers and management consultants.
3. *Service design* takes place in three steps: Designing the service; designing the service system: specifying the company's organization; and designing the service process.
4. *Service-policy deployment and implementation* concerns service implementation. Implementing a new service may lead to significant changes in the organization with new structures, roles, and procedures. This requires careful consideration, but also creates a new role for the user.

Table 2 Stages in the service-development model (Edvardssson et al. 2000)

Stage	How users can be involved
1 - Service idea generation	Users are source for service innovation ideas
2 - Service strategy and culture gate	Users for involvement are selected, along with other internal and external resources, into a mutli-team.
3 - Service design	Users collaborate in the development of the service.
4 - Service policy and deployment & implementation	Assisting the assessment of the new service

In which stage in the development projects will user involvement be most beneficial? Pitta et al. (1997) suggest that users are especially valuable to ideation. Alam (2002) suggests that user involvement is particularly important in ideation, design, and testing. Brockhoff (2003) highlights that user roles change, depending on the phase. These roles range from offering complaints and suggestions in the early stages, to collaboration and testing in the development phase, to drawing from experience to suggest improvements in the post-launch phase. In a recent study Witell et al. (forthcoming) show that obtaining customer information, especially in later design phases, increases margins for new services. When users experience the service, they know what they like or not (ibid).

Service design

Service design is the practice of applying design thought into the development of services. Ostrom et al. (2010) characterize service design as orchestrating clues, places, processes, and interactions to create a holistic service experience for users. The service design is typically led by a professional service designer, and emerged from consulting agencies that adapted the approach in the early 2000s (Segelström, 2013). Segelström defines service design as: "The use of a designerly way of working when improving or developing people-intensive service systems through the engagement of stakeholders (such as users and frontline staff)." This may include methods for identifying actors, defining possible service scenarios, and representing the service using methods such as prototyping or service blueprinting (Bitner et al., 2008).

The lead-user methodology

The concept of lead users (von Hippel, 1986) builds on the observation that some users have needs that do not yet exist for most other users. Two characteristics identify a lead user (von Hippel, 1986). They face general needs in the marketplace earlier than most users. Lead users are also positioned to significantly benefit by obtaining a solution to those needs. Because of this, lead users are more motivated to find solutions and often innovate by themselves. The notion of lead users assumes that the diffusion of information, ideas, products, and services always occurs gradually and does not simultaneously impact all users in a market (Lüthje and Herstatt, 2004).

Gradual diffusion of innovation has been thoroughly studied (Rogers, 1962). Rogers proposes that adopters of any new innovation or idea can be categorized as innovators (2.5 percent), early adopters (13.5 percent), early majority (34 percent), late majority (34 percent) and laggards (16 percent), based on a Bell curve. Each adopter's willingness and ability to adopt an innovation depends on their awareness, interest, evaluation, and trial. Individuals can fall into different categories for different innovations. For example, a farmer might be an early adopter for mechanical innovations, but a laggard for biological innovations. Lead users are not met by existing products and services. These users will typically attempt to address their needs and come up with solutions and innovations to solve these problems (von Hippel, 1986). The purpose of utilizing lead users is to identify strong market opportunities and develop concepts for new products and services (Lüthje and Herstatt, 2004; Churchill et al., 2009).

Schuhmacher and Kuester (2012) suggest that users who are dissatisfied and highly experienced provide the best ideas. They recommend that organizations identify these users for involvement in innovation activities. Piller and Walcher (2006) use a two-step method to identify lead users. First, by volunteering to participate, users show that they are motivated to contribute. Second, ideas are evaluated, and users' innovativeness is estimated. Motivation for users to participate can be extrinsic or intrinsic, and there are cases of extreme needs that force users to undergo an intense search for a solution (Bilgram et al., 2008).

The presented models for service development and innovation all require user input in terms of feedback, expressions of needs, or ideas. The method to achieve this in the current research is based on diaries.

2.3.4 Diaries in research and service development

In the context of service development, diaries are part of an ethnographic set of methods (Segelström, 2013), but the usage is broader in research and healthcare development. Diaries contain sequential, regular entries; are personal (written by an identifiable individual who controls it) and contemporaneous; and record information the writer finds relevant (Alaszewski, 2006). Diaries are either solicited or unsolicited. An unsolicited diary is a personal document that describes a subjective perception of social reality. A solicited diary is kept at the request of a researcher and may be structured into time, events, persona, or units of interest (Jones, 2000).

Studying unsolicited diaries has been useful in history and politics (Alaszewski, 2006). In studying more contemporary events, solicited and unsolicited diaries are used in various fields, such as ethnographic and anthropological research (Burgess, 1984; Hammersley, 2007), and psychology (Breakwell et al., 2006; Mackrill, 2008). There are also numerous examples of diaries used in the healthcare field (Furness and Garrud 2010; Jacelon and Imperio 2005; Milligan et al. 2005; Smyth and Smyth 2003). The purposes range from logging events of medical interest to long-term studies of emotional and social consequences of diseases.

Diaries also capture service development ideas in the context of technology-based services (Kristensson et al., 2004; Magnusson, et al., 2003; Matthing, et al., 2004). In these studies, diaries collected users' ideas for innovations concerning messaging (SMS). The diaries captured customers' ideas *in situ*, or in the natural setting of the service. The advantages of diaries and other ethnographic methods over methods such as interviews or focus groups are reduced retrospective recall bias and closeness to the natural context of events (Smyth and Stone, 2003). For these reasons, ethnographic methods are especially useful for service developers to understand how customers use and evaluate services (Wilson et al., 2008).

2.3.5 Summary of service innovation and user involvement

Service innovations may concern incremental or radical improvements. They may also involve multiple aspects of a service, such as strategies, processes or business models, and build on a change in the user role or resource reconfiguration. User involvement in service innovation is important, as it brings a user perspective to the service and adds creativity. Users may already have thought of solutions. Since much of value creation takes place outside the provider sphere and hinges on context, users are often in a better position to identify opportunities.

Incremental service innovation can draw from user complaints and ideas to achieve minor improvements and remove things that went wrong. For more substantial innovations, stage-gates models can be used. More recently, service design has emerged as an approach to innovate services. Service design includes users in the development project, and studies users by ethnographic methods, one of which is diaries.

The next section concerns service innovation and user involvement in healthcare specifically.

2.4 Service innovations and user involvement in healthcare

The healthcare market is one of the most vibrant industries for innovation, and a large share of the global research budget is allocated on this sector, which encompasses pharmaceuticals, biotechnology, medical devices, and health services (Herzlinger, 2006). However, these innovations are primarily biomedical, and a barrier to patient benefits is an overly narrow focus on gadgets (ibid), and the need for service innovation is widely acknowledged (Bitner and Brown, 2008).

2.4.1 Service innovation in healthcare

Within healthcare organizations, improvement typically takes place within the frameworks of the microsystems approach and evidence-based medicine. Drawing on experience from industrial applications of management practices, Laffel and Blumenthal (1989) and Berwick (1991) created a foundation for research into applying quality-management practices in healthcare. A number of relevant theses have been published on quality improvement in healthcare (see Lifvrgren, 2014; Andersson, 2014). Healthcare improvements from within the organization are managed by using process data, following industrial quality-management approaches, and concerted efforts to increase the use of best-evidence practices (Engström and Pettersson, 2011). These types of involvement methods often have a low level of user involvement (Andersson, 2013; Poksinska and Engström, 2013).

Challenges to patient involvement in service innovation

Surveys and interviews are the most common forms of user involvement in healthcare (Groene et al., 2009); however, the effects of patient involvement are unknown (Crawford, 2002). One reason for the limited degree of patient involvement could be related to the particular challenges relating to healthcare. Although innovation is viewed positively in healthcare, there are many challenges to innovations (Länsisalmi et al., 2006), including changing clinician and healthcare organizations, innovations in care, risky treatments and hospital procedures, and legal regulations. There is also a culture of blame caused by clinicians' tendencies to protect their autonomy and reputation, which inhibits organizational learning and a generation of innovations (Länsisalmi et al., 2006). Further, healthcare builds on a tradition of experimental research. While this tradition is important for developing new treatments and drugs, it is problematic in the context of organizational practices or structural innovations that build on social studies and rarely provide quantifiable answers to research questions. Consequently, structural and organizational innovations lack credibility among healthcare professionals (Pope et al., 2000, 2002).

2.4.2 Co-productive models

However, there are also reports of other methods in which patients have a more active role. Greenhalgh et al. (2010) described their experiences with the Modernization Initiative in the United Kingdom, an improvement initiative built on user involvement. User involvement has previously followed two approaches: the democratic approach or the consumerist approach (ibid). The democratic approach views involvement as a question of power, and involvement regards transferring power to patients. The consumerist model, on the other hand, builds on the model of the rational patient ("*homo economicus*"), who is capable of making his or her own decisions. The model assumes that patients know what is best for them and have access to the information they require. Both models have attracted considerable criticism on the basis of assumptions: the democratic model has been described as an outdated model of power, and the consumerist model has been attacked for building on false assumptions on preferences and ability of patients (ibid). Greenhalgh et al. (2010) suggested that co-productive models, in which patients are in the position of both producing and consuming services, is a way of moving beyond this rhetoric. One such model in the Modernization Initiative is the experienced-based co-design methodology (Bate and Robert, 2006).

Experience-based co-design

One approach for developing healthcare services that builds and extends on the service-design thinking is experience-based co-design (EBCD; Bate and Robert, 2007, 2006). Bate and Robert (2006) suggested that current methods and approaches, along with their underlying theories, cannot be relied on to create a more patient-centric care. Healthcare has emphasized two aspects of good design – performance (through process management, evidence-based management), and engineering (safety, through standards, safeguard for patients) – but not the third aspect, which is experience. The goal of EBCD is to address this third aspect, which has been defined as "how well people understand it, how they feel and how well it fits into the context in which they are using it" (Bate and Robert, 2006, p. 309).

The approach builds on the active participation of patients and carers. It gathers experiences from patients and staff through in-depth interviews, observations, and group discussions to identify "touch points" (emotionally significant points) and describe associated feelings (Bate and Robert, 2007). Patients and staff then work together to find solutions, which leads to both operational efficiency and personal experiences (ibid). A significant difference between experience-based co-design and other service design approaches is that instead of a professional designer or other consultant leading the work. An open toolkit exists for care providers to use (www.kingsfund.org.uk/projects/ebcd).

2.4.3 Summary of service innovations and user involvement in healthcare

While innovation in healthcare is significant, it is dominated by a focus on medical technology and pharmaceuticals. Service innovation in healthcare often consists of internally-oriented quality management techniques with little patient involvement. Barriers to service innovation include organizational structures, and an emphasis on clinical experiments as a basis for knowledge.

Patient involvement has followed either a democratic approach (concerned with the distribution of power) or a consumerist approach (which focuses on patient choice). Both approaches have been criticized, with patient and care provider collaboration to produce care being seen as a better way forward. Experience-based co-design is one such approach.

The final section of the theoretical framework concerns motivational theory, which is used to analyze why patients chose to become involved in service innovation and their activity levels.

2.5 Motivations for participation

Motivation is a crucial factor in relation to involvement – why users chose to engage, and at what level. This thesis applies the notion of intrinsic and extrinsic motivation (Ryan and Deci, 2000) to better understand patients' motivations. Further, the broaden-and-build theory, concerns how emotions affect tendencies to engage in activities (Fredrickson, 2001), which is especially important in healthcare where the emotional states of patients may be affected by the situation. These theories will be described in the following.

2.5.1 Intrinsic and extrinsic motivation

The notion of motivation means “to be moved to do something” (Ryan and Deci, 2000). Individuals show a great variety of motives for engaging in specific activities. Some people are highly motivated and active, while others may exhibit low energy levels and interest. Motivations also vary across time. For task performance, it is valuable to understand the inner drives for action. Self-determination theory explains two different types of motivation: intrinsic and extrinsic.

Intrinsic motivation arises when people find enjoyment and interest in performing tasks. It exists within the individual and is driven by inherent satisfaction, rather than external rewards. Furthermore, intrinsic motivation is commonly associated with high degrees of autonomy and subject competency (ibid).

In contrast, extrinsic motivation is present “whenever an activity is done in order to attain some separable outcome” (Ryan and Deci, p. 60). The external drivers of extrinsic motivation may be reward, competition, or punishment of various kinds. Ryan and Deci (2000) propose that there is a continuum of several different types of extrinsic motivation. The differences of these types are outgoing from the perceived locus of causality. In other words, a person’s understanding of the causes of action are internal (control within the individual), external (caused by the environment) and, at the end-point of the continuum, beyond the control of the individual. The different types of extrinsic motivation are: External regulation; introjection; identification; and integration. Amotivation is a third type of motivation. Amotivation emerges when people feel that they have no or little competence for the task, or they do not think the task is relevant.

2.5.2 Emotions and activity

Broaden-and-build theory (Fredrickson, 2001) suggests that people’s repertoires of thoughts and actions are influenced by emotions. An emotion begins with an individual’s assessment of the personal meaning of some antecedent event. The appraisal is either conscious or unconscious and triggers a cascade of responses, such as subjective experience, facial expression, cognitive processing, and physiological changes (Fredrickson, 2001). Negative emotions narrow the range of thoughts and actions to promote quick, decisive action. Positive emotions of joy, interest, contentment, pride, and love have the opposite effect and broaden the array of thoughts and actions (Fredrickson, 1998). Positive emotions allow individuals to access associated memories and frame their thoughts around related concepts, enabling them to consider a wider range of options. Negative emotions can make small problems seem insurmountable (Clore and Huntsinger 2007).

Gallan et al. (2013) show that the patient’s affective state may explain the level of participation in healthcare services. *Participation* is defined as the extent to which patients share information, make suggestions, and are involved in making decisions (ibid). Gallan et al. (2013) provide empirical evidence of customer affective state as a significant antecedent to patient participation. Positivity is associated with greater participation, and leads to greater satisfaction. An interesting finding is that despite patients' experience of high risk, they also experience strong positive emotions. Patients may attempt to increase their chances of positive outcomes by evoking positive emotions leading up to challenges (Fredrickson 2001).

2.5.3 Summary of motivations for participation

Motivation can be intrinsic, referring to the enjoyment of performing a task, or extrinsic, referring to a wish for an external outcome. A sense of non-control causes amotivation. The motivation to engage may also be affected by a person's emotional state. Negative emotions narrow the array of thoughts and actions, and the contrary is true for positive emotions. Emotional states influence patient participation.

3 RESEARCH METHODOLOGY

This thesis encompasses three research strategies. Firstly, a systematic literature review with thematic analysis was conducted to examine the concept of patient involvement. Secondly, an action-research approach was applied to develop a diary-based methodology for involving patients in service innovation. Thirdly, analysis of the data patients provided in the diaries was used to examine different aspects of patient involvement in service innovation.

3.1 Overview

A common division of research is between qualitative and quantitative. The former emphasizes words rather than quantifications in data collection and analysis (Bryman and Bell, 2011). This research, which uses diary entries as a primary data source, is predominately qualitative. There are different traditions within qualitative research (ibid): Naturalism; ethno-methodology; emotionalism; and postmodernism. I categorize this research as naturalistic, since it provides rich descriptions of people and interactions in their natural setting. To a limited extent it is emotionalistic, since it tries to understand patients' emotions and experiences using an ethnographic method, the diary. This combination is in line with the traditions of quality and service management, which regularly combines objective and subjective perspectives. It is rather pragmatic in its attempt to involve patients, rather than to understand social order (ethno-methodology) or how social realities are constructed (postmodernism).

The present research is exploratory, rather than explanatory. It contains new perspectives (the service perspective on healthcare) and explores the new field of patient involvement in service innovation. Although qualitative approaches are often inductive, by building theory from empirical data, the present research interactively uses theory in an abductive process (Alvesson and Karreman, 2011). For instance, we chose to use diaries as the basis for a methodology we developed for involving patients in service innovation, based on service innovation theory. This suggests that *in situ* methods for user involvement are more beneficial than alternatives for ideation (Article 2). Empirical findings that some patients were especially innovative led to the idea that lead-user methodology could also apply in healthcare (Article 5). The abduction process thus stretches across articles.

Overview of the applied methods

Table 3 contains an overview of the methodologies applied in each article. Article 1 builds on a systematic literature review to examine the literature of empirical research on patient involvement and associated concepts. Articles 2 and 3 develop a diary-based methodology for involving patients in service innovation. We developed the methodology by a management action-research approach. Articles 4 to 6 answer research questions concerning possible involvement in different situations, and patients' motivations. They build on analyses of patients' contributions in the diaries, complemented with interviews in Article 6.

Table 3 Overview of methodologies applied

Study design; Data collection	**Care units**	**Data**	**Method for analysis**
Article 1 - The antecedents and consequences of patient involvement – a systematic review and thematic analysis			
Literature review; systematic database search	N/A	132 articles concerning patient involvement	Thematic analysis
Article 2 - Solicited diaries as a means for involving patients in development of healthcare services			
Action research; workshops, diary method	Orthopedic, Gastro, Rehab	Workshop documentation; diaries from14 patients	Content analysis; Descriptive statistics
Article 3 - Co-creation and learning in healthcare service development			
Action research; workshops, diary method	Orthopedic, Gastro, Rehab	Workshop documentation; diaries from 53 patients;	Content analysis; Descriptive statistics
Article 4 - Patient participation in healthcare service development			
Diary method; quantitative analysis of patients' contributions	Orthopedic Gastro, Rehab	Diaries from 53 patients	Quasi-experimental
Article 5 - Patient involvement in healthcare service development – Who to involve and why			
Diary method;	Orthopedic Gastro Rehab Lung cancer	Diaries from 68 patients, focus on the four most innovative	Content analysis
Article 6 - Innovating service while fighting cancer? User involvement, motivation, and patient well-being			
Diary method; interviews	Lung cancer	Diaries from 13 patients and two next of kin, six interviews	Content analysis

Next I will describe the process for the literature review, the management action research and the following analysis of the patients' contributions.

3.2 Systematic literature review

While often neglected as a research methodology, it is equally as important to follow a transparent methodology in literature reviews as in other research (Greenhalgh et al., 2004). Tranfield et al. (2003) suggest that one purpose of systematic review is to provide collective insights by theoretical synthesis into fields and subfields. This should preferably be done in a structured manner, with a review protocol, clear inclusion criteria, and quality assessment of selected studies, Data is then extracted and synthesized (Tranfield et al. 2003).

Article 1 acknowledged that the topic of patient involvement was scattered between different concepts and approaches. The aim was to help gather knowledge in the domain and represent this in a model. We conducted the review in two stages. A database search was performed by a systematic review method, followed by a thematic analysis. We did not perform a quality assessment of the included studies because the literature, in terms of topic and methods, was highly heterogeneous. We reported the findings of the studies, rather than to draw conclusions from the aggregated data material across studies. For an overview of the process, see Figure 5.

3.2.1 Systematic article search

A search specialist at the university library helped with the systematic search. We identified relevant search words using standardized Medical Subject Headings (MeSH) search terms available in PubMed. The search terms were carefully chosen to capture the various aspects of patient involvement, without resulting in an unmanageable amount of articles (see summary of Article 1 for details). The search was conducted in PubMed, CINAHL and EBSCO (Academic Search Premier, EconLit, and PsycINFO). We also scanned the references and citations within the selected articles to capture additional articles.

We included articles that mainly focused on patient involvement; were peer-reviewed and empirical; did not have a psychiatric or pediatric/adolescent sample; were accessible; and were published in English between 1990 and 2012. The initial search yielded 3,392 articles. From a scan of abstracts and full articles, we selected 355 articles for further analysis, which we independently read. We identified 106 articles that met all inclusion criteria. From our additional hand search, we collected 19 more articles. The final sample included 125 articles.

3.2.2 Thematic analysis

We applied thematic analysis to identify patterns from the literature and describe the various facets of patient involvement. The analytic process was in line with the phases of thematic analysis Braun and Clarke (2006) identify. Familiarization with the data initially generated ideas for creating codes. These codes were linked together and grouped into potential themes. Each theme was reviewed to ensure that it reflected both its associated coded extracts and the entire data set. We discussed interpretations, disagreements, and questions throughout the process to reduce the risk of subjectivity and preconceptions.

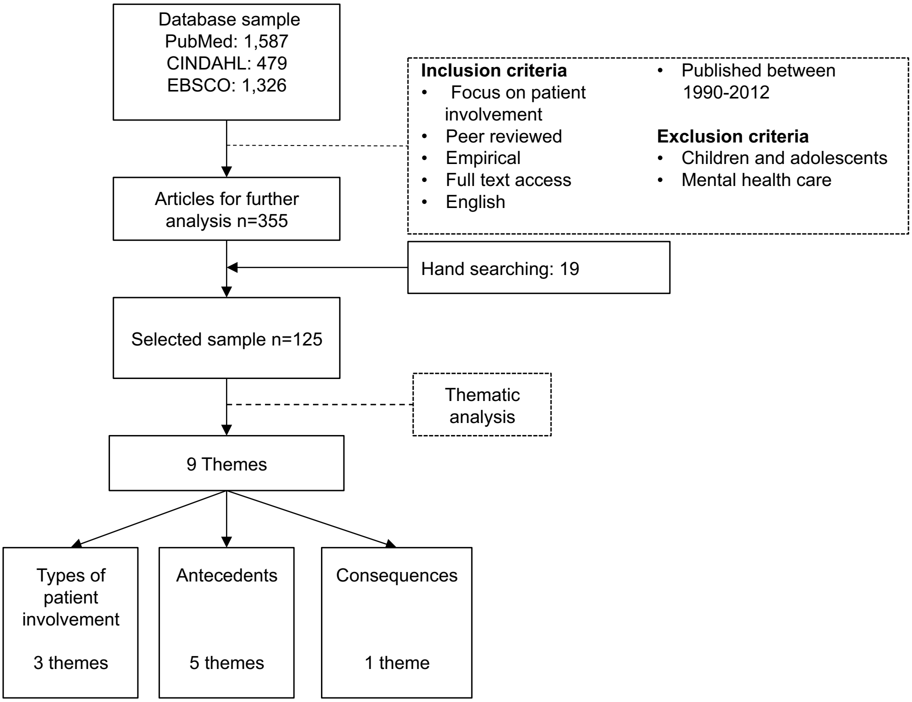


Figure 5 The process of the systematic literature review

3.3 Action research

To explore how to involve patients in service innovation and how a practical methodology could be designed, an action-research approach was used. In the following, I present the management action-research methodology, and how it applies in the current research, including participating units and patients.

3.3.1 Management action research

Action research builds on collaboration between researchers and practitioners (Gummesson, 2000). It typically has two objectives: Solve a problem in practice and expand the body of knowledge within a certain field. The approach originates in societal-action research, where researchers help underprivileged groups solve problems (Lewin, 1946). The approach is now applied in other fields, such as operations management (Coughlan and Coghlan, 2002) and marketing (Perry and Gummesson, 2004). Gummesson (2000) makes the distinction between societal-action science and management-action science. The first approach takes a political, social view. The latter focuses on companies. Although it contains empowering elements, I classify this research as management-action science.

Action research builds on mutual interest of researchers (the research system) and practitioners (the practice system) in solving a problem. Practitioners own the problem and understand its specific context, whereas researchers have theory-based knowledge (Perry and Gummesson, 2004).

A self-reflective spiral of cycles of planning, acting, observing, and reflection is central to the action-research approach (Figure 6) (Coughlan and Coghlan, 2002). As a sequence of events, the research includes providing data and feedback to practitioners, analyzing data, and planning actions. It is a scientific approach to problem-solving by collecting facts and experimenting through actions from organizational members. The desired outcomes not only solve the problems, but provide important insights that can contribute to theory (Coughlan and Coghlan, 2002).

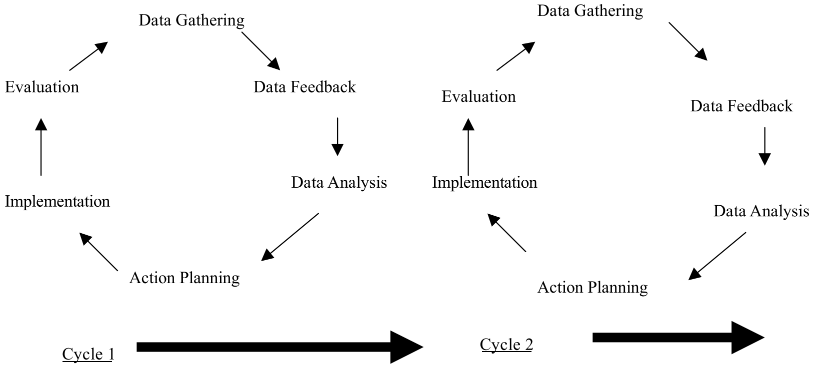


Figure 6. The action research spiral (Coughlan and Coghlan, 2002). Reprint with permission. Emerald Group Publishing © 2002

Traditional action research is "the most demanding and far-reaching method of doing case study research" (Gummesson, 2000, p.116). In both action-research and case studies, researchers and practitioners use numerous sources of empirical data collection and apply analytical tools to draw generalized conclusions.

3.3.2 The current research project

This action-research project came from a common interest between a care-providing organization and academic researchers to explore patient involvement in service innovation. The healthcare staff could provide the knowledge needed regarding the healthcare context, and researchers had knowledge concerning user involvement methodologies in other domains.

Selection of care units

The research system initially consisted of seven academic researchers with backgrounds in quality and service management. The practice system consisted of representatives from three care units at one healthcare organization. In the later stages of the study, one additional healthcare organization was added. The practice system was represented by a central development unit and three care processes were selected to participate. See Table 4.

We used theoretical sampling to select the processes to participate for the first three cases (Eisenhardt, 1989). The cases were selected because patients had different medical concerns and processes were of different lengths and complexity. The three cases were orthopedic, rehabilitation, and gastro-enterology. Later in the research processes, lung cancer was added as a fourth case. The lung-cancer unit, which belonged to a hospital in a different region, was added after its representatives asked to participate after hearing about the project. This was a significant addition, as lung cancer includes a set of unique challenges due to disease severity.

The orthopedic care process has a standardized care procedure. Treatment complexity is low, as it is a field with high clinical knowledge and standardized procedures. The orthopedic process has little patient co-creation.

The rehab process included patients with longstanding chronic pain who participated in a pain rehab program. The program goal was to help patients minimize their suffering and restore their ability to enjoy life. Active involvement of the patient and family was vital to program success.

The gastro-enterology process included continuously treating patients with chronic stomach and intestinal disorders. This is a highly complex process, as there is little knowledge of these illnesses, compared to other disorders. There was high patient involvement and co-creation, as the chronic condition made patients experts on their disease.

The lung-cancer process included treating patients diagnosed with lung cancer. Although this process is relatively standardized, it poses different challenges for both staff and patients. The severity of the illness puts mental and physical stress on patients. Patients spend a large part of time at home, but come in for treatments.

Table 4 An overview of the participating care units

Participants	Patient characteristics	Typical treatment	Involvement in own care
Orthopedic care			
21 male 16 female	Relatively old patients with referrals from primary care	Replacement of hip, standardized procedure to care. Short duration	Low. Patients are hospitalized during treatment, but recover from surgery at home.
Rehabilitation			
9 male 1 female	Patients of various ages, longstanding chronic pain in spine, back and shoulders	Participation in a pain rehabilitation program. Long duration.	High. Necessary since the aim of the rehab program is learning how to handle pain.
Gastro-enterology			
1 male 5 female	Patients of various ages, chronic stomach and intestinal disorders	Periods where the patient is doing well and periods of relapse. Continuous.	High. Patients are experts in their own preconditions and possibilities
Lung cancer			
13 male 2 female 2 next of kin (female)	Older patients with referrals from primary care	Periods of active treatment with chemotherapy and radiation, and periods without treatment. Continuous.	Low. Standard treatment and can do little to improve health situation

3.3.3 The research process

The starting point for the research was the idea that if care providers involve patients in service development, they could create more patient-centered care. We decided in the outset to apply a diary method for gathering patients' ideas and information.

The project started with joint workshops between researchers and practitioners. Problems, research questions, and actions were discussed and planned. From the healthcare providers' perspective, the problem was how to involve patients in developing more patient-centered care. The joint research and development activities included designing the diary and the data-collection process, as well as how to utilize the ideas and experiences gathered from the patients' diaries. The method for patient involvement was tested and applied in the participating healthcare organizations. These steps constituted the first cycle of the action-research process.

A second cycle of workshops refined the process and made amendments to the diaries. More attention was then given to the latter parts of the process, in terms of how care providers could learn from the diary data. The lung-cancer case was conducted after the previous cycles. This was conducted in two cycles. It added ethical dimensions due to the severity of the disease. In the first cycle, next of kin were also invited to participate. The care provider chose not to do this in cycle 2, due to low interest in first cycle.

Selection of patients

Patients were randomly selected for participation. The first contact with patients was a letter describing the project, including an acceptance form for patients to sign if they wished to participate in the study. It also clarified that participation was voluntary, and further contact with the care providers would not be adversely affected if patients chose not to participate. Patients were free to leave the study at any time. Patients could use a written diary or a blog. Patients were instructed to record events for 14 consecutive days. Participants in the lung cancer case were also asked if they wished to participate in an interview following the use of the diary. Convenience and illness determined who finally was interviewed. Table 4 contains an overview over participating patients.

Data from 70 participants (13 in the first cycle, 40 in the second cycle, and 17 in the added lung cancer case) was collected.

Thirty-seven patients (21 male, 16 female) belonged to the orthopedic process. Ten patients (nine male, one female) belonged to the rehabilitation process. Six patients (one male, five females) belonged to the gastro-enterology processes. Data from 17 patients was collected in the lung-cancer process (13 male, two female, two female next of kin).

The approximate mean ages were 67 years in the orthopedic group, 45 years in the rehabilitation group, and unknown in the gastro-enterology group (most participants did not to disclose their age). In the lung cancer group, the median age was 74.

Implementation of ideas

In the first three cases, the diary was aimed for the continuous improvement. Films were also used created from patients' experiences and used internally (see summary of appended Article 3). In the lung cancer case, diaries were used in the framework of a larger improvement initiative. A report was created building on the collected diaries which was used in the improvement work and which was also the basis for a masters thesis for two of the nurses (Andersson and Bettembourg Grundström, 2012). The research system did not systematically involve in the implementation of ideas from patients, which is a limitation.

Ethical approval

The research was approved by the Regional Ethical Review Board in Linköping (Ref. nos. 20029-09). The participants' autonomy was acknowledged by emphasizing in text, a cover letter, and the diary that participation was voluntary and participants could withdraw from the study at any stage. Participants were also informed that confidentiality was maintained when presenting results. All participants were over the age of 18.

3.4 Analysis of patients' contributions

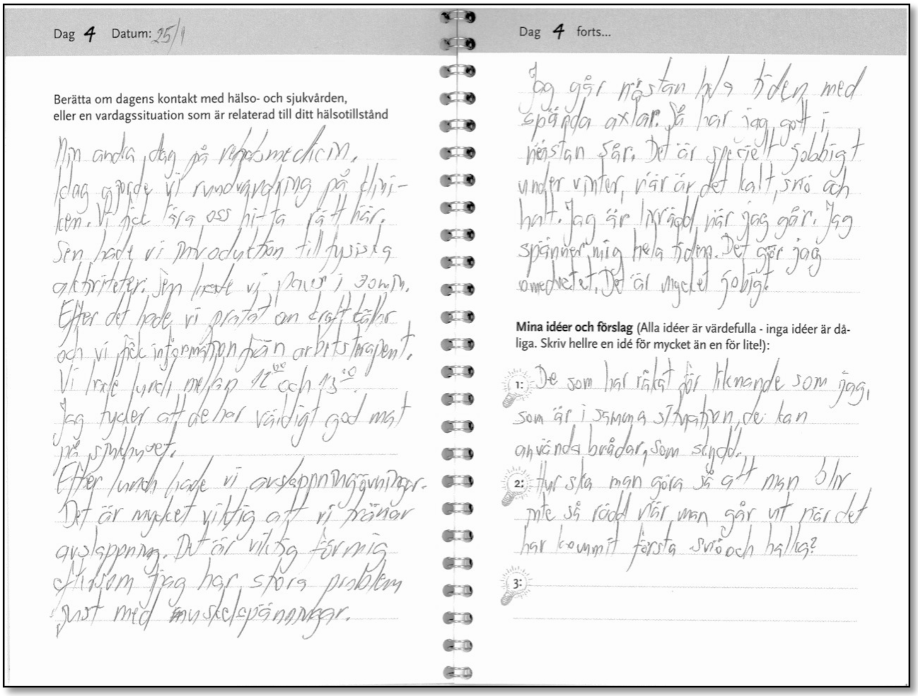
3.4.1 Data collection from solicited diaries

Although developing the diary process was a goal by itself, it was also a data-collection method. Diaries have been used in a number of research areas, such as ethnographic, anthropological (Burgess, 1984; Hammersley, 2007), and psychology studies (Breakwell et al., 2006; Mackrill, 2008). Diaries for data collection are either solicited or unsolicited. An unsolicited diary is a personal document that describes a subjective perception of social reality (Jones, 2000). A solicited diary is kept at the request of the researcher and usually is structured into time, events, persona, or units of interest.

The diaries in this study were solicited, as there were instructions for the subjects. The explicit goal was to identify ideas for improvements. The diaries had three data-collection parts. In the introduction, patients were asked to briefly introduce themselves and present reasons for their contact with healthcare. For each day, the diary was separated into two parts: An open recounting of the day's events and contacts; and a three-item list to fill in specific improvement ideas. See Figure 7.

In-depth interviews

In the last study, involving lung-cancer patients, interviews evaluated patients' experience of participating in service development. The interviews were 45 to 75 minutes long and conducted in patients' homes. An interview guide was used, which was based on relevant theory. The interviewees were asked how they felt about being asked to participate in the service-development project, why they participated, if they thought they or other patients could contribute, if they had any personal gains from participating, and positive and negative emotions associated with participating. The interviews were transcribed into text.



Dag 4 Datum: 25/1

Berätta om dagens kontakt med hälso- och sjukvården, eller en vardagssituation som är relaterad till ditt hälsotillstånd

Min andra dag på rehabmedicin.
Idag gjorde vi rundvandring på kliniken. Vi fick lära oss hitta rätt här.
Sen hade vi introduktion till fysiska aktiviteter. Sen hade vi paus i 30 min.
Efter det hade vi pratat om kraft källor och vi fick information från arbetsterapeut.
Vi hade lunch mellan 12^{00} och 13^{00}.
Jag tycker att de har väldigt god mat på sjukhuset.
Efter lunch hade vi avslappningsövningar.
Det är mycket viktig att vi tränar avslappning. Det är viktig för mig eftersom jag har stora problem just med muskelspänningar.

Dag 4 forts...

Jag går nästan hela tiden med spända axlar. Så har jag ont i nästan där. Det är speciellt jobbigt under vinter, när är det kalt, snö och halt. Jag är livrädd när jag går. Jag spänner mig hela tiden. Det gör jag omedvetet. Det är mycket jobbigt.

Mina idéer och förslag (Alla idéer är värdefulla - inga idéer är dåliga. Skriv hellre en idé för mycket än en för lite!):

1: De som har råkat för liknande som jag, som är i samma situation, de kan använda brådar, som skydd.

2: Hur ska man göra så att man blir inte så rädd när man går ut när det har kommit första snö och halka?

3:

Figure 7 The diary design used in the study

3.4.2 Data Analysis

Thematic analysis

We identified patterns in the interview material in the same way as we did in the diaries. The analytic process was in line with the phases of thematic analysis Braun and Clarke (2006) propose. Familiarization with the data initially generated ideas for creating codes. The different authors made this individually. These codes were linked together and grouped into potential themes in a group activity. Each theme was reviewed to ensure that it reflected both its associated coded extracts and the entire data set. We discussed interpretations, disagreements, and questions throughout the process to reduce the risk of subjectivity and preconceptions.

For the interview analyses (in Article 6), we used theoretical propositions from self-determination theory to define themes, in a top down approach. We used the NVIVO 10 software to code themes in diaries and interviews.

Inferential statistics

To investigate how types of disease (episodic/chronic) and context (home/care provider) influenced types of ideas we used a quasi-experimental design. Quasi-experimental designs are designs that are close to being experiments but does not meet the requirements fully (Bryman and Bell, 2011). In the present case, types of disease and context were independent variables. Using the coding from the content analysis, we coded each idea for relevant characteristics of types, characteristics, and sources of patients' ideas. We used logistic regression to investigate the influence that the independent variables and their interaction effect had on six dependent variables related to characteristics and sources of ideas. Logistic analysis was used, since the data points were binary. Through the differences in the dependent variables and the differences in the topics of the ideas, we identified what characterized the four groups. Based on the type of disease (episodic/chronic) and context (home/caregiver), we identified four different roles that a patient can have in healthcare service development.

3.5 Evaluation of the methodological approach

Construct validity, internal validity, external validity, and reliability are four common tests for empirical social-research quality. All except internal validity are relevant in exploratory research (Yin, 2009). I will use Yin's criteria to discuss this research. Because there are three types of findings in the study, I will discuss them separately. First, there were findings from the literature review. Second, there were findings about how to make a process for handling diaries. Third, there were findings about what we can learn regarding patient involvement in service innovation using diaries and from analyzing diary content.

3.5.1 Validity and reliability

Construct validity concerns the correctness of the operational measures for the concepts being studied (Yin, 2009). Qualitative studies are often criticized for not developing a sufficiently operative set of measures. Using multiple sources of evidence, establishing a chain of evidence, and letting key informants review the study report counters construct-validity weaknesses (ibid).

External validity is the confidence in generalizing study discoveries to people, contexts, and times not included in the study. This often concerns the study sample. Yin (2009) proposes strategies to use multiple cases and make analytical generalizations, using theory to make predictions and confirm them. Findings may be statistically and/or generalizable to theory. *Theoretical generalizability* means that theory is extended to new context. It may refer to theoretical advances at early stages or theoretical refinement (ibid).

Reliability ensures that study operations can be repeated with the same results in a specific case (Yin, 2009). Merriam (1997) proposes that researchers should clarify their position, triangulate different data-collection methods, provide trails for audits, and describe how the research was conducted.

The literature review

The review concerning patient involvement was performed in accordance with the Prisma criteria for literature reviews (www.prisma-statement.org), which is a requirement for publication in the journal to which the article was submitted. Because the primary aim was to describe the field, thematic analysis was suitable. In the search phase, we used standardized search terms and expert help to formulate research strings. In the analysis, both authors read the sampled articles in the inclusion process. Both researchers also analyzed all articles in the thematic analysis. We discussed findings to improve inter-coder reliability.

However, it is still likely that a different set of researchers would identify different articles for inclusion and made different interpretations of their significance. They would probably also synthesize the results differently. Our ambition was to remain true to the original articles, and not over-interpret any findings. As we point out in the article, the causalities in relation to patient involvement are understudied.

Developing the diary-based methodology for patient involvement in service innovation

In developing the model for involving patients, the primary measure was whether or not the process of administering the diaries worked in practice. The informants (healthcare staff) could judge this and were continuously involved in writing progress reports. The diary content and patients' actions were used as an additional evidence source. This included degree of participation, activity in writing and contributing, number of ideas and topic ideas. The study was strengthened by a multiple-case strategy, in which the four care units covered different types of care. This strengthened the generalizability and explained some of the variations expected in organizations, although not statistically.

Findings concerning the process of the methodology may be useful to other healthcare units by user generalization (Merriam, 1997), in which experiences from the cases in the thesis can be useful to the reader and generalized to their own domain.

Drawing conclusions from patients' contributions

Data collection was conducted in a well-documented, straightforward fashion. Data analysis is susceptible to greater variation, as it depends on the individuals performing the analysis. In the context of coding variables, inter-coder reliability is important for consistency (Bryman and Bell, 2011). In analyzing the diaries, the thematic framework was created in collaboration and discussion, and different categorizations were defined. Concerning patients' contributions, it is likely that the range of ideas and topics would be similar in different healthcare contexts, but the emphasis on aspects of care would differ. In Article 5, a procedure for selecting the most innovative patients was used. We rated diaries on two factors that were important for useful user contributions according to theory. Although the inter-reliability was measured and satisfactory, it is possible that a different set of researchers would have come to different conclusions or used different criteria. The strategy is an attempt to achieve analytical generalization by applying existing theory on user involvement to the healthcare context.

4 SUMMARIES OF APPENDED ARTICLES

This chapter summarizes the six appended articles. Each summary contains a brief background and objective, and describes how the article relates to the research question of the thesis. Summaries also contain the main findings of each article and a brief account of conclusions and contributions.

4.1 Article 1: The antecedents and consequences of patient involvement – a systematic review and thematic analysis

Snyder, H., Engström, J.

4.1.1 Background

Article 1 investigates patient involvement in healthcare by systematically reviewing the empirical research published in healthcare journals. The article primarily addresses Research Questions 1 of the thesis, concerning current forms, antecedents, and consequences of patient involvement.

To capture the concept of patient involvement, the searches were conducted using three categories of MeSH terms and keywords. Category A: patient involvement, patient participation, patient compliance, empowerment, and patient power. Category B: cooperative behavior, collaboration, co-creation, co-designing, and cooperation. Category C: self-care, attitude of health personnel, cost savings, self-help groups, and professional-patient relations. From a first sample of 3,329 articles, a final sample of 125 relevant articles from more than 40 journals was selected for analysis.

4.1.2 Findings and contributions

Themes about categories of patient involvement concerned decision-making, delivery of healthcare, and development and research. Themes of enabling factors concerned patients, staff, and the organization system. One theme concerned the consequences of patient involvement. The following model synthesizes how patient involvement was investigated in previous research (Figure 8).

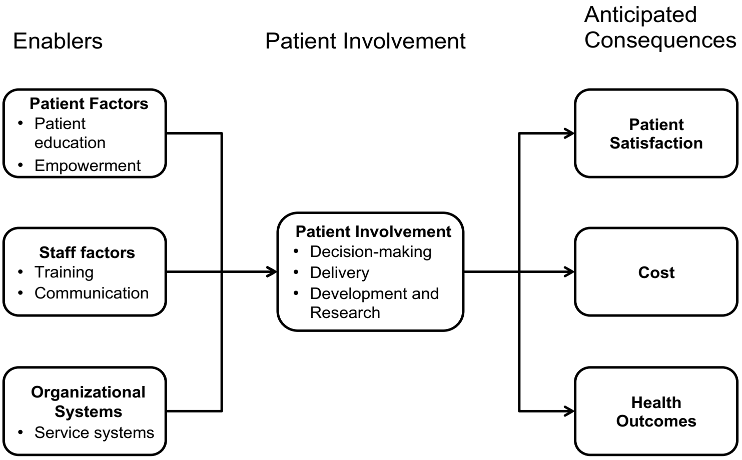


Figure 8 Model for patient involvement in healthcare

Forms of patient involvement

Patient involvement in decision-making: Decision-making studies concern issues such as attitudes, implementation methodologies, and decision aids that physicians can use. Although both physicians and patients are generally positive toward shared decision-making, patients are not actively involved in many cases and are not given a role in decision-making. A challenge lies in understanding the individual patient's decision-making preferences. *Patient involvement in healthcare delivery* concerns how patients are actively engaged in their own care, from self-medication to advanced self-management. Studies show that patient involvement in delivery depends on a complex interplay of personal, physician, and contextual factors. *Patient involvement in development and research* differs from the previous two forms, as it not only concerns treatment, but improvement of the healthcare system. This most commonly occurs by surveys, which are rarely used to improve quality, because supporting values, infrastructure, and training are not in place. Some researchers suggest qualitative methods understand patients' experiences.

Antecedents

Patient education regarding disease and treatments is seen as an important means to increase patient involvement in healthcare delivery and to improve adherence to treatment. Education is needed to reach involvement objectives. Staff may teach patients even when they do not define this as teaching. *Patient empowerment* aims to activate and enable patients, address patients' psychosocial aspects, and increase quality of life. Patients are empowered by collaboration and trust. It is influenced by patients' efforts to remain in control, support, acceptance, and the ability to maintain hope. *Training healthcare professionals* may concern how physicians can improve their communication skills and encourage patients to more actively participate. Through *communication*, staff can change patient behavior and promote activity and involvement. Physicians and nurses use a number of communication strategies for involvement, such as positive or negative reinforcements. However, patients sometimes feel involved when there has been objectively very little collaboration. *Service systems* support involvement. This includes specialized centers and programs with follow-up and educational opportunities, group sessions with patients, and chances for patients to meet other patients and their families. Communities can maximize the utility of scarce resources and strengthen patients. Information technology can help patients and physicians work together.

Anticipated consequences

We identified three types of effects reported in the literature: Health outcomes, patient satisfaction, and healthcare costs. These were found in connection to all three types of patient involvement. In relation to *decision-making*, a number of studies report effects of patient involvement. These involved decreased decisional conflict and stress, increased health-related quality of life, decreased work disability, and effective pain control. A number of studies focusing on education and patient involvement in *healthcare delivery* reported a positive relationship between self-management and health outcomes. Patient education and self-management increase independence and reduce the number of healthcare visits and days in the hospital. Self-management may also increase patient satisfaction and compliance.

The article contributes by taking a general view on patient involvement that is not dependent of specific type of involvement or a specific concept. It provides a framework for viewing patient involvement. The article point out to important research gaps. While the research can report indicative effects of patient involvement, more studies are needed concerning consequences. The proposed model can be a tool for thinking about patient involvement in practice and research.

4.2 Article 2: Solicited diaries as a means of involving patients in development of healthcare services

Elg, M., Witell, L., Poksinska, B., Engström, J., Dahlgaard-Park, S., Kammerlind, P.

4.2.1 Background

The objective of Article 2 is to explore the use of diaries as a means to involve patients in service innovation, and addresses the thesis' research question of how to involve patients in service innovation (Research Question 3 and 4). The potential benefits and shortcomings of doing so address Research Questions 3 and 4. The article describes the first attempts at using diaries to bridge the gap between the rhetorical view of patients as contributors and the lack of methods for actually achieving this. The methodology was developed in an action-research project in three healthcare processes. Patients were randomly invited to participate, until 10 patients in each clinic accepted. Participants were asked to recount events each day and give suggestions for improvements. The approach also helped identify the types of contributions, primarily in the form of ideas, patients would provide.

In the next section I will describe our main findings. It contains more and longer excerpts from the diaries than in the actual article to give a better picture of the patients' contributions than what was possible in the journal format.

4.2.2 Findings and contributions

Of the 30 patients who agreed to participate, 13 diaries were returned. These diaries contained 102 ideas for improvement and suggestions. On average, each participant wrote 800 words and provided seven ideas. There was wide variation, with one patient submitting 17 ideas, compared to none in another diary. The amount of text and number of ideas changed over time (Figure 9). The graph shows that patients started using between 60 and 80 words per day to describe their experiences, but that the writing became less extensive by the end of week one. After one week, we phoned participants to encourage them to keep writing, which explained the bump in the graph at day 9. The number of words and ideas dropped again by the end of week 2.

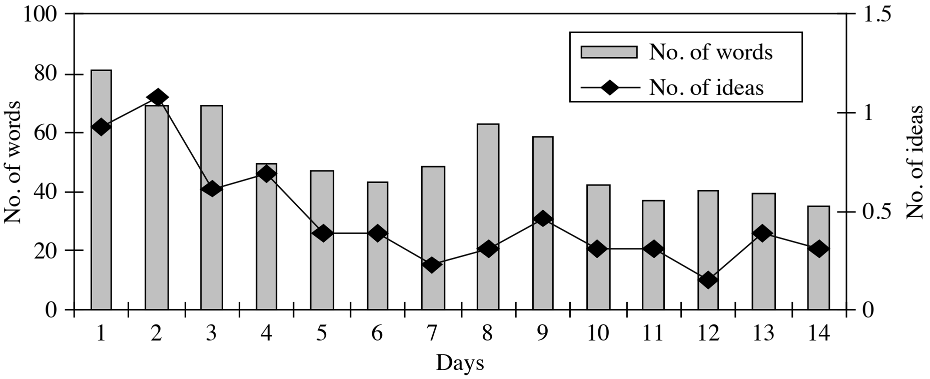


Figure 9 Average of written words per day

We identified four writing styles: Brief, reporting, reflective, and descriptive (Table 5). Brief diaries (n=5) had little content, and the text described the patient's everyday situation in a brief way. In the one reporting diary, the patient chronologically and objectively reported the day, similar to a captain's log. In the descriptive diaries (n=6), patients described situations during the day. These situations were often closely related to their health and contact with healthcare and adhered closely to the instructions. In the one reflective diary, the patient discussed the events of the day in a more reflective manner, as well as past and future events.

Table 5 Excerpts from diaries

Excerpts
An excerpt from a brief diary
"I have no difficult toilet visits today, feeling very tired and can't cope with everything that I normally do. I just do everything I need to when I have picked up the kids at daycare."
An excerpt from the reporting diary
"I wake up with a bit of nausea. Have difficulty eating and drinking. At 10 o'clock I'm transported to radiology, which goes smoothly. At lunchtime, I try to stand up on the floor but faint. A peculiarity of mine is that I faint easily. Most of the day spent in bed with the exercises recommended physiotherapy. Visit of the occupational therapist, who checks that I have gotten aids."
An excerpt from a descriptive diary
"Tired today. But a little better. Mobilized all forces for today's rehab. Nothing gets done at home. Cannot be bothered to cook. There will be tea and biscuits. Had enough energy to take a bath in the evening at least. I've stopped showering because it's a hassle to keep up my arms when I'm washing my hair. It is easier in the bath. Difficult to hold the pen. Pain in the hands and wrists. Want to read my thrilling novel but I have no energy to hold the book or keep focus on the content"
An excerpt from the reflective diary
"It feels like the assessment of work is one-sided (both from social insurance agency and healthcare) and only about how much work I can perform in the workplace. At least as much energy and effort is spent on the work that you have to do when you get home. They account of things like grocery shopping/cleaning/washing etc. But parent meetings/car inspection/bill payment/purchase new clothes for the children/gym bags/soccer practice/car repair/redecoration/cleaning supplies/polishing shoes (or leather sofa)/take up winter clothes. All that which is on top of everything else but still must be done. Every week there is at least one such thing and there is almost always something like that turns my life up-side down, takes all my strength"

Patients provided ideas that stemmed from their experiences with healthcare and their daily lives. The ideas concerned a wide range of aspects of the care, and aimed to change both healthcare and their own behaviors. In many cases ideas concerned how healthcare could support the patient.

Nine idea topics were identified (Table 6):

Table 6 Examples of ideas from patients

Topic with example
Access to healthcare activities
“When I was discharged in February, on a Saturday afternoon, I got a bunch of prescriptions – then the pharmacy at the hospital was closed.”
Manner of healthcare professionals
“Take the pain patient seriously, do not make it easy for themselves and lead talk into depression as the cause when the pain is the real reason why everything seems black as night.”
Self-care
“Get information about nutrition, for instance chamomile tea instead of sleeping pills.”
Technical tools
“Having a dog is so common that you daily see people’s sanitation problems picking up after their four-legged friends.”
Communication skills among healthcare personnel
“As soon as it is found that surgery is necessary physiotherapists and occupational therapists should come into the picture. Many tips and activities from them would facilitate the waiting time and perhaps also the procedure.”
Medicine and prescriptions
”Try all kinds of treatments. I’ll gladly try anything. It has to pay off, even if it would only help a little bit.”
Administrative and clinical routines
[I would like] help with reasonable planning! Maybe you write up everything you do in a week or two and then get help to go through it with an occupational therapist.
Coordination of healthcare-related activities
”The doctor you’re with at the beginning should turn and take advice from specialists.”
Waiting times
“The possibility to get time and contact, the waiting times. Some type of inquiry about how I felt during that long period.”

Article 2 contributes insights into the range of ideas patients provide, and shows that many patients are willing to participate. It also demonstrates that the diary method can collect ideas and narratives in a way that makes context understandable. Regardless of writing style, patients gave insights and ideas that can be the basis for service innovation. Article 2 also highlights that the format may contain barriers to participate for some patients. This issue is addressed in Article 3, in which the diary is further developed and there is more focus on how care providers can use the provided data.

4.3 Article 3: Co-creation and learning in healthcare service development

Elg, M., Engström, J., Witell, L., Poksinska, P.

4.3.1 Background

Article 3 further develops the diary-based methodology. It had more participating patients (54 patient diaries, including the patients from Article 2), but foremost it refined the process for handling the diaries and learning from the data. Article 3 also investigates how the material from the diaries could be used other than for collecting ideas. The experiences from the previous article showed that there was much to learn from both the ideas and the texts. This article addresses Research Questions 3 and 4, concerning how patients can be involved in service innovation.

4.3.2 Findings and contributions

The model for working with the diaries primarily resulted from the action-research workshops, which highlighted important aspects of how the model should be implemented and how organizations can learn from the material in the diaries. The model was divided into preparation, execution, and learning phases (see Figure 10).

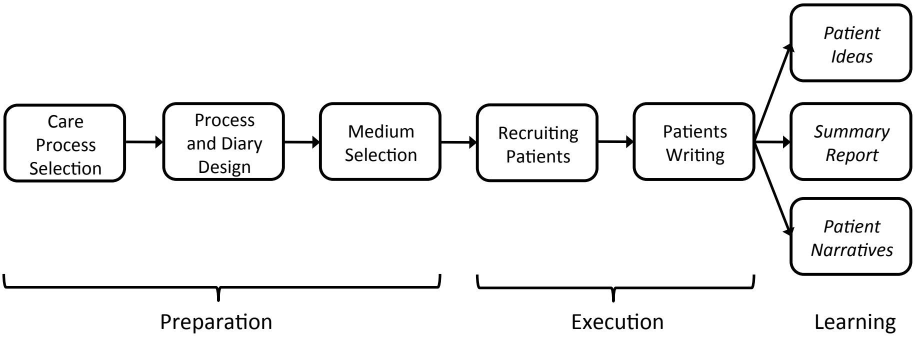


Figure 10 The model for patient co-creation in service development

The first step in the *preparation phase* is selecting the care process. The processes should be selected based on the quantity of patient flows, major costs, or lack of quality. The *medium selection* proposed physical diaries, private blogs, or phone calls, since patients may have preferences. Patients preferred physical diaries or blogs. *Diary and process design* contains choices about the content that the patient will be asked to write. In this case, there were two sections:

- Tell us about today's contact with healthcare, or an every day situation relating to your health status.
- My ideas and suggestions

Care providers should decide how patients will be approached, who should read the diaries, and how the data should be stored. Ethical aspects and patient safety must be considered.

Recruiting patients is the first step in the *execution phase*. A strategy to recruit patients should be random, typical, opportunistic (cf. Miles and Huberman, 1984). The choice should be in line with the development project's purpose. *Supporting patients' writing* means that staff must be available to support the writing. The diaries were kept for 14 days. The amount of text decreased over that time, which signified that 14 days was an adequate amount of time. Patients were contacted and encouraged to keep up the writing midway through the writing period. When the writing period was over, identifying information was removed.

The third phase in the model is the *learning phase*. We identified three ways of learning from the diaries. First, the ideas from the diaries should be used for continuous improvement efforts or as input for service-innovation projects. Second, a larger number of diaries can be used to create a report to identify strong and weak areas of the care process. This could be used in combination with statistical patient-satisfaction surveys to flesh out the numbers with qualitative meaning. Third, individual patient stories can be highlighted. The patient stories can be a basis for discussion within healthcare teams and a motor for change.

Article 3 contributes a methodological framework for working with diaries in the organization and highlights important aspects to consider when involving patients. It also suggests how qualitative data can help improve the healthcare process.

4.4 Article 4: The influence of disease and context on patient participation in healthcare service development

Poksinska, B., Witell, L., Engström, J., Elg, M., Snyder, H.

4.4.1 Background

A necessary first step for increasing patient participation in healthcare service development is determining which patients to involve and how to do so. Article 4 aims to clarify the various roles a patient may have in healthcare service development and examines how types of disease (episodic/chronic) and context (home/care-provider location) influence suitable forms of patient participation for healthcare service development. Article 4 builds on the same data as Article 3 and uses the identified ideas as basis for analysis.

All ideas were coded according to characteristics (solution orientation, value creation, and context for realization) and sources (triggers, context embeddedness, and idea's appearance). We analyzed significant differences between the groups. We suggest which method to use, depending on type of care and context.

4.4.2 Findings and contributions

The statistical analysis revealed significant differences between the groups on the majority of the coded variables (for details, see full article). Based on these differences, the study identified four possible patient roles: Patient as feedback provider (episodic disease at care-provider location); patient as problem-solver (episodic disease at home); patient as co-developer (chronic disease at care-provider location); and patient as an expert (chronic disease at home) (Figure 11). These will be described in the following.

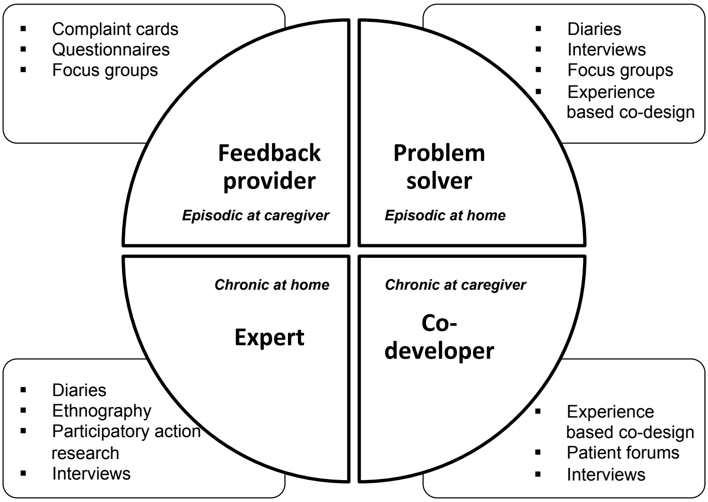


Figure 11 An overview of patient co-creation roles in service development

Patients as feedback providers – episodic at care provider

This group primarily provides ideas regarding administrative matters, information deficiencies, and attitudes of healthcare staff. The contributions were feedback on the care experience, such as deficiencies and suggestions to fix these problems. The ideas often appeared *ad hoc*, as the result of a specific event. We suggest traditional methods that efficiently capture experiences and complaints, such as surveys, complaint cards, and focus groups.

Patients as problem solver – episodic at home

Episodic patients at home typically provided more ideas upon which they would act, rather than just giving feedback to care providers. Ideas typically concerned daily living aids, practical issues, and medical care. The ideas in the areas of medical care and information subjects included improvements for self-management and suggestions to care providers on providing information.

The importance of the physical context, and patients' intent to implement the ideas themselves, suggests that methods for involving these patients should allow rich descriptions and build on active engagement. One such method is experience-based co-design (Bate and Robert, 2006), in which patients actively participate in the service design. Diaries, interviews, and focus groups are also suitable for collecting information.

Patients as co-developers – chronic patients at care-provider location

Chronic patients at care-provider locations provided ideas concerning treatment of their health problems, administrative matters, care providers' attitude, and informational subjects. As long-term patients, they often had much more information about their own disease and the caregiving process. Their ideas often concern the care-provider process. The ideas often stemmed from patients' personal experiences and concerned issues they repeatedly experienced and reflected upon for long periods of time.

These patients should primarily be involved in more long-term initiatives and collaborations than episodic patients. A large proportion of patients' ideas concerned staff interactions. The collaborative nature of the care should also be reflected in the involvement methodology. Care providers should use long-term, collaborative methodologies, such as patient forums and collaborative workshops for staff and patients (Bate and Robert, 2006).

Patients as experts – chronic patients at home

Patients with chronic diseases at home are not only knowledgeable about their illness, but have more information about their context, so are considered experts. This group provided ideas concerned medical care and administrative matters for improving treatment of their healthcare problem. Ideas from chronic patients at home often emerged from ongoing problems. These patients were specific regarding possible solutions and ideas concerning their own actions. Care providers may learn how to better support patients' self-management through these expert patients. Chronic patients at home should be involved by methods that enable care providers to understand patients' situations and how the care fits into their lives. Suitable methods are based on ethnographic methods. Service development may also be more far-reaching, such as participatory action research, in which patients, families, and care providers build forums to support quality of life and care (Marincowitz, 2003).

Article 4 contributes a tool to identify which forms of involvement are suitable in which situations. It suggests that episodic patients in the hospital (low degree of care co-production, with little patient control and involvement) contribute in different ways than do chronic patients in a home environment. The latter patients have a high degree of knowledge concerning their disease and context, and actively co-produce their care.

4.5 Patient involvement in healthcare service development – who to involve and why

Engström. J., Snyder, H.

4.5.1 Background

The idea behind this article came from the first attempts to use the diaries. We noticed that some patients were significantly more motivated to write and also more innovative (see Engström, 2012). We connected this to the notion of lead users. This article identifies the most innovative patients, investigates what separated them from other patients, and relates this to lead-user theory. The article addresses the thesis research questions regarding the involving patients in service innovation and Research Questions 3 and 4, and 5, which concerns motivation.

4.5.2 Findings and contributions

This is a summary of the four most innovative patients in the diary study. What did they write about? Did they attempt to implement ideas? What was reason for their needs?

Daily living aids – Henry. Henry is a 76-year-old retired farmer and a hip-replacement patient. Henry's contributions primarily concerned daily living aids and solutions to everyday problems at home. Hip-replacement patients encounter a number of practical issues when they return home, but this patient showed a remarkable ability and level of innovativeness in terms of overcoming these issues and suggesting solutions. His diary was full of useful solutions to problems at home, the hospital, and even on hunting excursions with his dog. Henry often came up with his own solutions. When he couldn't implement them for himself, he provided suggestions for how they could be solved.

Social aspects – Simon. Simon is a middle-aged teacher with a background in nursing. He was also an orthopedic patient in the hospital for a hip replacement. Simon focused on the social dimensions of healthcare and stands out in terms of his ability to constantly notice, reflect, and provide suggestions on social aspects. Simon shares reports of incidents, ideas, and suggestions from the entire experience of being a patient in the hospital, from admission, to surgery and rehabilitation at the hospital, to daily problems at home. Simon rarely implemented ideas himself, as he lacked the ability or power to do so. His ideas were often focused around organizational matters and education of healthcare professionals. However, his thoughtful reflections provided hard-to-get information on social aspects of being a patient in the hospital.

Life strategies – Agnes. Agnes is a 40-year-old mother of two who suffers from chronic pain. Agnes' contributions reflected her everyday struggle to manage her severe pain. These were expressed as life strategies. She participated in a “pain school” offered at the hospital. She learned about working more ergonomically and relaxation techniques. Despite her difficult situation, Agnes does not want to assume the role of a patient. She suggested: *“Chang[ing] the word ‘patient’ in care to something more positive ... such as ‘human being,’ ‘user,’ or ‘customer.’”* Agnes shared real-life anecdotes, such as choosing to celebrate her 40th birthday when, at the same time, she had so much pain that it was a huge effort to simply get through the day. Agnes implemented her ideas and wrote that she was willing to try anything at least once. She had insights about living in constant pain while managing her family life, which were very difficult for an outsider without such experiences to understand.

Administration – David. David is 69 years old and recently retired from a job as a technician and manager. He suffers from an advanced stage of lung cancer which makes his participation challenging. His contributions regularly contained insightful ideas and reflections related to administrative issues, including: Staffing must be increased to avoid mistakes; staff must be trained in problem-solving techniques and heard for improvements; and patient fees must increase to provide better funding. David did not implement ideas, as they primarily concerned the care provider, but he discussed solutions. For David, being creative and reflective was not optional. It was in his nature, and he wanted to contribute even though he was unlikely to reap the benefits himself.

The most innovative patients in this study had important differences from how lead users are described in the literature (Table 7). They are not enthusiastic users with strong interests, but can see and reflect upon needs or problems within specific areas. They are not primarily motivated by their wish to gain direct benefits from their solutions, but participate because they feel affinity with the care provider or other patients. These patients apply relational competencies and innovative competencies to suggest solutions and share their situation.

Table 7 Comparison of lead users and top performing patients

User situation	Motivation	Requires
Lead users		
Has strong needs and tries to find solutions, as solutions are not available. Enthusiastic user.	Direct benefit from use	Innovative competencies
Top performing patients		
Has or sees strong needs and reflects on solutions, but often lacks ability to implement. Involuntary user.	Affinity with provider Empathy with co-patients	Relational competencies

Building on Lüthje and Herstatt (2004), we suggest a four-step process to involve patients:

1. Form an interdisciplinary team, including different actors such as nurses, physicians, and healthcare management, but also other important stakeholders, such as patient organizations.
2. Identify problematic areas and unmet needs within the selected care process or area.
3. Identify suitable participants for involvement.
4. Involve and work with patients to improve or generate new solutions within the service system.

Article 5 contributes the first exploration on what makes some patients more innovative and sharing than others. It shows that some patients have particular interests in certain areas, and some have strong motivation to participate. It suggests that while these patients are different than lead users in other domains, the idea of carefully selecting which users to involve, depending on purpose, may be applicable in also in healthcare.

4.6 Article 6: Innovating service while fighting cancer? User involvement, ethics, and patient well-being

Engström, J., Elg M.

4.6.1 Background

The last article, Article 6, aims to investigate the motivations that patients have for being involved in service innovation, and how the participation influences them. It addresses the research questions concerning motivation and influence on well-being, Research Questions 5 and 6. The study was based on the project in the lung cancer unit. Analysis of their motivation to participate, and how this affected their well-being was based on their diaries, and interviews. The analysis draws from motivation theory and broaden-and-build theory, which connects emotional states and levels of participation.

4.6.2 Findings and contributions

Compared to the other care units, the degree of participation in this group of lung cancer patients was lower. Approximately 25 percent of the patients chose to participate. Of those who chose to say why they did not participate, the primary reason was poor health. We identified four motivators: restitution; sociality; obligation; and enjoyment, and the lack of motivation, amotivation (Table 7). In the following, I will present these, with examples.

Motivation and activity level

Amotivation. The relatively low degree of participation in this study compared to the previous study may be explained as amotivation; a sense of incompetency or lack or relevance of the task. One participant who had previously had a hip replacement compared her writing in the current project, to how it would have been after surgery of her hip: *"It would have been different, I would have written [more] then…I had control, in some way, but this…I can just decide to trust those who are specialists, and simply follow along."*.

Restitution. Some patients engaged in the service innovation initiative to voice their dissatisfaction with a specific event in their contact with healthcare personnel. We called this category of motivation *restitution*. One patient said that he only had one issue that was brought up in the diary: "*It took too long time between they discovered my cancer and when they started treatment*". One patient emphasized that he "*writes names and everything*" meaning that specific individuals involved in errors should be pointed out. This form of motivation seems to be related to strongly negative affects.

Sociality. To come get connection to the care provider and other patients is another motivator. We used the notion of *sociality* to give meaning to this category. One patient referred to the initiative: "*It is valuable to meet others [with cancer diagnosis] and not to be alone.*" One patient said: "*I think it is good to move a little bit closer to the personnel that you meet at the healthcare department… it doesn't do harm.*" In relation to restitution, which was linked to a negative affective state, motivation by sociality was more neutral.

Obligation. We identified a motivation for participation was linked to obligations as patients and citizens. The service-innovation activity was integrated into the patient's conscious valuing of the activity. One patient was excited about the initiative and said: "*When someone starts something like this you believe is promising you would like to show that you are interested and want to be there, then it's up to [the developers] to decide.*"

Enjoyment. A final motivator is intrinsic motivation, or enjoyment. The characteristics of such motivation are based on the enjoyment and interest of the task itself. Thus, external rewards are not the driving mechanism for these individuals. One patient writes: "*I like those kinds of things, it has always been my job, sort of speak, to help out*".

Influence of Well-being

Participation primarily affected psychological well-being and a sense of support. Some reported that the experience was stressing, or that they felt inadequate. Several patients expressed positive feelings of accomplishment and control in relation to the task. One patient wrote: *"I had managed to push trough the tiredness and done something. You should know it's hard…. I was actually happy, for me. […] Perhaps also because I had written down my emotions, but I feel no sorrow and have no fear that I have to express."* Patients who were motivated by restitution to participate felt a sense of relief and closure from expressing their concerns. *"It feels good to have it put forward* *and have it read, then when you move on it doesn't matter anymore, I have said what I thought and felt."*

This project was the first opportunity for many patients to meet others in the same situation. One patient was surprised that the atmosphere was so positive, despite the severe disease from which they suffered: *"We had some fun, we made fun of our selves, sort of speak, about how sick we were. They have lived it themselves, you can't experience other people's emotions if it didn't happen to you."* A woman wrote: *"I was really happy when you invited me… I felt that I wasn't forgotten when I came home, it was warming."*

Table 8 Motivations for participation in service innovation

Motivation and description	Associated emotions	Degree of participation
Non interest		
Disinterest because of lack of relevance, sense of competence.	Unknown	None
Restitution		
Patients who feel they have been mistreated in their care, motivated to voice their discontent and gain redemption.	Negative affect	Low
Sociality		
Patients who see the service development project as an opportunity to create relatedness between themselves, the caregiver and other patients.	Neutral	Medium
Obligation		
Patients who see participation as an obligation as patient an citizen to participate.	Neutral	Medium
Enjoyment		
Patients who are motivated to participated by the belief that they can contribute to themselves or the next of kin, and find enjoyment in doing so.	Positive affect	High

Article 6 contributes a new perspective on patient involvement in service innovation. It shows that patients have styles in the participation and suggests that patient involvement should not only be judged on the basis of direct outcomes in terms of how it affects the service, but also how it affects the patient. Patient involvement can lead to positive effects, but the goals of the care provider and patients do not always converge.

5 DISCUSSION

This chapter contains the final discussion of this research and underlines some of its main findings. The discussion aims to extend rather than replace the discussions in the appended articles. These articles are referenced in normal referencing style. Each subchapter briefly answers the research question, then highlights important aspects of the main findings and relates findings to previous research.

5.1 The forms, antecedents, and consequences of patient involvement

The first research question of the thesis concerns the concept of patient involvement and its forms, antecedents, and consequences. The literature review (Article 1, Snyder and Engström, 2014) investigates this question from the perspective of empirical research in the healthcare research field. The review shows that patient-involvement research primarily concerns three main types of involvement: Decision-making, delivery, and development and research. The desired level of involvement is often not reached. To increase involvement levels requires readiness of patients, staff, and service systems (ibid). Studies on the effects of patient involvement are scarce but indicate that different forms may lead to positive effects on costs and patient satisfaction, adherence, and health outcomes (ibid).

5.1.1 The gap between preaching and practice

An important finding is the gap between wanting to involve patients and the practicality of doing so (Snyder and Engström, 2014). The importance of patient involvement in decision-making is frequently discussed in relation to patient-centered care and evidence-based medicine (see Montori and Guyatt, 2008). However, there are disturbing gaps between rhetoric and practice. Physicians often do not practice shared decision-making (Charles et al., 2004). Even when they aim to do so, they often fail. One study showed that a majority of breast cancer patients did not feel they had the role they wanted in decision-making (Kremer et al., 2007). Some patients' felt they were not involved enough, while others felt they had to assume more responsibility than they wanted (ibid). To make things worse, even when patients and doctors perceive that decisions were made in collaboration, it was often objectively not so (Saba et al., 2006). This shows care providers cannot think about patient involvement as a mere function of a decision to implement the practice. It requires determined efforts to work with proper attitudes and skills, and an increased understanding of the patient (Snyder and Engström, 2014).

The need to understand patients is important in shared-decision making but also in delivery of healthcare, which may include advanced self-management (Barlow et al., 2002). To increase patients' involvement in delivery requires a holistic view of the patients. This includes understanding patients' cultural contexts (Wang and Abbott, 1998), but also their inner thoughts and narratives about themselves, which influence their activity levels (Haidet et al., 2006). The ways in which healthcare involves patients in development currently does not meet these requirements. Traditional forms of understanding the patient perspective dominate, such as reviews and focus groups. While our findings are limited to healthcare research (Snyder and Engström, 2014), they are coherent with those in a review specifically studying patient involvement in service innovation (Crawford, 2002) and empirical studies of service innovation in healthcare practices (Andersson, 2013; Groene et al., 2009). These traditional methods are insufficient to understand patients' experiences or contexts as a basis for improvement (Bate and Robert, 2006; Greenhalgh et al., 2010). Today, care providers spend much energy collecting data from patients that is not used for improvement (Coulter et al., 2014).

5.1.2 Bridging the gap

To bridge the gap between rhetoric and practice of patient involvement, care providers must prepare staff, patients, and systems (Snyder and Engström, 2014). One way to view the proposed model for patient involvement (ibid, see Figure 8 in section 4.1.2) is viewing forms of patient involvement as mediators between planning and preparation for involvement, and the consequences in terms of satisfaction, costs, and outcomes. The model suggests a system-wide perspective, where different forms of involvement are not seen as separate, but following a common logic. This is in line with ideas in the empowerment literature (Anderson and Funnell, 2005). Change may occur on a small scale by adopting tools that can aid patients and staff or, on a larger scale, by forming arenas in communities for improved health on a community level (Ozanne and Anderson, 2010). There are inherit cultural challenges that needs to be addressed, such as a culture of blame and tendencies among clinician's to defend their autonomy (Länsisalmi et al., 2006). It should be noted however, that involving behaviors are not only a preference but also a skill. While inclusive behaviors are natural to some staff, these behaviors can be learned to support an increased degree of patient involvement through communication, attitudes, and behaviors (see e.g. Boxer and Snyder, 2009). Complicating factors are, as previously noted, the desired level of patient involvement varies among patients, and that actual and perceived involvement is not the same.

5.1.3 The consequences of patient involvement

The article review (Snyder and Engström, 2014) shows that the literature contain indications that increased patient involvement leads to reduced costs, increased satisfaction and better health outcomes. This is in line with arguments for patient empowerment (Anderson and Funnell, 2005) and patient-centered care (Robinson et al., 2008): More engaged patients may increasingly accept, and adhere to, treatment. Patients are in a better position to take over tasks and follow treatments, which reduces the risk for re-hospitalization and decreases costs. Unfortunately, the evidence is weak, and it is crucial to further investigate to find empirical support. In an evidence-based environment, blind faith does not impress skeptical physicians and other decision-makers (Pope et al., 2002).

5.2 Understanding patient value and patients' value creation

To see patients as active participants changes how we view value and value creation. The second research question in the thesis was how the role of the patient can be conceptualized with regard to value creation. I will discuss this question from the perspectives of the healthcare and service research presented in the theoretical framework and the literature review (Snyder and Engström, 2014). Table 8 summarizes the evolving perspectives on value and how it is created in service and healthcare research perspectives. I emphasize differences between the perspectives.

Table 9 Overview of perspectives on value creation

Primary unit of analysis	Role of beneficiary in value creation/ Service innovation	Value
Healthcare: Traditional healthcare		
Physician	Passive receiver of care/Passive	Clinical outcomes, costs
Healthcare: Evidence-based medicine		
Patient-physician dyad	Complies to treatment/Passive	Clinical outcomes
Healthcare: Micro-systems approach		
Micro-system	Travels between, microsystems, Self manages disease/ Provider of information	Clinical outcomes, Functional health status, Satisfaction, Costs
Service: Traditional marketing		
Provider	Consume services / Passive	Added value to products
Service: Traditional services marketing		
Supplier-customer dyad	Service consumer / Provider of information	Satisfaction
Service: Current service thinking		
Customer's service system	Value (co)creator / Co-developer, source of innovations	Experienced value in use

In healthcare, the primary unit of analysis has traditionally been the patient-physician dyad. Improvements primarily concerned what doctors do (Laffel and Blumenthal, 1989). Today, there is a focus on the micro-system, wherein patients contribute to decisions and self-management (Nelson et al., 2011). Value has moved from being strictly defined as health outcomes and costs, to also encompass experiences. Nowadays, value is measured by objective and subjective measures. Increasingly, healthcare research acknowledges patients as a potential resource for innovation (Groene et al., 2009). In service management, the analytical focus has moved from the producer, to the customer-supplier dyad, to the customers service system (Edvardsson et al., 2006). The service literature uses customer experiences as a basis for defining value, building on a value-in-use view (Grönroos and Ravald, 2011; Vargo and Lusch, 2004). User involvement is integral to service innovation (Witell et al., 2011).

Given the commonalities and differences between these research fields, is it possible to integrate the views of value and patient roles in value creation, and accept knowledge from both traditions?

5.2.1 Determining value

The service perspective and healthcare perspectives clearly differ when it comes to determining value (Hardyman et al., 2014). From a service perspective it could be argued that the notion of value as experiential, idiosyncratic and contextual is true also for healthcare in the sense that it is the patient and no one else that experiences the consequences, and that experiences of value and preferences varies among individuals. But patients want healthcare to be delivered in accordance to best knowledge (Coulter, 2005) and in the evaluation of healthcare or, in the context of decisions, our own experienced value is not sufficient. As Blumenthal and Sremikis (2013) point out, the fundamental issue is that patients need help to determine value in practical situations. Seen as a tool to help estimate decision-making in collaboration with the patient, the value compass has many attractive features (Nelson et al., 1996). It presupposes accordance with best evidence, which is essential for ethical reasons; it is measurable in the present; it contains subjective components; and it contains costs involved for the patient. A crucial lesson from the service research however, is that value from the patients' point of view and the provider's point of view may differ, especially in relation to costs. These perspectives need to always be analytically distinguished. It is also, as will be discussed, necessary to other methods for understanding subjective values than is currently used.

The debate on value in healthcare, and the pursuit of high value healthcare will continue, as does the need to prioritize increase as a function of new and costly medications (Curfman et al., 2013). There are seemingly insurmountable problems to overcome, in measuring costs and evaluating care. It is possible that the question to ask is not how value can be calculated, but through which processes patients and care providers can come together at different levels (individual patients and physicians; patient groups; society) and make these prioritizations. This approach is in line with the reasoning of Greenhalgh et al. (2010) who see co-production models in healthcare as a way forward from a consumerist approaches or a discussion over power.

Based on the previous discussion, I suggest that value in healthcare should be viewed as *co-determined* (following service lingo) in the context of decisions and evaluation. This notion may be natural to healthcare researchers, but more foreign to service researchers. A more broad view of value in healthcare may lead to healthcare service research that extends beyond short-term experiences.

5.2.2 Understanding value co-creation in healthcare

The terms *patient involvement*, as used in healthcare research, and *value co-creation*, as used in service research, relate. Both concepts highlight that the beneficiaries' actions are integral to the outcome, but they are not the same. The service perspective's primary focus is on the customers' value-creating network (Grönroos and Ravald, 2011; Vargo and Lusch, 2004). In healthcare, the main focus is on healthcare's value-creating network, which is the primary unit of analysis (see Nelson et al., 2011). Through concepts such as *patient empowerment* and *patient-centered care*, the views are merging. Wassen et al. (2007) write: "Today, many of the most progressive micro-systems design care not only with the patient in mind but also with patients and families serving as full members of the team." A patient's value creating network encompasses resources within the healthcare system and private resources (Elg et al., 2012; McColl-Kennedy et al., 2012).

Learning more about patients' activities is important, considering the growing number of chronic diseases, for which treatment hinges on patient activity. The service perspective extends and reverses the question of patient involvement. In this view it is not only about how healthcare can involve patients, but how patients involve healthcare in their lives (Heinonen et al., 2010). When and how do patients utilize healthcare resources to improve health are important questions. Patient involvement should thus be viewed both ways: Patients are involved by care providers, and involve care providers in their lives. *Value in healthcare* is co-created by using healthcare resources and other resources in the patients' service network.

The fact that the public spends billions on alternative medicine shows that there is a willingness to participate, and that this ambition often is misdirected. This willingness is notable also in the diaries of patients, who often contain ideas regarding their own involvement, but where they are hindered from involvement due to lack of information or other resources (Poksinska et al., 2014). Shorter (1985) paints a picture of alienated postmodern patients. These patients apply unconventional treatments because they lack better alternatives. Involving patients as active participants in healthcare can direct their energy to something more fruitful with real positive change for their health.

5.3 Involving patients in service innovation

Research Question Three concerns how care providers can involve patients in service innovation.

The thesis proposes one method based on diaries, through which patients provided ideas and experiences, as a practical tool in service innovation (Elg et al., 2011, 2012, Articles 2 and 3). The process is divided into three phases: Preparation, execution, and learning (Elg et al., 2012). It contains concrete advice for how to apply the methodology for each phase: The processes in which the diary should be used, access and storage of patient data, how care providers can learn from the data, and how the process can be integrated in the organization (ibid). The diary is one of many opportunities. In the choice of method, a number of factors should be considered, including the intended context and whether patients are long term or short term patients (Poksinska et al., 2014). While the diary method is discussed in the articles, I will stress some points further. The content of diaries – what we can learn from patients – is discussed in the next section 5.4.

5.3.1 Learning from diaries – making it work

The methodology proposed pen and paper, blogs, and phone as the means for data collection (Elg et al., 2011). The crucial point of the method was that patients may submit thoughts *in situ*, where and when the care takes place (Kristensson et al., 2004). The patients' ideas often stemmed from the context in which they found themselves and as a result of *ad hoc* events. Likewise, the ideas in healthcare are often unique, innovative, and come from patients' perspective. Patients' contributions showed that through the diaries, they were able to provide ideas and experiences with a variety of aspects (Elg et al., 2012, 2011). Without a good process for managing these contributions, patients' efforts will be for naught.

Successful service innovation hinges on a systematic approach (Edvardsson et al., 2000; Gustafsson and Johnson, 2003). Patient involvement in healthcare is often symbolic, which may be a result of provider disinterest, but probably also because structures for improvement are lacking (Andersson, 2013). A crucial point in the preparation phase is that the diary should be part of an improvement system or a service innovation initiative for developing a healthcare process. The methodology proposes three ways to do so: Incorporating ideas in service innovation, creating a summary of multiple stories to provide statistical numbers with qualitative meaning, and using narratives as a basis for change (Elg et al., 2012).

Gustafsson and Johnson (2003) suggest that the necessary first step to improve a service is to remove things done incorrectly. The narratives and ideas can identify these things and be a basis for continuous improvement. The second level in Gustafsson and Johnsons model concerns improving things done correctly. Surveys are typically used to measure and assure progress. An aggregate of diaries can help give these reports qualitative meaning as basis for support. The final level in Gustafsson and Johnson's model concerns more radical service innovation. For radical innovation, such as redesigning a process, the diary may be used in the ideation stages of the development process, and in end stages that evaluate new services (Edvardsson et al., 2000). Finally, the service-innovation process happens in a organizational culture (ibid). The diary narratives can help staff understand the patient perspective and why it matters. In the first project, actors enacted three of the diaries. These films supported a culture in which patients' experiences matter.

5.3.2 Handling diary data - ensuring no harm

Diaries sometimes contain highly sensitive data. They are typically private documents, with no other intended reader. The solicited diaries used in these studies were different, as there was an intended reader. However, the diary format invited the writer to share personal thoughts. Patients depended on healthcare staff. This raises important questions: Who should have permission to read the diaries; how should diaries be stored; how to ensure that the blog diary data did not reach unintended readers. This is an overall complicating factor for patient involvement in healthcare service innovation (Elg et al., 2011).

On the one hand, healthcare providers need to listen to criticism. On the other hand, it must be ensured that these criticisms do not harm the patient. Additionally, staff must not be negatively affected. The diary may contain criticisms about individual staff members. The present study contains examples of patients who explicitly wanted to name physicians, and strongly expressed that the physician was unsuited for their job (Engström and Elg, 2014). This was problematic, as the complaints were not official and the cause was never investigated. Staff members risk accusations for wrongdoings, without a chance for defense in a formal process.

For these reasons, the care provider must have a strategy in place. In this study the diaries were made anonymous before being used. Healthcare providers who use diaries must choose a strategy for ensuring patient safety.

5.3.3 Selecting method for involvement

An important question is which method to use. The thesis demonstrates how context and type of disease influence contributions with regard to source and characteristics (Poksinska et al., 2014). Short-term hospital patients contributed ideas in terms of reactions to events, whereas patients at home, especially chronic patients, often had insights they considered for a long time (ibid). Care providers should choose an appropriate method for involving patients to get positive results and avoid frustration (ibid). Diaries are just one of many means for involving users in service innovation. Care providers must consider a number of factors: Budget, organization readiness, and goals of service innovation. In some cases, simple tools such as complaint notes may be useful (ibid). At the other end of the spectrum are activities in which patients and care staff work in close collaboration. Higher degree of involvement increases the chances substantial improvement (von Hippel, 1986; Witell et al., 2011). Experience-based co-designed activities (Bate and Robert, 2006) may be a template for service innovation that draws from service-design methods and adapts these to healthcare. Experience-based co-design is an approach rather than a methodology (ibid). It uses multiple methods and collaboration between care providers and patients. A potential use of the diary method, is to use as a complementary tool for collecting narratives in the framework of experience-based co-design.

5.4 What healthcare providers can learn from patients

The fourth research questions concerns what care providers may learn from patients. This research question is addressed in several of the appended articles by analyzing patients' contributions.

Patients share complaints, experiences and emotions, and have innovative ideas (Elg et al., 2012, 2011). Patients' contributions concern a range of aspects, from healthcare staff manners, to ideas concerning self-care, to administrative routines. Their contributions concern things the care provider can change, how they can support patients' activities, and what patients can do for themselves (Poksinska et al., 2014). Some patients are especially insightful in a specific aspect of the care that deeply concerns them and go to great length to think of solutions that they sometimes implement (Engström and Snyder, 2014, Article 5).

5.4.1 Development from the patient context

The approach of collaborating with patients is well grounded. Methods that build on co-creation with service users lead to more original ideas and better outcomes in service-development projects than traditional methods, such as interviews or focus groups (Witell et al., 2011). An important differences between patients and other customers is that patients must be seen from a holistic perspective (Berry and Bendapudi, 2007). Patients experience their disease and treatment in a physical, social, and emotional context. By involving patients in service innovation, the care provider gets access to the patients' sphere, which is hidden to the care provider (see Figure 12; more detailed version is Figure 3). Healthcare staff rarely get systematic feedback from patients in ways other than surveys (Groene et al., 2009), which bind patients to the survey framework. Patients' contributions collaboration are contextually connected, capture experiences, and relate to patient behaviors (Poksinska et al., 2014). Involving patients in service innovation accesses patients' service network and sees them from an outside-in approach to service innovation (Gustafsson and Johnson, 2003).

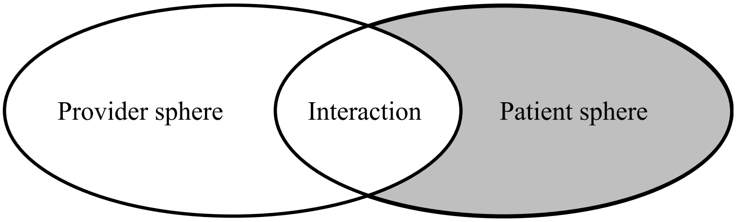


Figure 12 Provider and patient spheres. Adapted from Grönroos and Voima (2013)

5.4.2 Reconfiguration of roles and improved service offerings

Patients' ideas may concern both incremental (somewhere to put the crutch in the bathroom) and radical changes (integrated healthcare teams) (Engström and Snyder, 2014). Many of the ideas concern aspects of service quality (Parasuraman et al., 1988): Timeliness, communication, and courtesy were recurring issues. These types of ideas are often oriented towards incremental service innovations (Ettlie et al., 1984). However, what seems to be a small change to the patient may imply a radical reconfiguration of roles for the care provider, especially when multiple actors are involved. Service innovation can be viewed traditionally or, from a perspective of value creation, as the reconfiguration of roles and resources (Michel et al., 2008). Patients interact with a multitude of healthcare service providers, such healthcare centers or insurers. The ability of these actors to collaborate affects the patient. Viewing healthcare through the eyes of the patient allows the care provider to better understand how the services may fit into the patient's life and hopefully lead to improved coordination. It is also noteworthy that patients' ideas often concerned aspects of their treatments or lives in which they want to engage, but lack the knowledge and skills to do so. By supporting the patients' ambition, the care provider may help reshape the patients' role.

5.5 Patients' motivations for involvement in service innovation

Research Question 5 concerns patients' motivation for involvement in service innovation. Engström and Snyder (2014), Article 5, examines the most innovative participants, who combined an ability and motivation to contribute within a specific area. Engström and Elg (2014), Article 6, suggests that patients may have various motivations for participating in service-innovation initiatives: joy; social following norms; or seeking restitution.

5.5.1 Lead patients – the most motivated

The lead-user methodology suggests that some users will be especially motivated to innovate. In line with observations regarding lead users (von Hippel, 1986), our results indicate that these patients are valuable and innovative within a specific domain (Engström and Snyder, 2014). These patients have a particular need, as opposed to being innovative in a wider area. These needs may concern the realities of their personal situation, but also their contacts and experiences with the care provider (ibid). It also seems that the primary motive for involvement in development is not always the patient's own benefit or solution. Emotions such as empathy and affinity to the care provider and other patients are also important (ibid).

Will these contributions from a select number of highly motivated patients be valid for all patients? It is important to be clear about the purpose of innovation efforts. The differences between ordinary patients and these lead patients make them able to provide innovations that can later benefit all patients. It is necessary to separate the creative process with the process of determining which ideas are most useful.

5.5.2 The variety of motivation

Brockhoff (2003) studied user incentives for involvement in industrial settings, in which the motivation structure is different. In the case of patients, and especially those with very severe diseases, involvement in service development becomes a very personal and meaningful affair. McColl-Kennedy et al. (2012) provide a number of customer value co-creation styles in the delivery of healthcare. The present studies show that patients have different styles of value co-creation during service development, in which they seek to create value both for themselves and for other patients (Engström and Elg, 2014). A practical implication is that care providers who involve patients in service development must be aware of the wide range of motives that drive patients to participate. There are often strong positive and negative emotions that will be aired. Restitution is one important motivation to participate. These studies found several examples of patients who felt that they had not received the correct diagnosis in time or that waiting times for their treatment were too long, which they felt caused serious consequences (Engström and Elg, 2014).

5.6 The influence of participation on patients' well-being

The final research question the influence of participation on patient's well being. Patients may have both positive and negative experiences from participation (Engström and Elg, 2014). The personal benefits they perceive may primarily concern support and psychological well-being (ibid). The interactions that are inherent in the service-development process are a way to derive support and increase sense of connectedness, and offer an opportunity for patients to reflect on their own situation (ibid). The negative effects concern stress and negatives emotions of not being able to complete the task. Diseases may also inhibit patients from participating (ibid).

5.6.1 Support and accomplishment

The first important finding in relation to well-being is how patients felt support from being involved. While the project in which they participated did not contain many interactions between patients, just being part of a group that shared the same disease was rewarding (Engström and Elg, 2014). They were given the opportunity to meet both staff and other patients informally.

Research on commercial cancer centers shows that patients may derive support from coming together and having their experience acknowledged by a professional employee (Rosenbaum and Smallwood, 2013). Service innovation projects give patients a task. For patients suffering from a disease that may prevent them from working and assuming their usual roles, this may be important (Engström and Elg, 2014). Feelings of accomplishment are empowering. Unfortunately, the opposite may also be true. A large number of participating patients did not complete the diaries. This is a challenge and opportunity for healthcare providers. Care providers should strive to design their projects so that most users can be involved or that there is a number of ways in which the patient can contribute. The patients' ability to complete the project should also be considered to avoid patients feeling incompetent or pushing themselves too hard mentally and physically.

5.6.2 Well-being and creativity

An interesting aspect is that the effects of well-being are bi-directional. Positive emotions influence our ability to take on challenges and open our minds to a larger array of thoughts and actions (Gallan et al., 2013). By designing user involvement methods so that both the needs of the patients and the care provider can be achieved, there is a win-win situation. Such involvement methods achieve both short-term goals of increased current patient well-being and long-term goals of improved service for future patients. Patients' physical and mental states greatly affect their ability to participate. Patient involvement should be viewed from a social-context perspective. Not only is outcome important for involvement, but the processes whereby patients are involved also leads to positive effects.

This concludes Discussion. Next and final chapter is Conclusions, Contributions and Further Research.

6 CONCLUSIONS, CONTRIBUTIONS AND FUTURE RESEARCH

This final chapter consists of closing comments about the present research. It specifies some contributions of the research to the existing knowledge, and identifies some avenues for future research.

6.1 Conclusions

Healthcare is changing. Care providers increasingly rely on patients to perform tasks, seek information, and prevent disease. This is driven by necessity, as chronic diseases are becoming more common, but also by new enabling technology and of a marketization of society (Nordgren, 2008). The question regards whose terms this change occurs. The conclusion in this thesis is that healthcare staff often do not use involvement practices in decisions concerning individual patients or in developing healthcare (Snyder and Engström, 2014). When they do, they often fail, and when they believe they have succeeded, involvement is often symbolic. While the degree of patient involvement should be a function of the preferences and ability of the patient (Saba et al., 2006), it is too often a function of the preferences and abilities of the physician. At the same time, patient involvement is seen as a key in many of today's healthcare concepts. The vision of these concepts is patient-centered care in which empowered patients take control over their situation and lead better lives (Anderson and Funnell, 2005). However, the risk is that patient involvement in practice involves a lot of responsibility but little empowerment. The review of the empirical literature in the field (Snyder and Engström, 2014) suggests that patient involvement should not be seen as the function of a decision, but as the result of concerted actions of empowerment and education of patients and staff, communication, and the building of supporting service systems. It is expressed in forms of involvement in decisions, delivery, and development and may reduce costs and improve satisfaction and health outcomes.

Fundamentally, patient involvement requires a mental transformation from a paternalistic view in which care is *delivered* to patients, to one in which patients, care providers, and other actors create positive outcomes together. Healthcare has already taken important steps in this direction, and knowledge from service and healthcare research can be combined to further this transformation (Anderson and Funnell, 2005; Grönroos and Ravald, 2011; Vargo and Lusch, 2004; Wills and Holmes-Rovner, 2003). The position of the present thesis is that value should be understood as multidimensional and, in the context of decisions, *co-determined* by patients and physicians on the basis of evidence and preference. *Value is co-created* in the patient's service network, which also encompasses the care provider, other organizations, family, and friends. Care providers must not only understand how they can involve patients, but how *patients involve healthcare* in their lives.

Consequently, increased patient involvement requires a better understanding of the patients' behaviors, contexts, and inner worlds (Haidet et al., 2006; McColl-Kennedy et al., 2012; Nelson et al., 2011). The surveys that are most commonly used in healthcare contexts to understand the patients' needs and to develop services do not meet these requirements. Instead, methods that build on the active participation of patients are necessary (Bate and Robert, 2007; Witell et al., 2011). Patients are the only people who actually experience their complete healthcare process, from symptoms, to examination and treatment, to rehabilitation. They are also the only ones who experience the emotional processes within this process. Patient involvement in service innovation can open a window to the patient's life and allow the patient to share his or her emotions, reactions, and creative ideas (Elg et al., 2012, 2011). Given the opportunity, patients may provide ideas concerning a multitude of aspects, both regarding how healthcare can improve its processes (such as decreasing waiting times or improving collaboration across units), but also regarding what patients can do for themselves (Poksinska et al., 2014). These ideas may imply small but meaningful service innovations or radical role configurations. In many cases, the patients are seeking help from the care provider to actualize their ideas.

Many patients also want to help the care provider in return and are motivated to participate in improvement activities. Even in the face of a severe disease and with little hope of harnessing outcomes, some patients make the choice of giving, and find joy in doing so. Some patients may have a special interest in a specific aspect of healthcare and have a need to reflect on that (Engström and Snyder, 2014). There are several other motives for a patient to participate (Engström and Elg, 2014). Patients may use participation as an opportunity to find restitution after mistreatment. Others are driven by an obligation to give back, and some just want to meet other patients and find support. Health is laden with meaning, is personal, and occurs in a social context. By involving patients in service innovation, we should not only seek new innovations, but also positive and uplifting experiences of our participants. This can result in meaningful collaboration and understanding between healthcare staff and patients that leads to improved healthcare performance and better patient experiences.

6.2 Contributions

The aim of this thesis has been to explore patient involvement and service innovation in healthcare. To do so, it has incorporated elements from healthcare and service domains and contributed to these literature streams. It has especially contributed to the *transformative service paradigm*, which centers on creating uplifting changes of and improvements for individual, families, social networks, and collectives (Anderson et al. 2011). Indeed, it is among the first doctoral theses of this new paradigm. The current work specifically contributes to the fields of patient involvement and service innovation in healthcare, as well as in public organizations overall.

Through a literature review on patient involvement, the thesis contributes to healthcare management concepts that build on the active participation of patients through self-management (Bodenheimer et al., 2002), in decisions about their own care (Wills and Holmes-Rovner, 2003), and as a contributors for in-service innovation (Bate and Robert, 2006). Further, the thesis draws on service research (e.g. Grönroos and Ravald, 2011; Vargo and Lusch, 2004) to discuss conceptualizations of value and value creation in healthcare (Nelson et al., 1996). In this way, it contributes to a discussion on how knowledge from service research and healthcare research can be integrated, combining healthcare management research with transformative service research.

Concerning patient involvement in service innovation, the thesis proposes a diary-based methodology for involving patients in service innovation. This methodology showcases the vast array of ideas that patients can generate in service innovations, and also offers advice on where in the development process it should be used. This methodology can be used in healthcare and in other service organization, and adds to the field of user involvement in healthcare (Greenhalgh et al., 2010)

The present thesis also shows how the context and type of disease influences the types of contributions a patient can make. It makes suggestions about which methodologies for patient involvement are advisable in certain cases. This has not been studied previously and has important practical implications. The approach is not only unique to healthcare, but to service innovation in general.

The thesis examines an extension of the lead user methodology to healthcare (von Hippel, 1986), and points to similarities and differences among high-performing users among patients compared to other groups.

By analyzing patients' diaries and in interviews with participants, we have learned what motivates patients to participate in service innovation. Self-determination theory (Ryan and Deci, 2000) is applied to explain patients motivations. This theory helps explain the dynamics of user involvement, and has practical implications as care providers need to manage various types of motivation.

Finally, the thesis explores how patients are influenced in participation. It shows that a secondary outcome to patient involvement in service innovation has effects on the well-being of patients. Understanding the influence on patients' well-being is important for ethical reasons, and provides further support for the practice of involving users, as feelings of support and accomplishment are associated with participation.

Overall, the thesis explores patient involvement and service innovation in healthcare from new perspectives, thereby contributing to our collective efforts to improve healthcare.

6.3 Future research

As is usually the case, conducting this research has raised many more questions. In this section I point out some areas that I believe may have important implications.

Firstly, patient involvement is widely accepted and supported in the healthcare literature. However, what is preached is not always practiced. The review of patient involvement suggests that what is required is education, changes in attitude, and the creation of service systems. How this is achieved in practice, taking into account cultural factors within the medical profession, is a challenging but important area of research with great potential.

Secondly, self-management and self-care are essential in developing countries, where medical resources are scare. Involving patients and communities in healthcare service innovation should be especially rewarding. A community action research approach should be suitable (Ozanne and Anderson, 2010).

Thirdly, regarding service innovation, the present study has shown that patients found the involvement activity and meeting other patients to be rewarding. Following this view of healthcare, patients and healthcare come together, not only to improve healthcare, but also to create relations and support. To find forms of involvement, with the multiple aims of creating positive experiences and positive health outcomes, and improving the health system, is exciting.

The main driver for increased patient involvement, and the main driver for the transformation of healthcare, will be technology. A major trend in the short term is wearable technology, which makes it possible to gauge the body in real time. In the longer term, we will see the robotization of healthcare, which will dramatically challenge the professional roles in healthcare, and a biotechnology that challenges how we view ourselves as humans. Technology therefore needs to be coupled with an understanding of us, as human individuals and collectives.

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