

THESIS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

# Patient involvement in quality improvement

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CHALMERS UNIVERSITY OF TECHNOLOGY

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## ABSTRACT

Quality improvements (QI,) based on principles, practices, and tools developed in the manufacturing industry, is becoming a common approach in healthcare, as well as an increasing focus on patient involvement. Healthcare QI is driven by challenges such as future patients' demand for higher quality of care and their desire to have an amplified impact on their health situation and care. Additional challenges include rapid technical development; decreasing resources, and expansion in the elderly population. Patient involvement in QI is growing as a means to increase the quality of care in healthcare settings; however, the field is still short of practical examples and research.

This thesis explores the contributions and challenges of patient involvement in QI. The thesis is based on six appended papers, mainly based on action research (AR) in a specific hospital setting, where the research built on learning in action. Qualitative methods were predominantly used to generate the empirical material, although some quantitative methods were used.

The findings demonstrate that patient involvement in QI makes a difference because patients can identify improvement areas that healthcare professionals may not. In addition, patient involvement illuminates the importance of viewing care from a patient perspective, which may help overcome existing gaps in the organizational structure, such as separation into specialist functions like different wards. The improvements reported in the appended papers address both technical (service delivered) and functional (how service was delivered) quality of care. In addition, patient involvement demands new ways of defining quality in healthcare.

However, patient involvement in QI also presents challenges. First, patient involvement places patients and healthcare professionals in new roles as co-designers, which calls into question prevailing roles and relationships. Second, patient involvement in QI decreases power asymmetry in the relationship between healthcare professionals and patients. This power shift challenges healthcare professionals to revise their existing relationship to patients from one that creates value *for* patients to one that creates value *with* them.

The research in this thesis contributes to an emerging science of improvement in healthcare; it makes a methodological contribution to AR and its use in combination with patient involvement in QI; and it provides practical examples of patient involvement in QI that can be of practical value to healthcare professionals.

**Keywords:** healthcare, quality management, improvement knowledge, quality improvement, patient involvement, experienced-based co-design, patient roles, action research



## LIST OF APPENDED PAPERS

This thesis is based on the research contained in the following papers:

- Paper I** Gustavsson, S., Gremyr, I., & Kenne Sarenmalm, E. (2016). Using an adapted approach to the Kano model to identify patient needs from various patient roles. *The TQM Journal*, 28(1), 151–162.
- Paper II** Gustavsson, S. (2014). Improvements in neonatal care using experience-based co-design. *International Journal of Health Care Quality Assurance*, 27(5), 427–438.
- Paper III** Gustavsson, S., Gremyr, I., & Kenne Sarenmalm, E. (2015). Designing quality of care – contributions from parents. *Journal of Clinical Nursing*. Advanced online publication. doi: 10.1111/jocn.13050.
- Paper IV** Gustavsson, S., & Andersson, T. (2015). Patient involvement 2.0; Experience-based co-design supported by action research. Paper submitted for publication.
- Paper V** Hellström, A., Lifvergren, S., Gustavsson, S., & Gremyr, I. (2015). Adopting a management innovation in a professional organisation - The case of improvement knowledge in healthcare. *Business Process Management Journal*, 21(5), 1186–1203.
- Paper VI** Gustavsson, S., Elg, M., & Gremyr, I. (2016). Strengthening the patient role by involvement in quality improvements. Working paper.

## CONTRIBUTIONS

Gustavsson's contribution to the included papers is presented below. According to the action research (AR) approach used in Papers I–V, the research process was based on a collaborative methodology, including continuously reflective dialogues about the research process with all authors. The collaboration with co-authors in Paper VI was also conducted through reflective dialogues.

Paper I: Researched idea and design. Participated as inside action researcher (IAR) and collected the empirical material. Material jointly analyzed and paper written with co-authors.

Paper II: Single-authored

Paper III: Researched and planned the projects. Participated as IAR and collected the empirical material. Material jointly analyzed, and paper written with co-authors.

Paper IV: Researched and planned the projects. Participated as IAR and collected the empirical material. Material jointly analyzed, and paper written with co-author.

Paper V: Participated in the AR, generating empirical material. Material jointly analyzed, and paper written with co-authors.

Paper VI: Research idea. Jointly planned and collected the empirical material, and jointly wrote paper with co-authors.

## ADDITIONAL PUBLICATIONS

### JOURNAL PAPERS

Bergman, B., Hellström, A., Lifvergren, S. & Gustavsson, S. (2015). An emerging science of improvement in health care. *Quality Engineering*, 27(1), 17–34.

Gremyr, I., Gustavsson, S., & Gideberg, A. (2012). The medication process – a design for Six Sigma project. *International Journal of Six Sigma Competitive Advantage*, 7(1), 1–11.

### CONFERENCE PAPERS

Gustavsson, S., & Kenne Sarenmalm, E. (2014, September). *Experience-based co-design projects in pediatric care processes: Parents' perceived quality*. Paper presented at the 17th International Conference, Quality Management and Organizational Development (QMOD), Prague.

Gustavsson, S., & Severin Larsson, M. (2014, September). *Parents improve healthcare for children with diabetes*. Paper presented at the 22nd International Conference on Health Promoting Hospitals and Health Services (HPH), Barcelona.

Gustavsson, S. (2012, September). *Collaborative improvements; effects on simple, complicated and complex problems in neonatal care*. Paper presented at the 15th QMOD International Conference, Poznan, Poland.

Lifvergren, S., Gustavsson, S., & Hellström, A. (2012, March). *Patient safety learning audits: Towards organizational learning for improved safety*. Paper presented at the 2nd Nordic Conference on Research in Patient Safety and Quality in Healthcare, Copenhagen.

Gustavsson, S. (2011, August). *Identification of customer needs in healthcare – translating patient needs into critical-to-quality characteristics*. Paper presented at the 14th International Conference, Quality Management and Organizational Development (QMOD), San Sebastian, Spain.

Hellström, A., Lifvergren, S., & Gustavsson, S. (2011, June). *Transforming a healthcare organization so that it is capable of continual improvement – the integration of improvement knowledge*. Paper presented at the 18th Annual EurOMA Conference, Cambridge, UK.

Gremyr, I., Gustavsson, S., & Gideberg, A. (2010, June). *Design for Six Sigma in healthcare: The medication process*. Paper presented at the 17th International Annual EurOMA Conference, Porto, Portugal.

Gremyr, I., Chakhunashvili, A., Gideberg, A., et al. (2009, August). *Design for Six Sigma in healthcare: Identifying critical-to-quality characteristics*. Paper presented at 12th QMOD International Conference, Verona, Italy.

### POSTER PRESENTATIONS

Vilstrup, L., Andersson, L., Boberg, S., et al. (2013, May). *Involving children in the design of new facilities for a children's hospital*. Poster session presented at the 21st International Conference on Health Promoting Hospitals and Health Services (HPH), Gothenburg, Sweden.

Gustavsson, S., & Söderberg, M. (2012, April). *Collaborative improvements in neonatal care*. Poster session presented at the International Forum on Quality and Safety in Healthcare, Paris.

Gideberg, A., Gustavsson, S., Gremyr, I. & Chakhunashvili, A. (2012, April). *The design of a medication process*. Poster session presented at the International Forum on Quality and Safety in Healthcare, Paris.

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“Read not to contradict and confute, nor to believe and take for granted...  
but to weigh and consider.”

Francis Bacon, 1561–1626



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From my heart, my family, means the most – I love you Mikael, Stephanie (with her own little family), Anton, and Viktor.

Lundsbrunn, January 2016  
Susanne

# 1 INTRODUCTION

*Sitting with today's newspaper on the table, and I just have to send you an email. To help you remember, I was one of the parents that was included in the study. I have just read the article about your efforts to improve healthcare, on further international publications and on how it all started with the neo project. I got such a warm feeling in my whole body when I realized that it was actually I who was involved in this research. How easy it is just to talk to each other (healthcare professionals and parents), this is an important lesson that I always will carry with me. Now I am on parental leave again, gave birth to a lovely boy, the childbirth was incredibly much smoother than the last one.<sup>1</sup>*

Healthcare is currently facing major challenges (Berwick, 1998; Christensen et al., 2009; Mohrman et al., 2012). Technological development is moving quickly; new medications and treatments are being introduced; resources are decreasing; and the population is aging and in increasing need for care. In addition, future patients probably will demand even higher-quality care and greater involvement in their care on equal terms with healthcare professionals (Kettunen et al., 2002; Naidu, 2009). Such challenges make it crucial for hospital organizations to work on quality, delivery of better care without increased costs, and new ways of working with quality improvement (QI). Like many other industries and organizations, healthcare organizations have adopted quality management (QM) processes (Bohmer, 2009). QM is based on principles with related practices and techniques for QI (Dean & Bowen, 1994). These central principles are customer focus, teamwork, and continuous improvement (ibid.). But despite the challenges and an understanding of the need for improvement knowledge, healthcare still lags in adopting QM (Greenhalgh et al., 2004; Christensen et al., 2009).

The focus on QM in healthcare gave rise to a need for a new knowledge, called *improvement knowledge* (Batalden & Stoltz, 1993), which is based on an understanding of variation, psychology, knowledge theory, and system understanding (Deming, 1994). This knowledge, alongside healthcare workers' professional knowledge, is argued to generate increased quality in care (Bergman et al., 2015).

Customer focus, a QM principle (Dean & Bowen, 1994) in healthcare, views the patient as a customer, which is not an obvious perspective in healthcare, even among the patients themselves (Nordgren, 2008). Although a customer is often described as someone who buys a product, another definition is "the one we want to create value for" (Bergman & Klefsjö, 2010), which does not conflict with the current view of the patient in healthcare (Gallan et al., 2013). In addition, the influence of service management on healthcare emphasizes the patient as a co-creator of value during care (Normann, 2001; Berry & Bendapudi, 2007). This influence is congruent with the intention of patient involvement, suggesting that value is created in collaboration with the patient during the care process, instead of something created by healthcare professionals and awarded to patients at the end of the process (McColl-Kennedy et al., 2012).

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<sup>1</sup> This email was sent to me from a mother who was involved with healthcare professionals in QI in the neonatal care project. About a year after the project ended, an article in a local newspaper described the QI/research work in neonatal care at Skaraborg Hospital (SkaS), which prompted this mother's email to me.

Care with high quality is characterized as care that is safe, knowledge-based, effective, efficient, equal, and focused on the patient (IoM, 2001; WHO, 2006; National Board of Health and Welfare, 2009). National follow-ups by outcomes from all Swedish hospitals are made annually based on these characteristics, and patient-experienced quality has a small, but increasing, place in these follow-ups. As Grönroos and Ojasalo (2015) argued, traditional measures in healthcare are often productivity-based, and patient-reported outcomes are seldom included. One additional way to measure the outcome of patient care is to capture experiences categorized by quality dimensions. Dagger et al. (2007) argued for four dimensions of patient-perceived quality: interpersonal, technical, environmental, and administrative. However, these quality dimensions are based on healthcare organizations' ability to deliver quality without including patients as co-creators of that quality.

The patients' role traditionally has been to provide information to healthcare professionals about health conditions, treatment preferences, and their physical bodies (Gallan et al., 2013). The patient role also requires compliance with treatments, such as prescribed medications. Compared with healthcare professionals, who take the lead in many care situations, patients are often viewed as passive recipients (Kettunen et al., 2002; Berry & Bendapudi, 2007; McColl-Kennedy et al., 2012). Because professionals usually have more medical knowledge than patients, patients often view the healthcare professional/patient relationship as unequal (Kettunen et al., 2002).

Increasingly, however, the importance of involving patients as equal partners in healthcare is receiving greater emphasis (Tritter & McCallum, 2006; Lord & Gale, 2014; Batalden et al., 2015). Increased involvement of patients in healthcare will affect existing roles for both patients and healthcare professionals (Berry & Bendapudi, 2007; McColl-Kennedy et al., 2012). The intent is to strengthen the patient position, allowing them the right to be involved in making healthcare better and safer (WHO, 2006; Swedish Patient Law, 2015). The trend in healthcare is moving toward more equal roles based on collaborative initiatives for better health, grounded in democracy and ethics (Crawford et al., 2002; WHO, 2006; Boyd et al. 2012; Safaei, 2015).

Patients<sup>2</sup> can be involved in healthcare in various ways (Coulter et al., 2008; Abrahamsen Gröndahl et al., 2011). For example, patients may be involved in their own treatment and care (Eldh et al., 2010), and they may contribute to improvements in the care process, which creates better care for other patients as well (Bate & Robert, 2006). Patients can be involved to various degrees, in different activities and on different levels in healthcare (individual or group levels). However, the definition of patient involvement and suggested ways of practice remain unclear, with a gap between intentions and practice (Lord & Gale, 2014).

Healthcare professionals traditionally developed care based only on their knowledge and practical experience (Bate & Robert, 2006). Later, there was interest in asking patients about their satisfaction and experiences, although healthcare professionals still determined the questions, and prioritized and acted on the results. Bate and Robert (2006) suggested a new way to improve healthcare that involved patients as co-designers, which they called *experience-based co-design* (EBCD). The method is based on four steps: Catching the experience; understanding the experience; improving identified problems through collaboration of patients and healthcare professionals; and following up on improvements. Patients are highly involved and collaborate with healthcare professionals during all four steps (Bate & Roberts, 2007).

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<sup>2</sup>Sometimes patients cannot speak for themselves and need relatives to speak for them. Some of the studies in the thesis involved pediatric care, with parents representing their children. In this thesis, the term *patient* is used for patients and those who represent them.

Patient involvement in QI with EBCD can improve quality on a system level, which improves care for other patients (Bate & Robert, 2006; Bevan et al., 2007; Mugglestone et al., 2008; Tsianakas et al., 2012; Donetto et al., 2015) and saves economic resources (Mazur, 2003; Ovretveit, 2009). In addition to earlier mentioned contributions, patient involvement in QI also influences the power relationship between professionals and patients, supporting patients' new role as co-designers in collaborative improvements (Crawford et al., 2002).

Regardless of intentions and argued benefits, the application of patient involvement in QI has been problematic, and therefore, the practice is not widespread in healthcare (Crawford et al., 2002; Luxford et al., 2011; Armstrong et al., 2013). Patient involvement is considered time-consuming and competitive with daily work (Wiig et al., 2013; Donetto et al., 2014). In addition, a new relationship between healthcare professionals and patients implies changing healthcare culture from a provider to a patient focus (Luxford et al., 2011), although the old hierarchical mentality still exists (Kettunen et al., 2002). Asking healthcare professionals to decrease their traditionally exercised control over patients (Berry & Bendapudi, 2007; Luxford et al., 2011; McColl-Kennedy et al., 2012) can be threatening to healthcare professionals (Donaldson, 2008).

In summary, there is a need to develop deeper knowledge about patient involvement in QI, its effects on quality, and the new roles in QI for healthcare professionals and patients. Despite a high degree of consensus on the goal of involving patients in healthcare and strengthening their role, there is a lack of practical examples and research to guide further explorations of patient involvement in QI (Bessant & Maher, 2009; Armstrong et al. 2013; Lord & Gale, 2014).

## 1.1 Purpose

The purpose of this thesis is to explore contributions and challenges of patient involvement in QI in healthcare.

## 1.2 Research questions

The first research question addresses how quality in healthcare can be influenced by patients being involved in QI.

### **R1            How can patient involvement in QI influence quality in healthcare?**

The second research question emphasizes difficulties with patient involvement in QI. Although few examples of patient involvement in QI exist, preparing for challenges can increase the possibility of that involvement.

### **R2            What are the challenges with patient involvement in QI?**

The third research question focuses on roles and relationships between patients and healthcare professionals. Traditionally, patients have had a passive role as the recipients of care, which implies an unequal relationship with healthcare professionals. This relationship could change when patients and healthcare professionals collaboratively work with QI, and is therefore important to study.

### **R3            How does patient involvement in QI affect the relationship between patients and healthcare professionals?**

## 1.3 Relevance for practice

Involving patients in healthcare QI is not yet widely applied in practice (Armstrong et al., 2013; Lord & Gale, 2014; Bessant & Maher, 2009). To adopt this approach, healthcare professionals need training and guidance that includes practical examples demonstrating the opportunities

and challenges. This thesis contributes with such practical examples. The papers appended to this thesis elaborate on the development of the patient role, and the relationship between patients and healthcare professionals, and how co-design influences that relationship. This contribution is valuable for practice, as this new relationship is one of the major challenges of patient involvement in QI (McColl-Kennedy et al., 2012; Luxford et al., 2011).

## 1.4 Relevance for research

Although patient involvement in QI has recently received much attention, evidence of its contributions is limited (Armstrong et al. 2013), and additional research has been recommended (Crawford et al., 2002; Freire & Sangiorgi, 2010; Boyd et al., 2012). This thesis aims to help fill a gap about contributions and challenges of patient involvement in QI. These findings can be valuable for the development of a science of improvement in healthcare related to the grounding principle of patient focus. Earlier research has indicated a lack of reported outcomes for patient involvement in QI (Lord & Gale, 2014). Without evaluation of results, professionals might have little confidence in patient involvement in QI and might resist attempts to be engaged (Tritter & McCallum, 2006). Therefore, it may be helpful to identify possible contributions of patient involvement to the current approach to QI in healthcare. Moreover, Luxford et al. (2011) indicated that increased patient involvement might affect the relationship between healthcare professionals and patients; therefore, an investigation of whether such an effect exists and its influence on the patient role can be important.

## 1.5 Outline of the thesis

- Chapter 1 Describes the research background, purpose, and questions.
- Chapter 2 Provides a theoretical framework, including previous research and concepts central to this thesis.
- Chapter 3 Describes the research design, methods used for generating and analyzing the empirical material, and methodological reflections.
- Chapter 4 Includes summaries of the appended papers and their common themes.
- Chapter 5 Discussion.
- Chapter 6 Conclusions.
- Chapter 7 Provides ideas for future research.

These chapters are followed by a reference list and the appended papers.

## 2 THEORETICAL FRAMEWORK

*This chapter includes an elaboration of QI in healthcare and patient focus as a guiding principle for QI in healthcare. There will next be a section about patient involvement in healthcare and finally a presentation of patient involvement in QI.*

### 2.1 Quality improvement in healthcare

Healthcare faces several challenges that accelerate the need to improve care (Berwick, 1998; Mohrman et al., 2012). Future patients may demand greater healthcare quality (Kettunen et al., 2002) and require involvement in their care on equal terms with healthcare professionals (Naidu, 2009). Second, despite new expensive treatments and technology, resources are limited (Christensen et al., 2009; Mohrman et al., 2012). Third, the population is aging, increasing the need for care (WHO, 2000). These challenges call for a change in healthcare (Christensen et al., 2009).

Since the early 1990s, industrial principles, practices, and tools for quality improvement (QI) have received increasing interest in healthcare (Batalden & Stoltz, 1993; Berwick, 1998). Quality improvement in this thesis is defined as: “The combined and unceasing efforts of everyone – healthcare professionals, patients and their relatives, researchers, payers, planners, and educators – to make the changes that will lead to better patient outcomes (health); better system performance (care); and better professional development (learning)” (Batalden & Davidoff, 2007 p. 2).

One of the central principles in QM is a customer focus (Dean & Bowen, 1994; Bergman & Klefsjö, 2010), which implies finding out what customers need and want and fulfilling these needs (Dean & Bowen, 1994). Dean and Bowen (1994) maintained that a customer focus and continuous improvement are best realized through collaboration between different stakeholders – co-workers, customers, and suppliers.

In the public sector, the concept of customer has been debated, and some have questioned the idea of patients as customers (Kaboolian, 2000). However, the role of the customer has evolved from that of the recipient of a product or service, to one of a source of information, and finally to one of a co-producer and co-creator of quality (Normann, 2001). Similarly, the patient is now closer to this newer customer concept, which is becoming easier to accept in healthcare (Nordgren, 2008; McColl-Kennedy et al., 2012).

When QI initially was introduced to healthcare, it was mainly based on examples from production logic, such as process orientation (Batalden et al., 2015). Later on, influences from the service area were introduced, and patients were viewed as service users instead of products to be refined (Nordgren, 2009; Davidoff, 2011). Vargo and Lusch (2004, p. 7) described service as a process of “doing things in interaction with the customer,” which means that value is created during the process in co-creation with the customer, rather than being delivered at the end of the process (Normann, 2001).

The area of QI in healthcare is often referred to as an emerging science of improvement (Berwick, 2007; Bergman et al., 2015). Positive effects on quality, such as increased availability and safety, have been achieved as interest in improvement knowledge has increased in healthcare, and more practical examples are being published (Berwick, 1998; Olsson et al., 2007; Lifvergren et al., 2010). However, there are also challenges related to QI in healthcare. For instance, the healthcare arena lacks improvement knowledge and its prevailing focus is on the professional rather than on the patient, although a patient focus is an important factor for

successful QI (Bergman et al., 2015). In addition, cost reduction is often a primary motivation for healthcare to work on QI (Kaboolian, 2000).

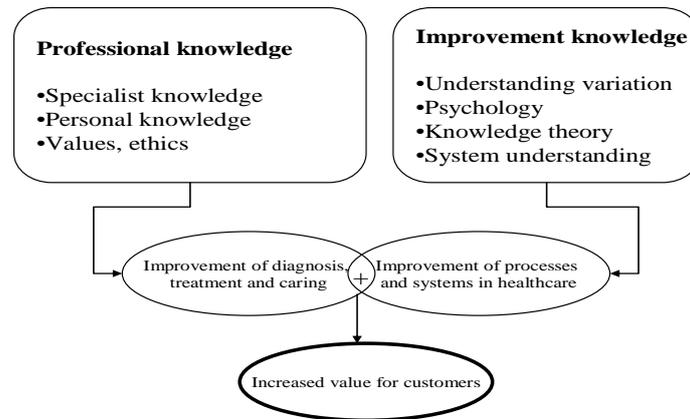
A further challenge is that increasing pressure for change comes from multiple conflicting directions, including patients, unions, media, managers, politics, and professional groups such as physicians (Kaboolian, 2000; Bessant & Maher, 2009; Porter, 2010). Healthcare professionals strongly depend on their specific expert knowledge to retain their positions and exercise influence. By dominating with professional knowledge, healthcare professionals may exclude other stakeholders, such as patients, from influencing healthcare development (Freidson, 2001).

Stakeholders in healthcare have various definitions of quality, which indicates that QI in healthcare is complex and dynamic (Yasin et al., 2002). Differing and often conflicting desired outcomes, such as a professional versus a patient focus, lead to a lack of clarity about QI goals, which slows progress (Porter, 2010). Furthermore, Glouberman and Zimmerman (2004) illuminated that healthcare often tries to solve complex problems with methods for solving simple problems. This approach often leads to failure, as complex problems require knowledge about complexity (Glouberman & Zimmerman, 2004). All of these challenges indicate a growing need for new knowledge about improvements in healthcare.

### *2.1.1 IMPROVEMENT KNOWLEDGE*

A management innovation is the invention and implementation of a management practice, process, structure, or technique that is new to an organization (Birkinshaw et al., 2008; Alänge & Steiber, 2011). Healthcare lags in adoption of management innovations (Greenhalgh et al., 2004; Christensen et al., 2009); however, some innovations connected to QI have recently occurred. Quality Improvement efforts in many healthcare organizations began with process orientation (Batalden & Stoltz, 1993; Hellström, et al, 2010). Practices such as Lean production and Six Sigma later inspired many hospitals to work toward QI (Batalden & Stoltz, 1993; De Souza, 2009; Lifvergren et al., 2010; Gremyr et al., 2012).

Adopting industrial improvement principles, practices, and techniques in healthcare requires knowledge of these approaches, as well as improvement and professional knowledge (Batalden & Stoltz, 1993). Deming (1994) first introduced the type of knowledge required to lead improvement efforts as *profound knowledge*. Figure 1 shows a model by Batalden and Stoltz (1993), based on Deming's view of profound knowledge as consisting of knowledge of variation, psychology, knowledge theory, and system understanding.



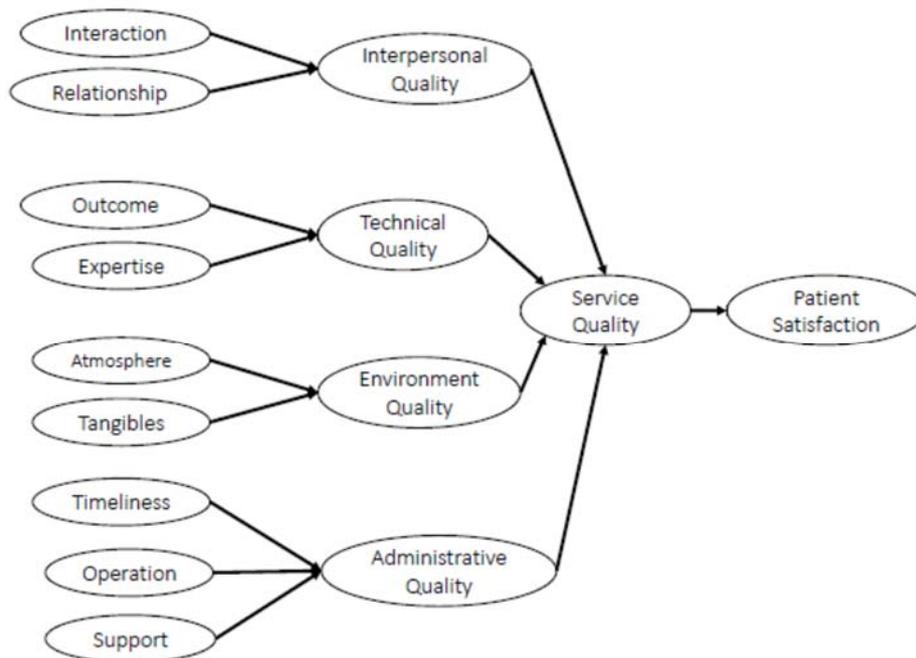
**Figure 1: Professional and improvement knowledge (adapted from Batalden & Stoltz, 1993)**

Batalden and Stoltz (1993) argued that a combination of professional and improvement knowledge supporting QI in healthcare creates increased value for patients. This additional improvement knowledge is valuable because, according to WHO (2006), healthcare has become overly disease-focused and technology-driven. Additionally, WHO (2006) stated that medical education includes insufficient consideration of patients' psychosocial, emotional, and cultural contexts. Although healthcare professionals have tried to adopt improvement knowledge, they have faced challenges. Even among healthcare organizations with the best improvement results, professionals continue to argue that the majority of QI initiatives conflicts with daily work (Olsson et al., 2007). QI must be better integrated into daily healthcare work to achieve its full potential (Batalden & Stoltz, 1993).

### 2.1.2 QUALITY IN HEALTHCARE

Shewart (1931) discussed the objective and subjective aspects of quality, and later, Juran (1988) described quality as an individual product's characteristic, associated with its functionality or aesthetic, developing the current definition of quality as "fitness for use" (p. 15), based on specifications on customer requirements and satisfaction.

Defining quality in healthcare is complex because the concept comprises several objective and subjective dimensions (Parasuraman et al., 1988; Grönroos, 2006) differentiated as technical and functional quality. Technical quality refers to the service delivered (skill and expertise), and functional quality to how it is delivered (interactions) (Donabedian, 1988; Grönroos, 2006; Gallan et al., 2013). Inspired by Parasuraman et al. (1988), Dagger et al. (2007) linked patient satisfaction to quality, suggesting that patients' perceptions were based on four dimensions: interpersonal, technical, environmental, and administrative quality (See Figure 2), each with sub-dimensions.



**Figure 2: Quality dimensions and sub-dimensions of service quality in healthcare that lead to patient satisfaction (adapted from Dagger et al. 2007).**

In their model, Dagger et al. (2007) suggested functional quality is manifest in three of the dimensions: interpersonal, environmental, and administrative. The quality dimensions can provide healthcare professionals with insights about patients’ perceptions of quality and can help to visualize differences between patients’ and healthcare professionals’ experiences of care.

Lillrank (2015) argued that patients’ experience of quality, clinical decision-making, and patient safety are the three types of healthcare quality. In addition, patients’ experiences are mentioned in the National Health Service NHS, UK definition for quality: “care that is effective, safe, and provides an as positive experience as possible” (Swinglehurst et al., 2014, p. 65). If patients are viewed as co-creators of value, their capacity to influence service and quality of care increases (McCull-Kennedy et al., 2012; Kim et al., 2014).

### 2.1.3 THE PATIENT IN FOCUS

Patient focus as a grounding principle for QM in healthcare has been demonstrated as a way to address the power inequality and underlying tensions in the relationship between healthcare professionals and patients (Tritter & McCallum, 2006). Power can be manifested as dominance, asymmetry, and control (Kettunen et al., 2002). Interactions between patients and healthcare professionals that enhance patients’ feelings of control and help them achieve their desired health goals require power sharing through participatory processes. Healthcare professionals and patients construct the patients’ power jointly during interactions, such as dialogues (Kettunen et al., 2002). Tritter and McCallum (2006) argued that creating more opportunities for patients to be involved in various activities in healthcare might produce a shift in power structures between patients and healthcare professionals.

Traditionally, patients have been expected to be grateful to receive care and to rely on healthcare professionals' skills and knowledge (Kettunen et al., 2002; Bohmer, 2009; Naidu, 2009), providing only their physical selves and information on their conditions (Gallan et al., 2013). Therefore, patients were passive responders, rather than active actors in care, leaving matters to the professionals (Kettunen et al., 2002). This strong professional dominance in healthcare may be a reason why patient involvement has been problematic (Luxford et al., 2011). Healthcare professionals have legitimacy in society as experts and are trusted always to put their patients' needs first. In addition, they guard their positions by dominating the healthcare arena and actively precluding other actors, such as patients (Andersson, 2015). Sharing the arena with patients can challenge their professional status and identity (ibid.).

According to this traditional view, healthcare is seen as a manufacturing process led by healthcare professionals with a beneficial outcome for patients (Normann, 2001; Batalden et al., 2015). Although many patients and clinicians operate under this older paradigm, some researchers have found that patients' passive role is transforming into one in which they are expected to be more involved in their own care (Kettunen et al., 2002; Naidu, 2009). Carman et al. (2013, p. 228) argued: "We are in a midst of an important and potentially transformative shift related to patients' roles in healthcare."

The close coupling of creation and consumption of value in care processes emphasizes the patient as an active partner who co-creates value in collaboration with healthcare professionals (Normann, 2001; Bessant & Maher, 2009; McColl-Kennedy et al., 2012; Grönroos & Ojasalo, 2015). Although the earlier focus in healthcare was on applying expert knowledge to treat illness and maintaining healthcare professionals' routines, the current focus is moving toward healthcare delivery from a patient viewpoint, based on patient experience (Freire, & Sangiorgi, 2010). If healthcare professionals and patients better understand how to interact, and if patients are invited to take responsibility for their own care, the care process can be smoother and quicker (Normann, 2001). In addition, more patients can be served by the same amount of resources, and the perceived service quality might be better (Grönroos & Ojasalo, 2015).

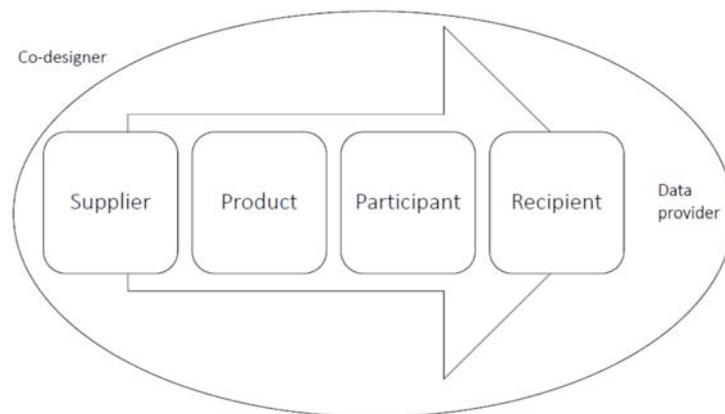
Involving patients in co-creation of value with healthcare professionals changes their relationship to each other (McColl-Kennedy et al., 2012). Healthcare professionals must move their competence from producing value for patients toward organizing collaborative value-creation involving patients as the focus of care (Normann, 2001; McColl-Kennedy et al., 2012). According to Normann (2001), healthcare situations must be seen from different perspectives with different realities. However, assessing situations from the patient perspective does not guarantee healthcare QI; a new orientation based on learning in collaboration with patients is also needed (Bate & Robert, 2006).

Lord and Gale (2014) presented three obstacles to patient focus: a mismatch between the needs of healthcare organizations (objective processes) and the needs of patients (subjective processes); difficulties in changing routines; and organizational and professional structures. Underpinning these obstacles are the existing healthcare and political systems that emphasize clinical outcomes rather than patient experiences (Lord & Gale, 2014). Nevertheless, patient focus is the guiding principle for healthcare and is central in concepts such as patient-centered (Lord & Gale, 2014), family-centered (Kuhlthau et al. 2011), and person-centered care (Leplege et al., 2007; Ekman et al., 2011).

#### *2.1.4 THE PATIENT ROLE*

When discussing QI in healthcare, it is fruitful to consider that patients can have several roles (Lengnick-Hall, 1995; Bate & Robert, 2006), each with a different view of the patient in the

care process. Viewing the healthcare as a manufacturing process, Lengnick-Hall (1995) argued that patients have four roles: supplier, product, participant, and recipient. As a *supplier*, patients deliver themselves to the care process as the raw material that must achieve better health. Seen as a *product*, the patient is refined during the process. The *participant* role is an active member of the care team with healthcare professionals (Nordgren, 2009; Davidoff, 2011). A consequence of failing to involve patients in care processes is that the quality of care can suffer from the patient’s lack of compliance with treatment (Naidu, 2009). As *recipients*, patients are customers of the healthcare system, receiving care from healthcare professionals. The importance of feeling satisfied with care is connected to this role (Lengnick-Hall, 1995). Bate and Robert (2006) noted one additional role of the patient as a *co-designer* in relation to improving the care system, not only for themselves, but also for other patients. Service co-designs are powerful in several contexts (Bessant & Maher, 2009); however, healthcare has fewer examples (ibid; Lord & Gale, 2014). In addition, patients can have a role as data providers, based on their experiences and health outcomes (Tritter & McCallum, 2006; Jaques, 2012; Nelson et al., 2015). Figure 3 depicts examples of various patient roles in the patient process (the arrow – one’s own care), as well as on a system level of healthcare (for others).



**Figure 3: Different patient roles.** The figure illustrates suggested patient roles in the patient process (the arrow symbolizing – one’s own care), and the healthcare system level (surrounding the arrow - for others) (adapted from Lengnick-Hall, 1995; Bate and Robert, 2006).

Patient involvement in various activities at various organizational levels and to various degrees paves the way for new patient and professional roles in healthcare (Reijonsaari, 2013). Consequently, challenges can arise as the current distribution of power and responsibility between patients and healthcare professionals is disrupted (Batalden et al., 2015).

## 2.2 Patient involvement in healthcare

Many researchers emphasize the critical importance of patient involvement in healthcare, indicating that a focus on patients’ needs alone in healthcare is not enough (e.g., IoM, 2001; Tritter & McCallum, 2006; Lord & Gale, 2014; Batalden et al., 2015; Dent & Pahor, 2015). Patients should also be given increased opportunities to participate in healthcare activities. Patient involvement in healthcare is based on democracy and human rights, and strengthening patient involvement is part of healthcare quality (IoM, 2001; WHO, 2006). Patient involvement supports patient empowerment, a process through which people gain greater control over the decisions and actions that affect their health (WHO, 2006). The phrase “nothing about me without me” has become widespread (Delbanco et al., 2001). Tritter and McCallum (2006, p 157) defined patient involvement as: “a complex phenomenon through which individuals formulate meanings and actions that reflect their desired degree of participation in individual

and societal decision-making processes.” In this thesis, patient involvement not only includes decision-making, but also is defined as opportunities for patients to participate in healthcare activities, from low to high degrees, on different organizational levels. Patient involvement is an interactive, collaborative, and dialogical process based on knowledge and experience between patients (sometimes relatives) and healthcare professionals about actions that affect patients’ health.

Carman et al. (2013) noted three categories of factors that can contribute to patient involvement. The first category includes individual factors related to the patient, such as knowledge, attitudes and beliefs based on earlier experiences of healthcare; health literacy, and health status. The second category comprises the organizational level, including healthcare organizations that make patient involvement central to their improvement goals. The third category includes societal, political, and social influences, such as steering documents and new laws that support patient involvement (ibid.). In addition, Tritter and McCallum (2006) argued that patients must be given an opportunity to shape practices for patient involvement, which may change over time.

However, patient involvement also can decrease empowerment (Dent & Pahor, 2015). For example, patient empowerment may decrease in instances of forced responsibility (patients must make choices even if they do not want to), paternalistic proto-professionalization (doctors focus more on compliance than co-creation), and manipulation (patients attend advisory committees but have no opportunity to participate in decisions) (Nordgren, 2009; Dent & Pahor, 2015). Batalden et al. (2015) also highlighted contextual standardization (traditional routines such as ward rounds) and a healthcare culture resistant to change as factors that decrease patient empowerment. In addition, some patients may be too sick to be actively involved in their care, which demands that healthcare take into account patients’ individual variations (Bergman et al., 2015). Even if a higher degree of involvement is not ideal for all patients and adjustments must be made, many patients want to be more involved in healthcare activities (Carman et al., 2013).

Patients are not the only ones who desire being involved; their families and (more generally) private citizens (Dent & Pahor, 2015) also may seek a role. Not all patients can speak for themselves, which means that a patient focus must include partners or parents. In this thesis, I use the term *patient* to include both patients and their relatives.

In comparison to other European countries, Swedish healthcare only offers limited opportunities for direct patient involvement in healthcare policy and planning (Tritter & McCallum, 2006). In contrast, the Netherlands successfully shifted from a consultative approach to a patient involvement approach, for example establishing it in policymaking (ibid.). Because of the limited opportunities for patient involvement, a Swedish national initiative recently resulted in a new law to strengthen patients’ position in healthcare (Swedish Patient Law, 2015).

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### 2.2.1 DEGREES OF INVOLVEMENT

Patient involvement can be seen as a continuum with various degrees of involvement. The pioneering work of Arnstein (1969) suggests an eight-rung ladder for citizen involvement. The lower rungs represent non-participation; the middle rungs indicate degrees of tokenistic participation (meaning being invited to participate, but not being involved), and the upper rungs represent degrees of citizen power. In addition, Carman et al. (2013) suggested three degrees of involvement in healthcare: consultation; involvement; and partnership with shared leadership. Similarly, Bate and Robert (2006) discussed three degrees of involvement in QI: without the patient (non-involvement), listening to the patient, and in collaboration with the patient. Carman et al. (2013) stated the lowest degree of involvement as consultation (listening to patients but not allowing their involvement in QI), which equates to Bate and Roberts' (2006) second degree.

On the other hand, Tritter and McCallum (2006) have questioned sectioning involvement into degrees. They maintain that pre-defined degrees of involvement suggest a static perspective that fails to capture the dynamic and evolutionary nature of patient involvement. Beyond degrees of involvement Tritter and McCallum suggest that increased attention to the outcome of the involvement process, and diversity of knowledge and experience of both professionals and patients also must be considered.

For this thesis, I consolidated the degrees of involvement suggested by Carman et al. (2013) and Bate and Robert (2006) into the following four:

- (1) *Patient focus* – In this lowest degree of patient involvement healthcare professionals keep patients' needs in focus, but patients are not invited to participate in healthcare activities. Arnstein (1969) referred to this degree as non-participation.
- (2) *Consultation* – At this degree, healthcare professionals listen to patients and seek to include their voices in activities, such as surveys, although healthcare professionals carry out the care and any improvements. Consultation may also include situations in which patients are given information but have no power to make decisions (Carman et al., 2013), which some have referred to as tokenism (Arnstein, 1969).
- (3) *Participation* – Patients are asked about their preferences and participate in shared decision-making, but are not involved in collaboration with healthcare professionals throughout activities.
- (4) *Collaboration with power equality* – Patients and healthcare professionals collaborate and share power. This degree of involvement may be referred to as partnership and shared leadership between patients and healthcare professionals (Carman et al., 2013). The patient role is strengthened in relation to healthcare professionals (Arnstein, 1969).

In addition to degrees of involvement, patients may be involved in various activities at different levels of healthcare. Four levels for patient involvement will be presented here, with descriptions of related activities. First, at the *individual level*, the most common way to increase patient involvement is to allow patients to make decisions concerning their own healthcare options (Coulter et al., 2008; Abrahamsen Grøndahl et al., 2011; McColl-Kennedy et al., 2012; Dent & Pahor, 2015). Decisions regarding care, treatment, and rehabilitation are made collaboratively (Ekman et al., 2011). If care processes are seen as services and patients are allowed to participate as co-creators, these processes become a resource largely outside the

control of the healthcare organization (Grönroos, 2015). Patient involvement in the form of shared decision-making has been shown to increase well-being, improve medical status, increase satisfaction, and reduce length of stay (Ekman et al., 2011; McColl-Kennedy et al., 2012).

In addition, involvement can extend to the patient’s family. A family-centered approach in pediatric care has positive effects on quality in many ways: health status, satisfaction, more efficient use of healthcare resources, communication, and family function (Kuhlthau et al., 2011; McColl-Kennedy et al., 2012). The core concepts for family-centered care comprise sharing information, dignity and respect, and partnership and collaboration between families and healthcare professionals (Kuo et al., 2011; Kuhlthau et al., 2011).

Second, patients can be involved in service-delivery activities in care on a *group level* that includes other patients (Batalden et al., 2015). Patients may want to share their experiences with others, offer support to other patients during their care, or participate in educational initiatives for patients and healthcare professionals (Tritter & McCallum, 2006; Towle et al., 2010; Carman et al., 2013). System design is a recent activity related to patient involvement. Patients are invited to join with healthcare professionals in QI to improve the experiences for all patients in a group (Bate & Robert, 2007; Tritter & McCallum, 2006; Carman et al., 2013; Batalden et al., 2015; Dent & Pahor, 2015).

Third, patient involvement can take place on a *governance and management level*, such as participation on hospital board to influence policies or visions (Hubbard et al., 2007).

Finally, patient involvement on a *societal level* may include participation in research (Gillard et al., 2012; Armstrong et al., 2013; Ives et al., 2013), follow-up healthcare quality (quality-registers) (Tritter & McCallum, 2006; Jaques, 2012; Nelson et al., 2015), or national policy making (Cornwall & Gaventa, 2000; Batalden et al., 2015). Dent and Pahor (2015) referred to this level of involving as the patient voice.

Table I shows examples of various activities and at these four levels of patient involvement.

**Table I Patient involvement in healthcare – examples of patient activities at four levels.**

Activities	Level
Activities concern one’s own care: Co-creating value in one’s own care; being engaged in treatment options and decisions, including the patients family if necessary	Individual level
Service delivery activities: Co-designing care systems in collaboration with healthcare professionals Educating other patients, relatives, or healthcare professionals	Group level
Being a part of leadership; included in management teams or boards Decision-making for policies or visions	Governance and management level
Co-researching healthcare Policy making on national level Follow-ups of quality, such as national quality registers	Societal level

Activities in healthcare take place within social systems as individuals learn, adapt, and make choices based on their perceptions. Such a social system is a potential joint venture between patients and healthcare professionals, stipulating mutual learning in an interactive, collaborative, dialogical process that is both challenging and rewarding (McColl-Kennedy et al., 2012; Reijonsaari, 2013; Grönroos & Ojasalo, 2015; Safaei, 2015). Because of this mutual learning, there is a need for patient involvement at various levels and through various activities strengthens the patient’s role (Tritter & McCallum, 2006; WHO, 2006).

### 2.2.2 CONCEPTS RELATED TO PATIENT INVOLVEMENT

Concepts related to patient involvement have diffuse meanings, definitions, and purposes (Dent & Pahor, 2015). These concepts are often used interchangeably with patient involvement, such as patient-centered care, patient participation, co-production, co-creation, and patient engagement. For example, participation, which means associating or sharing with others, or can be seen as synonymous with involvement (Fergusson et al., 2000). Concepts may have many definitions, but they share key components, which may cause confusion among healthcare professionals who seek to understand and use the concepts in their daily work (Eldh et al., 2010; Andersson & Olheden, 2012; Lord & Gale, 2014). Table II presents a brief compilation of examples of concepts and references related to patient involvement and their key components.

**Table II: Concepts related to patient involvement at various levels; examples of concepts and references, their key components, and the level in healthcare. A: Individual level, B: Group level, C: Governance and management, D: Societal level (described in Section 2.2.1).**

Concept	Reference	Key components	Level			
			A	B	C	D
Patient-centered care	IoM (2001)	Respectful of and responsive to individual preferences, needs, and values. Shared decision-making in patients’ own care.	X			
	Lewin et al. (2001)	A focus on the patient as a person with individual preferences within unique social contexts. Shared control and decision-making about interventions/management of health problems with the patient during consultation.	X			
Family-centered care (most common in pediatric care)	Kuo et al. (2011)	A philosophical approach and partnership in decision-making in healthcare.	X			
	Kuhlthau et al. (2011)	Information sharing, dignity, respect, partnership, collaboration, negotiation, and care in the context of family.	X			
	Shields (2006)	Planning care around the whole family, not just the individual patient. All family members are considered care recipients.	X			
Person-centered care	Ekman et al. (2011)	Highlights the importance of a person’s life story; partnership between the patient and healthcare professionals; and collaborative care planning.	X			
	Leplege et al. (2007)	Addressing the person’s specific and holistic properties and difficulties in everyday life. Sees the patient as an expert: participation and empowerment. Respect for the person behind the impairment or the disease.	X			

Patient participation	Eldh et al. (2010)	Mainly regards patients' right to be informed to support decision-making concerning care.	X			
Patient engagement	Coulter (2011)	Promoting and supporting active patient and public involvement in health and healthcare and strengthening influence on healthcare decisions at both individual and collective levels.	X	X	X	X
	Carman et al. (2013)	Patients, families, their representatives, and healthcare professionals working in an active partnership at various levels across the healthcare system to improve health and healthcare.	X	X	X	X
Co-production	Batalden et al. (2015)	Relates to a service view of healthcare. Patients and healthcare professionals co-produce value in collaboration, service delivery, and service design	X	X		
Co-creation	McColl-Kennedy et al. (2012)	Benefit realized from integrating resources through activities and interactions with collaborators in patients' networks. Co-creation of value is extended outside the healthcare system to include patients' social network (family and friends).	X			
Co-design	Bate & Robert (2006, 2007)	Collaboration between healthcare professionals and patients during QI. Moving from redesigning the system around the patient to co-designing services with the patient	X	X	X	X

The varied concepts related to patient involvement in healthcare underscore the interests of diverse stakeholders, such as professionals, patients, and the public, and illustrate the underlying tensions in relationships between them (Tritter & McCallum, 2006). Patient involvement challenges how healthcare professionals view their patients and might illicit new models for providing care (Reijonsaari, 2013). Tritter and McCallum (2006) argued that there is uncertainty about how much power or influence patients should have in healthcare. Patients' movement from a passive to a more active role could be seen as a paradigm shift (Snyder & Engström, 2016). Such a shift in the prevailing power structures between patients and healthcare professionals can be supported if patients have the opportunity to be involved in different aspects of healthcare (Tritter & McCallum, 2006).

However, neither the definition of patient involvement nor how to cause it to occur is clear, and there is often a gap between intentions and practice (Lord & Gale, 2014). Organizational support and effective processes are needed to support patient involvement in practice (Armstrong et al., 2013; Lord & Gale, 2014). More attention must be given to evaluating the impact of patient involvement on the practice of healthcare and health outcomes (Tritter & McCallum, 2006).

### 2.3 Patient involvement in quality improvement

In this section, I discuss patient involvement in QI, improving care for other patients, a specific healthcare activity at the group level of service delivery. I define patient involvement in QI in this thesis as activities in which patients and healthcare professionals share experiences and build a collaborative understanding of the care process in order to improve it. More specifically,

patients and healthcare professionals, as active partners in a co-design process, collaborate in diverse degrees to identify improvement areas, and prioritize needs for improvement, improvement suggestions, and actions related to the care process.

For a long time, healthcare professionals improved healthcare based only on their point of view (Bate & Robert, 2006; Donaldson, 2008). The patient was often left out of the initiatives. Donaldson (2008) argued that healthcare professionals stayed in their comfort zone without challenges to their attitudes, beliefs, or practices. Today, there are demands for increased openness and transparency about improvement areas in healthcare, which support patient involvement. However, patient involvement still mainly refers to being involved in one's own care. Patient involvement in QI is an emerging approach, with a strong connection to organizational culture (Renedo et al., 2015). Renedo et al. (2015) referred to four key elements in organizational structure that contribute to successful patient involvement in QI: (1) an emphasis on non-hierarchical, multidisciplinary collaboration between and among healthcare professionals and patients; (2) organizational staff members' ability to model desired improvement and patient involvement in QI with behaviors of mutual recognition and respect; (3) a commitment to rapid improvement, which ensures implementation of research; and (4) a constant and iterative process of data collection and reflection facilitated by the use of QI methods and the commitment to act on that learning.

Even if healthcare professionals are doing their best for the patient based on medical knowledge, they may find it difficult to have a patient focus when improving care (Freire & Sangiorgi, 2010). Patient involvement in QI is one way to overcome this problem, although the traditional professional-patient relationship can be a barrier (Freire & Sangiorgi, 2010).

Involving patients in QI is often a way for healthcare organizations to meet democratic or ethical requirements (Boyd et al., 2012; Safaei, 2015) for equity and understanding, rather than merely fulfilling a need for improvement (Crawford et al., 2002). However, other motives may be at play, such as the desire for better clinical outcomes (Lord & Gale, 2014), cost reduction (ibid.), patient safety (Vaismoradi et al., 2014), and improved patient experiences (Lord & Gale, 2014). Initiatives for patient involvement in QI may be related to specific services, which may have limited opportunities to change outcomes of a whole process or system (ibid.). On the other hand, involving patients in QI can have a long-term impact with sustainable changes in healthcare (Freire & Sangiorgi, 2010). Patients can and should take a more direct and ongoing role in identifying, implementing, and evaluating QI's in healthcare (Bate et al., 2015). Engström and Elg (2015) presented several possible motives for patients to get involved in QI: a desire for restitution (wanting to report about negative experiences); a need for social support; a way to show loyalty and to volunteer; a belief in making a significant contribution; and enjoyment of the task for its own sake. However, some patients do not want to be involved at all (Engström & Elg, 2015). These various motivations necessitate healthcare organizations' ability to adjust the practice and tools for patient involvement in QI.

### *2.3.1 QI BASED ON EXPERIENCES*

One of the main elements of patient involvement in QI is the ability of patients and healthcare professionals to share experiences and build a collaborative understanding of the care process (Tritter & McCallum, 2006), which encourages mutual learning (Olsson & Lau, 2015). Although healthcare professionals may try to maintain a patient focus as they engage in QI, every interaction and situation with a patient is unique. The patient is an expert by experience, and patients' and healthcare professionals' diverse knowledge bases are complementary (ibid.). According to Bate and Robert (2006), knowledge of the experience, which only the patient

holds, is unique and precious. Therefore, patients' experiences of healthcare are an important source of unique information for QI initiatives (Zeithaml et al. 1990; Bate & Robert, 2007; Naidu, 2009).

Until recently, healthcare professions tended to eschew stories about patients' bad experiences (Donaldson, 2008). Donaldson (2008) argued that healthcare professionals did not want to face the painful reality of medical errors. Today, healthcare professionals' ability to listen to patient experiences has increased; however, the stories are often seen as complaints and explained as natural complications (Donaldson, 2008). If healthcare professionals do not listen, patients may instead go to the media (Francis, 2013). Listening to patients can move healthcare professionals outside their comfort zones, presenting an emotional and sometimes confrontational challenge (Donaldson, 2008; Boyd et al., 2012).

Over time, healthcare professionals have recognized the importance of including patient experiences in QI (Lord & Gale, 2014). Patient involvement brings diverse views and breadth of engagement, adding validity and depth to identified improvement areas, while grounding the improvement in a particular healthcare setting (Tritter & McCallum, 2006; Coulter et al., 2014). However, collecting data on patient experiences is not enough; the experiences also must help improve care. To ask patients about their experiences through questionnaires and interviews and then fail to use the data raises expectations and could be unethical (Coulter et al., 2014). They suggested that narrative methods, such as dialogues and focus groups, can produce richer, more detailed, and more useful information than fixed-response options in questionnaires.

Listening to patients provides more insight, but healthcare professionals will remain in their comfort zone if they do not involve patients in identifying and prioritizing improvement areas and accomplishing improvements. According to the Beryl Institute (Wolf, 2015), moving organizations to a state of strong and sustained patient experience performance may well be one of the greatest culture shifts for a healthcare organization. Berwick (2003) argued that patient experience should be included as a dimension of quality in its own right, and suggested that patients always should be asked if there is anything about the care they experienced that could have been better. The experience matters for patients and not just for the moment; it also may affect choices for future interactions with healthcare (Bate & Robert, 2006).

### *2.3.2 CO-DESIGNING QI*

Co-design is a collaborative approach to design improvements or new solutions for better quality; therefore, co-design is patient involvement at a high degree. Although widely used in architecture and product development, co-design approaches are still sporadically used in healthcare (Bate and Robert, 2006; Donetto et al., 2015). Bate and Robert (2006) were inspired by the design field when developing patient involvement in QI, including important ingredients of great design: performance (functionality), engineering (safety), and aesthetics of experience (usability). They argued that healthcare mainly has been engaged with the first two, functionality and safety. Co-design is about direct involvement of patients and healthcare professionals in face-to-face collaborative ventures to design services for good care experiences (Robert, 2013).

Co-design contributes to QI in two ways: it offers a new perspective for identifying improvement areas, and it brings new QI tools and practices to healthcare (Bevan et al., 2007; Wiig et al., 2013). Practices and tools from the design field can be valuable when working with QI in healthcare, especially when it comes to involving customers in the design process (Pickles et al., 2008; Bessant & Maher, 2009). QI approaches inspired by the design field can support

organizational development as well, for example, impacting a leadership mindset and supporting healthcare professionals' engagement (Bevan et al., 2007). Bate and Robert (2006, p. 307) argued that healthcare is moving from "redesigning the system around the patient" to "co-designing services with the patient." The co-design process is both a dialogue process through which practical improvements can be derived, and at the same time, a methodological QI process defined for project participants (Iedema et al., 2010). In addition, social relationships are a basis for motivation (Carr & Walton, 2014).

Patient involvement in QI changes priorities for improvements (Boivin et al., 2014). Earlier research has shown that patients who were involved in QI suggested more improvements related to support for self-care and to patient participation in clinical decisions compared with healthcare professionals who were involved in QI without patient involvement. The professionals were more likely to emphasize the technical quality of care regarding a single disease rather than involving patients in their own self-care (ibid.). Patients also called for more inter-organizational collaboration in their improvement suggestions and urged expanded collaboration outside the organization (Renedo et al., 2015). Berry and Bendapudi (2007) referred to patients as quality detectives, identifying improvement areas earlier hidden for healthcare professionals.

When patients are involved in QIs, they draw upon their broader knowledge, skills, and experiences, which are not often used in the traditional patient role (Armstrong et al., 2013). Patients involved in QI are stimulated to reflect critically on their previous roles in healthcare (Renedo et al., 2015). Their experiences of the co-design process affect how they perceive their role in their own care, which supports them as active participants in their care and QI (Renedo et al., 2015). However, co-design is both powerful and challenging because it requires healthcare professionals and patients to renegotiate their roles and expectations (Donetto et al., 2015).

### 2.3.3 EXPERIENCE-BASED CO-DESIGN (EBCD)

Bate and Robert (2006) stated three ways to improve healthcare. First, healthcare professionals rely on their own experience and knowledge as they work with QI, excluding patients. Second, healthcare professionals listen to patients (through surveys and complaints), but still decide the questions and define improvement goals. Third, patients collaborate with healthcare professionals in QI efforts. Not many examples of this latter high degree of patient involvement exist; however, one that Bate and Robert (2006) introduced and that has spread recently is experience-based co-design (EBCD). Experience-based co-design supports a deliberate process to involve patients, their relatives, and healthcare professionals as active partners in identifying problem areas and co-designing improvements for better experiences (Bate & Robert, 2007; Bevan et al., 2007; Mugglestone et al., 2008; Tsianakas et al., 2012).

Experience-based co-design is described as a complex social intervention and dynamic process (Iedema et al., 2010). Several factors contribute to the outcomes, such as participants' personal development, changes in the healthcare professionals' motivation, skills and self-confidence, and the development of trust and new relationships between various participants (Donetto et al., 2014). The importance of collaborative, deliberate reflection as a tool is illuminated both for co-designing QI's as well as in co-producing research (Gillard et al., 2012).

Advantages of EBCD include promotion of learning about new ways to think, feel, act, and relate to QI among by healthcare professionals and patients (Robert, 2013). *Experience-based* means that the QI is based on listening to narratives that create new images about the care process (Bate & Robert, 2006; Bushe & Marshak, 2009). A distinguishing feature of EBCD is

sharing human experiences and sense-making emotions connected to activities in the care process that can change behaviors and mindsets (Bushe & Marshak, 2009). Narratives and storytelling are important parts of EBCD (Bate & Robert, 2007). In face-to-face encounters and through sharing narratives, patients and healthcare professionals can experience a collaborative sense making, as they try to understand how the other makes sense of experiences (Weick, 2000), and as a result, come to a common understanding of improvement areas.

Experiences with EBCD have been reported from several areas: breast, lung, head, and neck cancer care; geriatric outpatient services; and emergency departments (Bate & Robert, 2007; Bowen et al., 2010; Iedema et al., 2010; Piper et al., 2012; Tsianakas et al., 2012). Examples of improvements include maps to help patients find their way (Bowen et al. 2010); improvements to triage arrival and registration (Iedema et al., 2010; Piper et al., 2012); more frequent contact with patients in the waiting room; patients no longer being separated from loved ones during outpatient surgery (Tsianakas et al., 2012); updated patient information; improvements in communication; and more appropriate positioning of weighing scales (Bate & Robert, 2007; Maher & Baxter, 2009).

However, EBCD also has challenges, such as how to motivate healthcare professionals and patients to dedicate time to work together on QI. Healthcare professionals' may feel they are too busy, and patients may live far from the hospital or may not be enthusiastic about returning to the hospital after discharge (Iedema et al., 2010; Greenhalgh et al., 2011; Boyd et al., 2012). Experiences from some EBCD projects showed that patients lacked focus during implementation and evaluation of improvements, compared with the processes of catching experiences and prioritizing improvements, which negatively affected sustainability of QI (Iedema et al., 2010). One solution to this problem could be to decide on follow-up measures of QI in collaboration between patients and healthcare professionals (Bate & Robert 2007).

Experience-based co-design are accomplished through four steps: catching experiences; understanding experiences; improving experiences; and following up on improvements.

#### *2.3.4 CATCHING EXPERIENCES*

The first step is about catching experiences from patients and healthcare professionals about the care process (Bate & Robert, 2007). Tools for catching experiences may include diaries, interviews, observations, filming, photos, and questionnaires (ibid.). Filming is particularly valuable for communicating patient experiences to healthcare professionals (Tsianakas et al., 2012).

#### *2.3.5 UNDERSTANDING EXPERIENCES*

In this step, the caught experiences are presented to the entire QI team, consisting of patients and healthcare professionals. Patient journey mapping or emotional mapping may be used to graphically depict patient experiences over a timeline, with attached activities mentioned when catching the experiences (Bate and Robert, 2007). Each activity is depicted with connected expressed emotions (Boyd et al., 2012). Collaborative group meetings are held to identify touch points of meaningful situations and to prioritize improvements. Touch points are situations that matter to both patients and healthcare professionals (Bate & Robert, 2007).

#### *2.3.6 IMPROVING EXPERIENCES*

Once improvement areas from the recorded experiences are identified and prioritized, improvement teams (including both patients and healthcare professionals) are formed around a common improvement area (Bate & Robert, 2007). The teams can work with the QI according to "plan, do, study, act" (PDSA) cycles (Langley et al., 1996), as they design the experience of moving through a care process. This step may take up to three months to accomplish.

### 2.3.7 FOLLOWING UP IMPROVEMENTS

The final step is to gather all involved parties for a celebration and follow-up meeting, as follow-up measures help to sustain the improvements (Bate & Robert, 2007). In some cases, maintaining patient interest in this step has been difficult because the earlier steps of problem diagnosis and solution generation may be more exciting (Iedema et al., 2010).

A planning step was recently added as the first step in EBCD by Robert and colleagues (Donetto et al., 2014; Robert et al., 2015). Involving participants in the planning step builds trust, which can be important in certain contexts (Donetto et al., 2014). In addition, the catching step was divided into two sub-steps (Donetto et al., 2014), one for catching experiences of patients/relatives and one for catching healthcare professionals' experiences. As a result of these additions, EBCD typically has six steps (Robert et al., 2015), and projects may take six to 12 months to complete (Donetto et al., 2014).

## 2.4 Patient involvement in QI – Easier said than done

Although interest in patient involvement in QI is increasing (Andersson & Olheden, 2012), a gap exists between intentions and expectations of patient involvement and actual day-to-day practices (Bate & Robert, 2007; Maher & Baxter, 2009; Iedema et al., 2010; Tsianakas et al., 2012; Wiig et al., 2013). Wiig et al. (2013) presented multiple reasons for the lack of patient involvement in QI. These reasons included interactions between various processes within the hospitals (such as lack of collaboration between wards), politics, managers' priorities, and attention to patient experiences and involvement; the resource situation; and knowledge and competence regarding patient involvement as part of QI (ibid.).

One frequent argument against involving patients in QIs is that a few patients cannot represent all patients (Lord & Gale, 2014). Who should be involved in patient involvement? Which patients are suitable? Can a few patients represent for many others? This reasoning does not highlight that healthcare professionals also differ when it comes to representativeness (Tritter & McCallum, 2006). A second argument is that patients are unsuitable for QI because they may lack familiarity with, and information about, the healthcare system (Armstrong et al., 2013). However, patients' strength can be their lack of insight in the healthcare system: They can ask questions that healthcare professionals may never consider, which may challenge the existing system (Armstrong et al., 2013). Furthermore, patients can see shortcomings in care that staff members may not, which can affect quality related to patient safety (Vincent & Coulter, 2002; Jaques, 2012).

Armstrong et al. (2013) argued that patient involvement in QI must be carefully managed to reach its full potential. Hospital managers must devise strategies to help healthcare professionals recognize and value the contribution that patient involvement and experiences can bring to QI (Wiig et al., 2013). Making patient involvement in QI a common practice requires early involvement, effective communication channels, nonhierarchical structures, and a clearly defined role for participants (Armstrong et al., 2013). Moreover, there is a need for new practices, tools, and knowledge/expertise for patient involvement in QI (Bessant & Maher, 2009; Wiig et al., 2013; Lord & Gale, 2014). This thesis explores contributions and challenges of patient involvement in QI in healthcare, and thus, fills a gap in practice and research.

### 3 METHODOLOGY

*This chapter presents the research approach in this thesis, beginning with the overall design and a description of the action research approach used in Papers I–V and continuing with an account of the empirical context. It also provides an overview of the empirical material and analysis in the six appended papers and ethical considerations. Methodological reflections are presented at the end of the chapter.*

#### 3.1 Research design

This thesis is mainly based on an action research (AR) approach (Papers I–V). Action research is based on the epistemological assumption that the purpose of academic research and discourse is not just to describe, understand, and explain the world through a common knowledge-generating process, but also to achieve change (Greenwood & Levin, 2007; Coghlan & Brannick, 2008; Reason & Bradbury, 2009). Values close to AR and the research presented in this thesis reflect democracy and human equality.

The empirical studies in this thesis are based on experiences narrated by patients and healthcare professionals. When people share experiences, listen to stories, and interact in reflecting dialogues, they share social constructions of the world and find new ways of acting, based on shared pictures of reality (Gergen, 2007; Edwardsson et al., 2011). Bringing views of several stakeholders together can produce knowledge that is more penetrating and insightful than when researchers work alone (Van de Ven, 2013).

The collection of empirical material in AR can be both qualitative and quantitative (Coghlan & Brannick, 2008). Integrating qualitative and quantitative research methods gives a complementary picture of a studied problem (Länsisalmi et al., 2006; Flick, 2009; Morse, 2010). Qualitative methods and analysis are prominent in this thesis, although there are some quantitative elements (in paper VI). A mainly qualitative approach was chosen, as suitable for interpreting and understanding a problem area that has not been extensively studied (Bryman & Bell, 2007; Flick, 2009). Qualitative research methods often help to gain an in-depth understanding of a specific phenomenon by asking *how* and *why*, rather than *what*, *when*, and *where* (Bryman & Bell, 2007). Such an approach gives a detailed, rich, and descriptive collection of empirical material (Bryman & Bell, 2007; Coghlan & Brannick, 2008).

The research process in this thesis is pragmatic, exploratory and features learning cycles (Coghlan & Brannick, 2008) in both the empirical and theoretical arguments. The approach does not show one optimal way of doing things; finding better, new ways of managing situations is always possible.

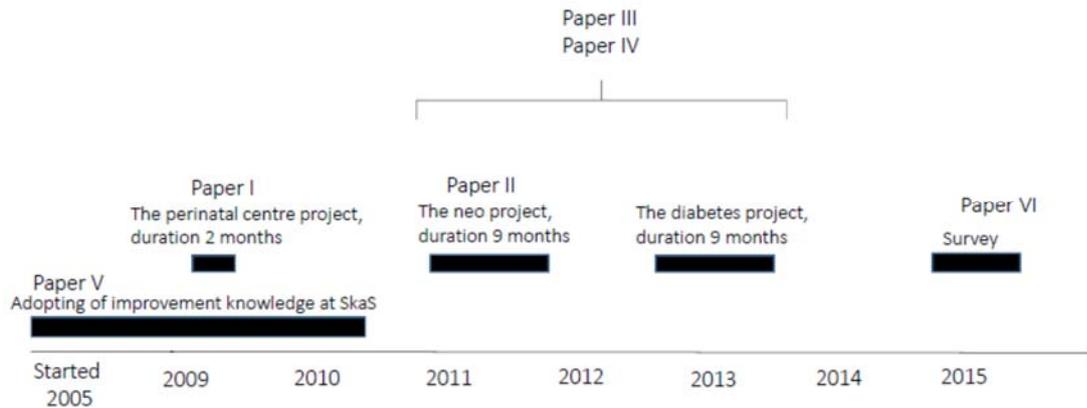
The empirical studies were mainly conducted at Skaraborgs Sjukhus (SkaS), Sweden. Three improvement projects conducted in the pediatrics and women's divisions were explored using an AR approach. The first project, The Perinatal Centre, was a planning project for new buildings and new process design for obstetric and neonatal care. The new building underwent construction, and the first ward moved in during the fall 2015.

The second project was conducted within the neonatal care as a complement to ordinary process-orientation work. The project involved patients and healthcare professionals, and used EBCD as practice. The third project was conducted among children with diabetes and also was an EBCD project with patient involvement.

Skaraborg Hospital, which has had an ambition to work with structured QM initiatives since the late 1990s and emphasizes introducing improvement knowledge as a complement to professional healthcare knowledge (Bergman et al., 2015), as presented in Paper V. The hospital's QM approach is based on process orientation, and SkaS started the first major

Swedish project to apply and adapt Six Sigma to healthcare (Lifvergren et al., 2010; Gremyr et al., 2012).

Paper VI is a national study that complements the AR studies in the local context at SkaS. Figure 4 presents a timeline of the projects and related papers. (The papers are described further in section 3.4 and in chapter 4).

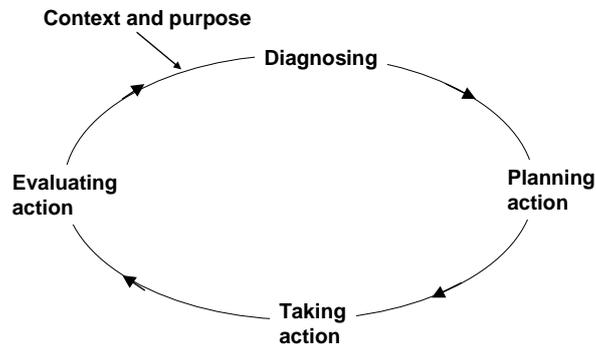


**Figure 4: Timeline – projects and papers that are included in this thesis.**

### 3.2 Action research (AR)

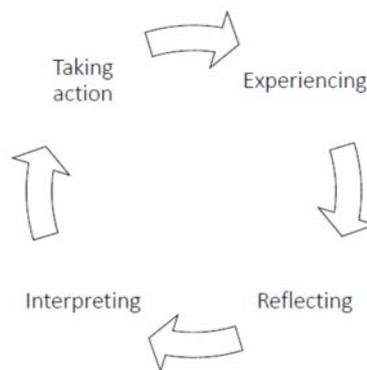
Action research builds on a collaborative democratic process, in which the researcher creates a partnership with local actors (Coghlan & Brannick, 2008). Healthcare professionals, patients, and their relatives at SkaS were involved in the AR projects included in this thesis. The AR process is in line with the intentions of patient involvement described in the theoretical framework. Characterized by a continuous participative learning process, rather than a short-term intervention (Greenwood & Levin, 2007), AR is powerful because the researcher has direct access to the area of investigation (Coghlan & Brannick, 2008). According to Hughes (2009), the holistic view of understanding health includes looking at the whole person in a context. This viewpoint is equivalent to the paradigm of AR, which looks at problem solving from a holistic view. Therefore, AR can be appropriate in a healthcare context when QI involves patients in efforts to improve their experiences of care (Hughes, 2009).

Action research uses a cyclical working process (Figure 5) of conscious and deliberate planning, acting, and evaluating of actions, leading to further planning, and so on (Coghlan & Brannick, 2008; Reason & Bradbury, 2009). The action-reflection loop (Coghlan & Brannick, 2008) shares many similarities with the plan, do, study, act (PDSA) cycle used in QI (Langley et al, 1996; Coghlan & Brannick, 2008; Hughes, 2009).



**Figure 5: The action-research cycle. A cyclical working process during AR (Coghlan & Brannick, 2008, p. 22).**

The action learning cycles in the studies in this thesis took place in diverse improvement projects with patient involvement at SkaS. According to Coghlan and Brannick (2008), learning comes from experiencing, reflecting, interpreting, and taking action with members of the organization as they perform the improvement project. This *experiential learning cycle* (ibid.), is parallel to the AR cycle, as shown in Figure 6.



**Figure 6: The experiential learning cycle (adapted from Coghlan & Brannick, 2008).**

During empirical material collection in qualitative AR studies, the analysis is continuous and iterative. The researcher switches between collection, use, and analysis (Eisenhardt, 1989; Coghlan & Brannick, 2008). Because actions intended to generate empirical material are themselves interventions, it is more appropriate to speak of generating empirical material, rather than gathering it (Coghlan & Brannick, 2008). The experiential learning cycle in AR has many similarities with the PDSA cycle that is frequently used when working with QI (Langley et al., 1996).

The AR process requires continuous adjustment to new information and events, and reflection is a key factor (Greenwood & Levin, 2007; Coghlan & Brannick, 2008; Reason & Bradbury, 2009). According to Alvesson and Sköldbberg (2008), reflection is thinking about the conditions for what one is doing and investigating how context and individual involvement affect interaction with the research area. In AR, stakeholders with different perspectives work together. The purpose of engagement should be to obtain complementary perspectives for

understanding the problem in a holistic way (Van de Ven, 2013). Co-producing knowledge in collaboration with patients gives potential for exploring the learning process and how patient involvement impacts research (Gillard et al., 2012).

Reason and Bradbury (2009) illuminated the importance of integrating research and practice by including self-reflection through first-, second-, and third-person inquiry. The author of this thesis regularly undertook *first-person* reflections about her own work as an improvement facilitator and a researcher. These reflections were included in her role as an insider action researcher (IAR), and answered questions such as: What happened today? What went well or badly? What shall I do differently next time? What did I learn?

In group reflections with participants (*second person*), considerations were often about learning that occurred with respect to different improvement approaches. For instance: How might the Kano model help us identify customer needs? How do we experience the use of EBCD? In second-person inquiry the IAR were engaged with the other participants in both dialogue and action.

The *third-person* inquiry moves to a more theoretical level. The empirical material and earlier inquiries are examined for underlying explanatory patterns to obtain a deeper understanding. Such patterns are not necessarily apparent to members of the organization, but are essential if the study is to be meaningful to other researchers (Coghlan & Brannick, 2008; Reason & Bradbury, 2009). Third-person inquiry emerged mainly from dialogues with supervisors and co-writers as we analyzed the first- and second-person reflections while writing the papers and this thesis.

### 3.2.1 INSIDER ACTION RESEARCHER

Researchers conducting AR in their own organizations are considered IARs (Coughlan & Brannick, 2008), full members of the organization being studied. An IAR remains involved in the studied organization after the formal research project is finished. The management at SkaS was interested in the idea of solving practical problems, including patient involvement and conducting research at the same time.

However, three issues must be considered when the researcher is an insider: pre-understanding, role duality, and organizational politics (Coughlan & Brannick, 2008). Pre-understanding is what the researcher brings to the research process in terms of knowledge, insights, and experiences before undertaking the research project (Bryman & Bell, 2007; Coughlan & Brannick, 2008). I had pre-understanding based on my 30 years of professional experience in healthcare, which included being a nursing assistant, registered nurse, midwife, ward manager, improvement facilitator, and nursing director. Consequently, I had a number of different perspectives on care processes at SkaS from various professions, specialist functions, and organizational levels.

An IAR has the advantage of valuable knowledge about organizational culture and informal structures, such as history, key events, jargon, and people to turn to for information (Coughlan & Brannick, 2008). One disadvantage of being an insider is that it can be difficult to be a part of the organization's culture while simultaneously standing back to interpret it more objectively from a third-person inquiry. As AR aims to provide a constant analysis of experiences, the insider must reflect on lived experience and that of the organization culture throughout the process (Bryman & Bell, 2007; Coughlan & Brannick, 2008). Therefore, collaboration with researchers outside the organization can help the IAR to make sense of experiences and reflections. As a PhD student, I frequently collaborated with researchers at Chalmers

University of Technology in Gothenburg, who supported my sense-making progression of research findings.

The issue of role duality in AR means that the role of the IAR is added to the practitioner role (Coghlan & Brannick, 2008; de Guerre, 2002). According to de Guerre (2002), an IAR walks a thin line to avoid the pitfalls of these dual roles. Difficulties as a practitioner could include getting too caught up with the action to practice reflexivity, as the organizational role may demand total involvement (ibid.). Second, the researcher role is more theoretical, objective, and neutral, and may fail to get close enough to understand what is going on (Coghlan & Brannick, 2008). Therefore, the relationship between these roles must be managed for the IAR to be efficacious (de Guerre, 2002). The dual roles must be permeable and flexible. The researcher may be at the workplace, doing her usual job and also searching for answers to research questions in the research role (Coghlan & Brannick, 2008).

Despite these difficulties, an IAR holds several advantages. These might include being familiar with the organization's culture, language, and history, and having an extensive personal network, accessibility, credibility, trustworthiness, commitment, and familiarity with the research context and staff. These factors are referred to as *organizational politics* (de Guerre, 2002; Coghlan & Holian, 2007; Coghlan & Brannick, 2008). In addition, being a member of the organization gives primary access to material in the empirical context (Coghlan & Brannick, 2008).

### 3.3 Empirical context

Context can be objective and tangible, but can also relate to subjective constructions of reality (Bate, 2014). Pettigrew (1987) suggested that the context can be divided into inner (organizational culture, group norms, leadership, and micro) and outer contexts (social, political, and macro). Context awareness is one of several forces that combine to produce improvements and learning in healthcare (Batalden & Davidoff, 2007). Other forces, which support each other, include: generalizable scientific evidence, performance measurements, plans for change, and execution of planned changes.

Knowledge of a specific context in healthcare is developed by reflecting on the uniqueness of local care settings and their processes, behaviors, and traditions (Batalden & Davidoff, 2007; Bate, 2014). It is important to consider context when working with improvements in healthcare (Pettigrew, 1987; Pettigrew & Whipp, 1990; Batalden & Davidoff, 2007; Bate, 2014): "Nothing exists, and therefore can be understood, in isolation from its context, for it is context that gives meaning to what we think and do" (Bate, 2014, p. 3). Involved stakeholders in co-design projects should share their views to avoid looking at context from a single standpoint. Therefore, patients must be involved as stakeholders in QI (Bate, 2014).

Additionally, the context of a change is just as important as the content of the change initiative (Pettigrew, 1987). How a change is introduced into the context, known as the *process of change* (ibid.), can be critical. Even if change efforts are successful, they often remain local and do not easily spread to the rest of the organization (Berwick, 2003). A model that explains the differences between improvement initiatives is related to context (where), content (what), and process (how) (Pettigrew & Whipp, 1990). When transferring practices from one setting to another, there must be considerations not only of the local context adopting the change, but also the change's original context.

### 3.4 Methods in appended papers

This section presents the research methods in each of the appended papers. Table III provides an overview of the papers, which are then individually presented.

**Table III: Methodological summary of appended papers, focusing on design, methods, and analyses.**

Paper	Title	Design	Method	Analysis
Paper I	Using an adapted approach to the Kano model to identify patient needs from various patient roles	AR	Reflective dialogues Participative observations Interviews Internet-based survey Focus group Documents (meeting notes)	Qualitative content analysis, organizing, structuring, and eliciting meaning  Second order analysis
Paper II	Improvements in neonatal care using experience-based co-design	AR	Interviews Participative observations Documents (emotional mapping)	Qualitative content analysis, organizing, structuring, and eliciting meaning  Categorizing problems as simple, complicated and complex
Paper III	Designing quality of care: contributions from parents	AR	Interviews	Qualitative content analysis  Categorizing quality dimensions
Paper IV	Patient involvement 2.0: Experience-based co-design supported by action research	AR	Reflective dialogues Participative observations Questionnaire Documents (IAR, field notes)	Qualitative analysis, organizing, structuring, and eliciting meaning  1st, 2nd, and 3rd person inquiry
Paper V	Adopting a management innovation in a professional organization: The case of improvement knowledge in healthcare	AR	Interviews Focus groups	Qualitative content analysis  Structure, process, and outcome categorization
Paper VI	Strengthening the patient role by involving in improvement projects	Survey	Web-based questionnaire	Quantitative analysis using SPSS version 22.

Although each paper is individually presented with descriptions of design, empirical material, methods, and analysis, readers are referred to the appended papers for detailed information.

#### 3.4.1 PAPER I

Paper I is based on a study with an AR approach. The empirical material was generated during two months in a planning project for new buildings at the perinatal center. The first author was an IAR involved as an improvement facilitator and part of the management team. The empirical material was generated with patients and their partners, and healthcare professionals.

Patient and partner experiences were collected during one month, via a web-based questionnaire available for all parents. Responses were due up to two weeks after delivery (n = 113 responses). Additional material was gleaned from a focus-group interview with five parents about experiences of neonatal care. The focus group lasted about 2.5 hours, and was recorded and transcribed.

In addition, reflective dialogues between the IAR and participants (healthcare professionals) on the management team were generated in participative observations and meeting notes. Complementary interviews with involved healthcare professionals in the building project group (n = 7) were also performed. According to Pope et al. (2002), acting as a participative observer

during group meetings can help contextualize and explain the process from both the healthcare professionals' and the patients' viewpoints. The IAR also made meeting notes that were used in the study.

Researchers performed a qualitative content analysis (Flick, 2009), organizing, structuring, and eliciting meaning from the empirical material, and focusing on practical implications of the Kano model and patient roles. The data from the first part of the analysis was then related to the theoretical framework through a second-order analysis, according to Reason and Bradbury (2009). The second and third authors were not involved in generating empirical material, but helped to analyze data and write the paper. These authors were external investigators who contributed to triangulation by multiple investigators, which strengthens confidence in the findings (Bryman & Bell, 2007).

### *3.4.2 PAPER II*

Paper II is also based on a study with an AR approach. The empirical material was generated during about nine months in a neonatal project initiated in the neonatal ward and then expanded to the maternity and delivery wards. The first author acted as an IAR, involved as an improvement facilitator and a researcher.

The empirical material included experiences and collaborative dialogues between participants in the project (healthcare professionals, patients, partners, and parents) and the IAR. The empirical material was generated by interviews, participative observations, and collaborative reflections, which are suitable methods for a qualitative research strategy (Bryman & Bell, 2007; Flick, 2009). The methods used for generating empirical material for a research project are often the same as those used in the improvement approaches. In the EBCD projects (Papers II–IV), interviews with patients and healthcare professionals were used to record their experiences. These experiences were then put into an emotional map connected to activities in the care process to identify improvement areas.

Interviews were conducted by the IAR and two master's students. The interviews with healthcare professionals (four nurses, two nursing assistants, and one midwife) were performed by the author, and the interviews with patients and their relatives (three mothers and two fathers) were performed by the students. The interviews with the healthcare professionals were conducted at the hospital, while those with the patients and relatives were conducted in their homes (the interviewees were allowed to choose where the interviews took place). All interviews were recorded and transcribed, and each lasted one to two hours.

The analysis focused on organizing, structuring, and eliciting meaning (Graneheim & Lundman, 2004) from the experiences. The author also categorized the project's improvement areas, according to Glouberman and Zimmerman's (2004) simple, complicated, and complex healthcare problems.

### *3.4.3 PAPER III*

This paper used a qualitative, descriptive design and was based on an AR approach in two EBCD projects: The neonatal project and the diabetes project in children's care. The empirical material consisted of experiences from patients, partners, and parents. The parents were spokespersons for their children, who could not participate as co-designers. The first author was IAR in both projects, acting as an improvement facilitator.

Interviews were conducted with 12 parents participating in the projects. The interviews were all approximately one hour long and conducted in the parents' homes. The recorded and transcribed interviews were based on one open-ended question: "Please describe your experiences, beginning when your child was in need of care at the hospital until discharge/today?" The groups differed in that parents in the neonatal project finished their care experiences, but those in the diabetes projects still had a care relationship with the healthcare professionals. All parents at the clinic were invited to participate as well as their children (children with diabetes). There were no exclusion criteria.

Data analysis was conducted manually using a qualitative-content analysis, according to Graneheim and Lundman (2004). The procedure for analyzing textual material is to provide knowledge and understanding of a phenomenon (Graneheim & Lundman 2004). The first part of the analysis was inductive, looking for the meaning in the parents' experiences. Meaning units were captured and extracted from the text, which were condensed to codes that were categorized. The results from the qualitative content analysis were presented in two parts. The first included the results in relation to the quality sub-dimensions, as suggested by Dagger et al. (2007). The second part outlined experiences not covered by the original set of quality dimensions, which were then condensed into new, suggested sub-dimensions of quality.

#### *3.4.4 PAPER IV*

This paper had an inductive, qualitative design based on AR in two EBCD projects (neonatal project and diabetes project). The first author acted as an IAR in the role of improvement facilitator in the projects, and the second author was one of the parents in the diabetes project. Empirical material consisted of reflections on experiences from the participants (healthcare professionals, patients, partners, and parents) in the combined AR/EBCD methodology used in the projects.

Empirical material was generated from three sources using several methods in order to obtain a holistic view of the project (Bryman & Bell, 2007; Flick, 2009). First, there were continuous, reflective dialogues between healthcare professionals and patients/relatives during group meetings that were recorded and transcribed. Second, after the completed projects, participants (28) filled out a questionnaire about their experiences from the improvement method in the project. A third source of empirical material came from the IAR's field notes/diaries.

The first part of the analysis used first-person inquiry, based on the author's reflections of being an IAR recorded in a diary. Coghlan & Brannick (2008) argued that some thoughts and reflections are perishable and may be difficult to remember if they are not documented correctly.

Second-person inquiry was based on the reflections and learning of the participants in the described AR projects. A qualitative content analysis (Graneheim & Lundman, 2004) was conducted on the empirical material from transcribed group meeting recordings and questionnaires. The text was read several times to understand it; then meaning units were captured, coded, and translated to categories.

The third-person inquiry – reflections upon the organizational learning and theoretical contribution to research – was managed through dialogues between the authors and between the IAR and her supervisors at the university. The reflection and analysis continued between the IAR and the co-writer (a parent in one of the projects) while writing this paper.

The results were presented as four themes that emerged when interpreting the inquiries with a qualitative-content analysis. The text was first read several times, and meaningful units were

then captured, coded, and categorized. Finally, the results were presented in themes. According to Flick (2009), qualitative-content analysis is a classical procedure for analyzing textual material. One essential feature is the use of categories to reduce the material (Flick, 2009). The qualitative content analysis was conducted according to Graneheim and Lundman (2004).

#### *3.4.5 PAPER V*

An AR approach was used in the longitudinal study. This paper reports on the hospital-wide transformation that the organization managed during a five-year period. Practitioners and researchers were part of a participative community that generated actionable knowledge. Two academic researchers from Chalmers University of Technology were external researchers. Two IARs, the development director and the nursing director, were involved in the transformation and integration of improvement knowledge.

Data was generated from 2003 to 2011 in the local context, mainly from co-workers' experiences. The empirical material was generated by 250 interviews and 25 focus groups with co-workers (physicians, nurses, improvement facilitators and the top management team). The aim was to capture knowledge in action through collaborative reflections during practice.

In the qualitative analysis, empirical findings were interpreted by collaborative reflections between IARs and external researchers. Elements of improvement knowledge (Batalden & Stoltz, 1993) in relation to the structure-process-outcome-model (Donabedian, 2003) were captured. Critical practices for adopting management innovation from 2005 to 2010 at SkaS were identified, which were then presented as the results of the study.

#### *3.4.6 PAPER VI*

The research design in Paper VI was quantitative. The empirical material in Paper VI consisted of experiences from healthcare staff, with additional education in improvement knowledge. The informants were nurses, physicians, or administrative positions in healthcare, from different parts of Sweden.

A survey method was used to collect data. A semi-structured questionnaire was sent by email to informants (n = 491) from the healthcare sector who had completed courses on improvement knowledge. As a foundation, three validated questionnaires extracted questions suitable for the purpose (Gustafsson et al., 2012; Andersson et al., 2013; Donetto et al., 2014). Most of the 44 questions were structured and close-ended, but a few had open-ended answers. A pilot questionnaire was tested by a focus group, which led to improvements of the original questionnaire.

The response rate was 60 percent. However, several participants did not answer all the questions, mainly due to technical problems. A total of 155 respondents answered the entire questionnaire, giving a response rate of 32 percent. After accounting for respondents who no longer worked in healthcare or did not answer the questionnaire, the adjusted response rate was 34 percent.

Data was analyzed using IBM SPSS Statistics version 22. Demographic data was analyzed by calculating frequency and percentage for gender and profession. Studying the impact of a strengthened patient role on the degree of novelty of the new ways of working, we used Pearson correlation coefficient. To explore the relationship between patient involvement, professionals' experience in improvement science, and the patient role a moderated regression model using Generalized Linear Model (GLM) was used. Two different regression models were generated,

each with a different dependent variable (such as strengthened patient role and changed power relationship between patients and healthcare professionals). Both models were built on two terms: the main effect for the degree of patient involvement and an interaction effect between the covariate patient involvement and the fixed factor professionals' experience and knowledge.

### 3.5 Ethical considerations

This research complies with research ethics in the humanities and social sciences (Codex, 2013). The results were used to do well, prevent harm and suffering, and seek goodness. The patients and their families who took part in the EBCD projects (Papers II–IV) were informed that participation was voluntary and they could withdraw from the study at any time. They also gave written, informed consent. An ethical review was required for the EBCD projects that directly involved patients and their families (Papers II–IV) and was approved by the regional ethical review board in Gothenburg (Dnr 135-10).

### 3.6 Methodological reflections

The process of generating and collecting empirical material evolved during the research. It was difficult to plan this aspect in detail before the project started, which is usual in AR (Coghlan & Brannick, 2007). The studies generated large amounts of empirical material, which complicated matters. On the other hand, the range of material confirmed the findings that emerged during the QI, and also provided increased understanding about the studied area (Bryman & Bell, 2007).

The research methods included focus groups, observations, and interviews, even though the focus groups and interviews consisted more of dialogues than interviews. The group meetings that followed the interviews provide one way to use several methods from the EBCD projects (Papers II–IV). In the meetings, patients could agree or disagree with each other, and elaborate on each other's experiences. The possibility for dialogues gives the research credibility and validity (Lincoln & Guba, 1985; Bryman & Bell, 2007; Flick, 2009). The author also provided her own reflections, and invited those of co-researchers and participants in the three studies. Group meetings were often concluded with the questions: What have we learned today? What were your experiences of this improvement work so far? However, the reflection stage of the group meetings did not always happen because of lack of time; in those cases, IAR met with participants outside of the group meetings to ask for their reflections.

#### 3.6.1 *TRUSTWORTHINESS*

AR's focus on practical improvements means that each situation is unique. The basis for validation is conscious, deliberate enactment of the cycle of planning, taking action, and evaluating that action, which leads to further planning (Coghlan & Casey, 2001). Coghlan and Brannick (2008) explained that triangulation (of methods as well as investigators) and continuous validation secure the credibility and reliability of the empirical material. The results and interpretations should be validated with different parties, both in the academic domain and the organizational setting. Multiple methods should be used to collect the empirical material (Lincoln & Guba 1985; Eisenhardt, 1989; Bryman & Bell, 2007). Diverse viewpoints can yield a richer picture of the research questions (Van de Ven, 2013). I brought my thoughts and knowledge of the improvement projects to theoretical discussions and analyses with

supervisors. I then went back to the improvement project participants for validation and development into new thoughts and knowledge. This process confirmed the accuracy of the analysis and allowed the change process to continue.

The analysis of the individual interviews in Papers II–IV were brought back to the group members and contributed to the improvement process, confirming and validating the results with the participants. During the analysis, the author, patients, internal healthcare professionals, and co-researchers worked together on the analysis to increase credibility and internal validity, which is an advantage of using multiple investigators (Bryman & Bell, 2007; Eisenhardt, 1989; Lincoln & Guba, 1985). The triangulation during analysis consisted of multiple investigators, such as patients, healthcare professionals and researchers. The IAR's intention of remaining a complete member of the organization after the project was finished could guarantee the relevance and validity of the research outcomes (Coghlan & Brannick, 2008).

The reliability must be discussed related to the importance of local context and participants in the AR. It is unrealistic to believe that outcomes will be exactly the same in another context, and generalizability can be described as analytical rather than statistical in AR (Reason and Bradbury, 2009). Therefore, local circumstances must be described in detail when it comes to AR (Coghlan & Brannick, 2008). In this thesis, my intention has been to describe in detail the local context both at the hospital and in the different projects.

### *3.6.2 THE ROLE AS INSIDER ACTION RESEARCHER (IAR)*

Conducting observations during group meetings while simultaneously facilitating the QI was not easy. As the IAR, I had to remind myself to continue to observe the sessions. Completing a diary entry directly after the meetings helped me to reflect on what had occurred. As Coghlan and Brannick (2008) noted, keeping a diary facilitates reflections in first-person inquiry. Some thoughts and reflections are perishable, and if not documented correctly they will be difficult to remember later on (Coghlan & Brannick, 2008). In this way, the researcher is an instrument in the generation of empirical material (Coghlan & Brannick 2008). Some diary notes were incomplete, probably because of lack of time. However, I returned to the meeting notes and the participants for reminders to fill the gaps. During the research process, I increased my understanding of the importance of always documenting the work in a structured way.

The pre-understanding I have gained as a healthcare professional helped me to understand the range of experiences of the various healthcare professionals included in the studies. This pre-understanding offered several advantages in the research process. I already knew people in the organization, and these relationships (and related politics) made it easier to interpret the interviews and focus groups. I could ask questions that would have been hard to ask without prior insider knowledge of the organization (Coghlan & Brannick, 2008). However, such pre-understanding could have been a trap if I had assumed knowledge before it was made explicit. It was vital that I continually reflect on the process and try to see it from a third-person perspective.

According to de Guerre (2002), being an insider and a researcher at the same time equates to being an inside-outsider. In these studies, I was more of a practitioner but struggled to be more of a researcher. I often found it easier to reflect as an improvement facilitator because this role was more familiar, while the role of researcher was fairly new and unexplored. As the IAR, my role and knowledge developed within the five AR-based papers. The subjective experience meant that my capability of taking a theoretical perspective increased.

### *3.6.3 COLLABORATIVE RESEARCH*

The patients and healthcare professionals played a key role in acquiring new knowledge and determined the validity of the research, as dialogues about research findings were continuous during the projects. According to Greenwood and Levin (2007), participants have the ability to validate new knowledge in a real-world scenario. In Papers II–IV, the interviews with patients were mainly conducted in their homes, where their feelings of safety may have contributed to their openness. The interviews with the healthcare professionals in Papers I–III and V might have been affected by the fact that the researcher was an insider colleague. The effect of my understanding of the organizational context and my knowledge of the care process probably was more positive than negative, which is in line with advantages earlier presented by Coghlan and Brannick (2008).

One difficulty within the EBCD projects (Papers II–IV) arose from uneven recruitment: A number of healthcare professionals wanted to join the project, but patients were hard to recruit. I had to restrict the participation of the healthcare professionals and stop recruiting patients (because the time from interview to group meeting should not be too long) to have groups that were equal in the numbers of participants. I assumed that if the group containing the healthcare professionals were larger than the patient group, the patients might feel subordinate. During the meetings, the improvement work competed with families' work and child care schedules, and sometimes participants had to skip meetings. To compensate, I emailed and telephoned the absent participants afterwards for further dialogue.

In the AR projects, patients, healthcare professionals, my co-researchers, and I worked together to construct the analysis to increase reflection, understanding, and change. The involvement of many stakeholders is recommended when aiming to understand a problem that is too complex for any party to study alone (Van de Ven, 2013). This collaboration can contribute to credibility and internal validity (Eisenhardt, 1989; Van de Ven, 2013). Collaborative reflections during the meetings yielded ideas for new, interesting areas to explore. In addition, Paper IV was co-authored with one of the parents from the diabetes project. The writing process presented opportunities for additional collaborative reflections, which supported in-depth analysis. Ives et al. (2013) noted that patients could be invited to participate in research as consultants or as partners involved through the entire study. Partnership in research works from the bottom up based on rights and processes, and should encourage new ideas and joint decision-making (Ives et al., 2013).

### *3.6.4 RELEVANCE FOR PRACTICE OR RESEARCH?*

The methods in the QI and the research methods complemented each other, which sometimes made it difficult to separate the practical from the theoretical. I also faced difficulties in interpreting the empirical material at a theoretical level, which is expected when conducting AR in one's own organization (Coghlan & Brannick, 2008). Therefore, second-order analysis (Reason & Bradbury, 2009) and writing papers with supervisors as co-researchers proved useful. The supervisors were external and not involved in generating the empirical material. Thus, external parties contributed to the theoretical analysis in accordance with the IAR's understanding of the local context (Lincoln & Guba, 1985; Eisenhardt, 1989; Bryman & Bell, 2007).

## 4 SUMMARY OF APPENDED PAPERS

The following summary of the six appended papers describes the underpinning research for this thesis. Each paper is presented by title, purpose, and contributions in tabular form and in textual summaries. This chapter then outlines the common themes in the papers.

### 4.1 Summary of appended papers in tabular form

Table IV shows an overview of the six papers included in this thesis, according to their title, purpose, and contributions.

**Table IV: Overview of appended papers. Including the papers titles, purposes and contributions for research and practice.**

Paper	Title	Purpose	Research contribution	Practical contribution
Paper I	Using an adapted approach to the Kano model to identify patient needs from various patient roles	To study how an account of multiple patient roles, when using the Kano model in healthcare improvements, can support identification of a wide range of patient needs.	Contributes knowledge on how to bridge the gap, identified in earlier research, which may occur when relying solely on either patients or healthcare professionals to identify patient needs.	A basis for planning a new perinatal center. Illuminates the need for capturing input from various stakeholder groups (such as patients, relatives, and professionals) by various methods to capture as wide a range of patient needs as possible.
Paper II	Improvements in neonatal care using experience-based co-design	To identify and improve patient care processes by collaborating with patients, relatives, and healthcare professionals	Patients and healthcare professionals during collaboration can address simple, complicated, and complex problems in healthcare. Illuminates that patients and healthcare professionals identify various improvement areas. The study adds an example of patient involvement in QI.	Categorizing problems helps with planning improvement efforts and decisions on how to handle them for positive, sustainable results. The study contributes with a practical example of patient involvement in QI.
Paper III	Designing quality of care: Contributions from parents	To explore whether current quality dimensions for healthcare services were sufficient to capture how parents perceive and contribute to quality of healthcare	Questions current models of quality dimensions in healthcare and suggests additional sub-dimensions such as family and involvement. The study adds examples of patient involvement in QI.	Underscores the importance of involving parents in pediatric healthcare improvements with healthcare professionals to capture a wide range of quality dimensions. The study contributes with practical examples of patient involvement in QI
Paper IV	Patient involvement 2.0: Experience-based co-design supported by action research	To address some of the challenges by combining AR with EBCD in healthcare improvement to describe and analyze the experiences of healthcare professionals, parents, and researchers participating in collaborative projects.	The AR approach and the EBCD method strengthen the results of the actual improvement project and generate knowledge of the method.	A combination of AR and EBCD challenges both professionals and parents in their roles, leading to new ways of working that embrace new perspectives, such as patient information from their experiences. These experiences are valuable and cannot be

				captured by healthcare professionals alone.
Paper V	Adopting a management innovation in a professional organization: The case of improvement knowledge in healthcare	To study critical practices when adopting improvement knowledge as a management innovation in a professional organization	Understanding critical aspects when adopting management innovations in a professional organization. In a healthcare context, this points to the value of improvement knowledge for improving quality of care.	Practices to consider when adopting improvement knowledge in professionally driven organizations for adopting a management innovation.
Paper VI	Strengthening the patient role by involvement in improvement projects	To investigate whether a higher degree of patient involvement in QI led to a strengthened patient role with a more equal power relationship between healthcare professionals and patients.	Involving patients in QI not only leads to higher quality of care, but also influences the role of the patient and supports more equal power relationships between patients and healthcare professionals.	Patient involvement in QI supports a stronger position for the patient and could contribute to person-centered care.

The purpose, findings, and contributions of the studies are presented in the following summary of the papers.

#### 4.2 Paper I: Using an adapted approach to the Kano model to identify patient needs from various patient roles

Previous research shows that healthcare organizations obtain better results by improving processes based on patients' point of view, rather than by simply improving existing work processes (Narver et al., 2000; Mazur, 2003). This paper describes how an account of multiple patient roles, when using the Kano model in healthcare improvements, can help identify a wide range of patient needs.

The study showed that incorporating a view of multiple patient roles into use of the Kano model, and using input on customer needs from patients and relatives (such as surveys or focus groups) and healthcare professionals' experiences and knowledge, helped to identify a larger share of patients' needs. This study contributes knowledge on how to bridge the gap, identified in earlier research, which can occur when relying solely on either patients or healthcare professionals to identify patient needs. Instead, input merged from diverse stakeholders is valuable. This paper elaborates on a hands-on application of the Kano model for visualizing patient needs as a tool for QI.

#### 4.3 Paper II: Improvements in neonatal care using experience-based co-design

Previously, improvements in healthcare rarely focused on patient experiences of care processes (Bate & Robert, 2006). As involving patients in improving care is new, only a few examples are described in the research (Bate & Robert, 2006; Pickles et al., 2008; Iedema et al., 2010). This study's purpose was to describe the efforts to improve care with an EBCD approach in a

neonatal care process within a Swedish hospital and investigate problem areas, according to Glouberman and Zimmerman's (2004) categorization scheme.

Although most of the problems the study identified in healthcare based on patients' experiences were classified as simple, some were complicated and complex. Healthcare professional and patient experiences of care differ, and a collaborative approach can enable identification of a wide range of areas as possible for QI. The paper contributes to the limited numbers of studies of patient involvement in QI in healthcare using EBCD. The study has implications for healthcare professionals encouraging patient involvement in QI. A categorization of problems when working with QI can be of value when prioritizing and planning efforts.

#### 4.4 Paper III: Designing quality of care – contributions from parents

Current models of quality dimensions (Dagger et al., 2007) are based mainly on a traditional view, in which only healthcare professionals improve care processes (Bate & Robert, 2006). There is a need to question the traditional way of improving care processes and to elaborate on new ways of improving care in collaboration with patients (Bate & Robert, 2006; Maher & Baxter, 2009). Paper III's purpose was to explore if current quality dimensions for healthcare services are sufficient to capture how relatives perceive and contribute to healthcare quality.

This paper discusses the tendency for healthcare professionals to overemphasize their own significance in creating value in care processes and to underappreciate patients' abilities to influence and contribute to better quality. However, the study illuminated that patient perceived quality is not based solely on how professionals accomplish their tasks, but is co-created with patients. Consequently, assessment of quality outcomes must also include the ability of patients and their families to co-create value. Paper III questions current models of quality dimensions in healthcare, and suggests additional quality sub-dimensions, such as family involvement.

#### 4.5 Paper IV: Patient involvement 2.0: Experience-based co-design supported by action research

Healthcare professionals dominate QI initiatives in healthcare (Coulter et al., 2008), but patient involvement in QI can challenge this dominance (Armstrong et al., 2013). However, both practical examples and research about patient involvement are limited (Lord & Gale, 2014). The paper addresses some of the challenges of roles and approaches for patient involvement in QI in healthcare by combining AR with EBCD. In addition, the paper describes and analyzes the experiences of healthcare professionals, parents, and researchers who participated in EBCD projects in healthcare.

Paper IV shows that combining AR and EBCD has many advantages. The AR approach increased reflection, both during and beyond the scope of the project. The AR approach supported the project's legitimacy when recruiting participants and disseminating the results afterward. The AR approach and the EBCD method interacted to strengthen the outcomes of QI. A combination of AR and EBCD challenged both professionals and parents in their roles, leading to new ways of working that embrace new perspectives.

#### 4.6 Paper V: Adopting a management innovation in a professional organization – The case of improvement knowledge in healthcare

The healthcare sector faces challenges from an increasingly aging population and from a new generation of people who are making new demands on care services (Christensen et al., 2009; Mohrman et al., 2012). However, the ability to adopt new management innovations is lagging compared with the manufacturing sector (Walley, 2003; Greenhalgh et al., 2004; Christensen et al., 2009). This study examined critical practices when adopting improvement knowledge as a management innovation in a professional organization.

The paper identifies five critical practices for adopting a management innovation in a professional context: labeling and theorizing to create an organization's own vocabulary; focusing on the role of internal change agents; allowing for an evolutionary adoption process; building new professional competence through change agents; and adopting a research-driven approach to adopting a management innovation. The findings contribute to understanding critical aspects when adopting management innovations in a professional organization, and point to the value of improvement knowledge held by healthcare professionals.

#### 4.7 Paper VI: Empowering patients by involvement in improvement projects

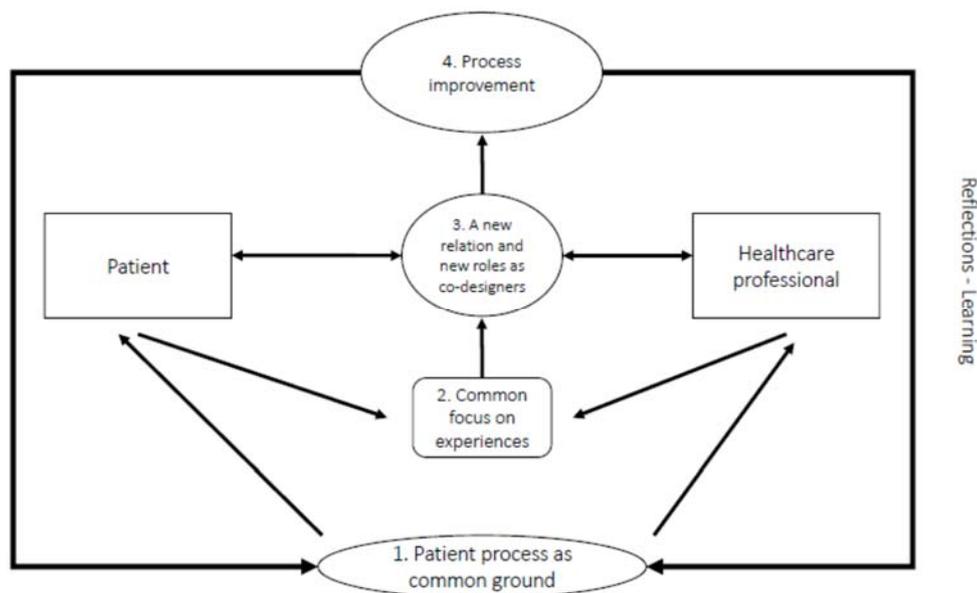
Society aims to strengthen the patient role by increasing patient involvement in care (WHO, 2006; Swedish Patient Law, 2015). Patients can be involved in various ways and at several levels, but there is a lack of knowledge about the actual contribution to better care (Lord & Gale, 2014). Involving patients and relatives in QI has recently been a suggested way of optimizing healthcare processes (Bate & Robert, 2006). However, there is still a gap between intentions and practical examples (Lord & Gale, 2014). This study investigated whether a higher degree of patient involvement in improvement work would strengthen the patient role in general, creating a more equal power relationship between healthcare professionals and patients. In addition, the study examined whether healthcare professionals' experiences and knowledge in the area of improvement science would moderate the effect of the degree of patient involvement on a strengthened patient role.

The findings show that a strengthened patient role is correlated to the outputs from improvement projects in terms of how radical the ways of working are changed. In addition, the degree of patient involvement is a means to strengthen the patient role and support a more equal power relationship between patients and healthcare professionals. Healthcare professionals' experiences in the area of improvement science moderate the effect of the degree of patient involvement on a strengthened patient role and a more equal power relationship.

#### 4.8 Common themes

This section presents common themes from the appended papers. The empirical work in the papers aimed to improve patients' experiences of care, by patients doing well for other patients. Patient involvement in QI occurred to various degrees, from healthcare professionals who simply had a patient focus to a high degree of collaboration between patients and healthcare professionals. Healthcare professionals viewed patient experiences as an important point of departure when aiming for higher quality in care. The experience of patient involvement in QI was predominantly positive, although some challenges arose.

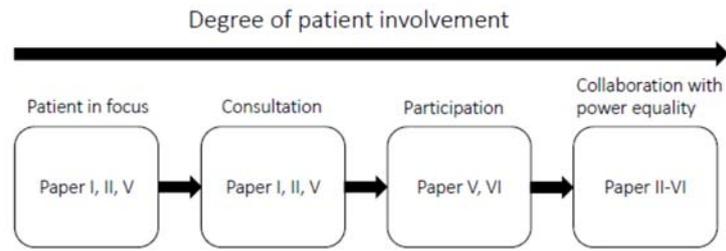
Figure 7 shows a model of patient involvement in QI based on the included papers. The model illuminates how patients and healthcare professionals can collaborate on QI in healthcare. First, the patient process is the common ground (1) for both patients' and healthcare professionals' experiences. Perceived quality in the patient process is illuminated by these experiences, which were the main base for QI in Papers I–IV. If patients and healthcare professionals have a common focus (2) on these experiences (such as in the EBCD projects in Papers II–IV), they can develop their relation (3) with new roles as co-designers. During reflective dialogues, experiences can be translated to improvement areas, as described in Papers II–VI. The outcomes of collaborative QI can solve simple and complicated problems and contribute to solutions in complex ones (Glouberman & Zimmerman, 2004) in the patient process, (4) thereby contributing to higher quality. The outcome goes back into the patient process (1), not just for those who participated in the QI, but also for other patients and healthcare professionals (Paper II). Reflection and learning support QI, as described in Papers IV and V. This model is congruent with earlier research proposing that patient involvement supports new opportunities for improvement (Bate & Robert, 2006; Batalden et al., 2015).



**Figure 7: A model of patient involvement in QI, based on included papers.** The model illustrates the relationship between patient experiences in care processes and a common focus (2) shared by patients and healthcare professionals collaborating in QI (3). In turn the outcomes – process improvements – will affect other patients' experiences (4, 1).

#### 4.8.1 DEGREES OF INVOLVEMENT

The QIs described in the papers were completed on different levels in the healthcare organizations and with various degrees of patient involvement. Figure 8 gives an overview of the degree of patient involvement in the studies described in the papers. Paper IV and VI indicate that the degree of patient involvement strengthened patient roles and created a more equal relationship between healthcare professionals and patients.



**Figure 8: Overview – degree of patient involvement in included papers (adapted from Carman et al. 2013).** From left to right: lowest degree of patient involvement (patient focus) to the highest degree (collaboration with power equality). References to appended papers show the degree of patient involvement in the studies.

The lowest degree of patient involvement was *patient in focus*, a guiding principle for the QI described in Paper V. Patients were not involved in any activities.

*Consultation* refers to patient involvement to a low degree, as exemplified in Paper I. Patients experiences were recorded by a survey and a focus group, but patients were not invited to be actively involved in the QI.

*Participation* is the degree of involvement in which healthcare professionals listened to patients’ experiences. Patients might have been invited to identify and prioritize improvement areas, but were not involved in the actual QI (see Paper VI).

*Collaboration with power equality* is the degree of involvement in which valuable reflecting dialogues between patients and healthcare professionals positively contribute to the QI (Papers II–IV and VI). These reflections helped open healthcare professionals’ eyes to situations that they did not earlier think were important to patients. The patients involved in the EBCD studies referred to a difference when it came to healthcare professionals’ ability to listen to patients’ experiences during the dialogues. With collaborative QI, there was time to listen to each other in a new, valuable way. Listening to each other’s experiences, and having reflective dialogues about them, seemed to strengthen the capability to improve identified problems (Paper II–VI).

#### 4.8.2 PATIENT INVOLVEMENT AND ITS INFLUENCE ON QUALITY

Papers I–V contributed to several improvements in the care processes, which influenced the quality of care in diverse quality dimensions (see Dagger et al., 2007). Moreover, the studies examined projects at different levels of healthcare, such as at a hospital-wide level, which is referred to as governance and management (see Carman et al., 2013).

Table V gives an overview of Papers I–V, with examples of quality dimensions that were influenced by the QI. Each paper is presented with the level of involvement in healthcare and examples of QI related to dimensions of quality, including sub-dimensions in brackets (according to Dagger et al. 2007).

**Table V: Examples of influence on quality dimensions (adapted from Dagger et al. 2007 and Carman et al. 2013) in the studies.** The table shows the included papers, at which level in healthcare the QI were completed, and examples of the effected quality dimensions (and sub-dimensions).

	Level of healthcare	Interpersonal quality (Interaction, relationship)	Technical quality (Outcome, expertise)	Environment quality (Atmosphere, tangibles)	Administrative quality (Timeliness, operation, support)

Paper I	Governance and management			Family-adjusted rooms	A new patient process-oriented building
Paper II	Group	Interaction during breastfeeding advices	Training nurses how to care for women who recently had a baby	More convenient beds; hygiene equipment	Improved collaboration between wards
Paper III	Group	Information to patients, such as about diagnoses	Training nurses in how to handle diabetes	More convenient beds	
Paper IV	Group	Increased involvement in one's own care			Families supporting each other; social network for families with a child with diabetes were established
Paper V	Governance and management		> 65 percent of parameters in national quality registers are over the average of the national level		Short length of stay in emergency departments

In general, patient involvement in QI contributed to the following three areas:

*Illuminating additional improvement areas*

Patient experiences provided a base for identifying improvement areas, which helped open healthcare professionals' eyes to new possibilities for improvements, since patients and healthcare professionals experienced different kinds of problems in care. QI that involved patients identified more improvement areas than QI involving only healthcare professionals (Papers I–IV). The majority of identified improvement areas could be categorized as simple problems, but some also addressed complicated and complex problems (Paper II). The improvements related to several quality dimensions, and the completed improvements were not just tangible environmental changes, such as better beds or hygiene equipment. The improvements also were related to technical quality, such as healthcare professionals' skills, aiming for safer care.

*Overcoming gaps between organizational functions*

Patient involvement supported healthcare professionals in different hospital wards to have a holistic view of the patients' care process. The patient journey became clearer to the healthcare professionals when a common picture of patient experiences was achieved during reflective dialogues with patients. This finding indicates that patient involvement can help overcome existing gaps between organizational functions, such as different wards. For example, the cooperation between the maternity ward and the neonatal ward increased during the project described in Papers II–IV. Having a patient focus and involving patients in QI can contribute to a process view of care, which can lead to increased process understanding among healthcare professionals (Paper I–V).

### *Contributing to additional quality dimensions*

The findings, especially in Paper III, indicated that consideration should be given to how to evaluate patient-perceived quality in healthcare. When patients are involved, the view of quality becomes co-created by healthcare professionals and patients. The findings suggested that if this change occurs, healthcare quality cannot be evaluated based only on how healthcare professionals do their job. Quality evaluation must also include patients' contributions to value in the care process. In Paper III, quality dimensions added by patients were the ones of the family and the patient's own ability to be involved in care.

#### *4.8.3 ROLES AND RELATIONSHIP*

Patient involvement in QI brings some challenges to roles and relationship, which may increase with the degree of involvement. For example, at a higher degree of involvement, the patient role as co-designer is new and very different from the traditional patient role. Patients said they feared making improvement suggestions in regular meetings with healthcare professionals. There was neither the time, nor the right place to discuss quality of care. However, in their new role, patients' experiences were taken seriously and not considered complaints.

*Very nice! Good to work with them (healthcare professionals), and nice to be taken seriously. (Parent in the diabetes project)*

*As a patient, you might not dare to give as much feedback to the healthcare professionals, but when you work together like this where everyone is on the same terms, it was very positive. (Mother in the neo project)*

However, healthcare professionals often overemphasized their own significance for creating QI value and underestimated patients' abilities, which made them unwilling to allow patients to act as co-designers.

*It felt strange and frustrating that the healthcare professionals did not receive the input and offer of assistance to the same extent as the offers were given by parents. (Improvement facilitator in the diabetes project)*

A second challenge was the effect of the patient's role as co-designer on healthcare professionals' traditional role. Healthcare professionals had to move out of their comfort zones and some experienced patient involvement as a bit frightening and inconvenient. Before the first meeting, one nurse (from the project in Papers III–IV) feared what the patients would say.

*Stressful first, given that I felt very hanged out, as I was their nurse.*

Those fears were unfounded. At the end of the QI project, healthcare professionals were overwhelmed by what had been accomplished, the fun they had had, and were more relaxed during collaboration with patients.

When patients were involved in QI, healthcare professionals had difficulties at first allowing patients to be included in implementation of improvements. Healthcare professionals thought it was their job to improve patients' experiences. However, patients were eager to participate in the improvements and talk about their experiences. With the patient in the room, healthcare professionals started discussing improvements to solve complex problems of which they already were aware of, but did not handle earlier. The experiences of patient involvement in QI supported new social agreements and adoption of roles for both patients and healthcare professionals that will likely influence future QI actions.

The relationship between patients and healthcare professionals also was affected when introducing patient involvement in QI. New roles for patients and healthcare professionals indicated the need for a new relationship. Patients experienced the new relationship to be on a more equal level than in ordinary care meetings (Papers II–IV).

#### 4.8.4 AN ADDITIONAL OBSERVATION

This research explored patient involvement in QI, and the findings may be valuable for understanding how patient involvement in QI can be turned into practice. Other ways of involving patients in care also may be affected. For example, parents and healthcare professionals from the diabetes project (Papers III and IV) started a local association for families with children with diabetes, which allows parents and family members to meet and support each other.

*It was nice to talk with others who had the same, similar experiences – others who truly understand what you are going through. (Parent in the diabetes project)*

This local association ultimately supports the children’s care situations and reinforces increased involvement in one’s own care as well as in co-designing the care processes for other patients.

#### 4.8.5 SUMMARY OF MAJOR FINDINGS

Table VI presents a summary of the most important findings from the six papers, which are discussed further in the next chapter in relation to the research questions and earlier research.

**Table VI: Important findings to be discussed further**

<b>To be discussed further</b>	<b>Found in paper</b>	<b>Related to research question (RQ)</b>
Patients and healthcare professionals experience different kinds of problems in care	I, II	RQ 1
Patient involvement in QI contributes to overcoming existing gaps between organizational functions	I, II, III, V	RQ 1
Quality dimensions in healthcare may be expanded with additional sub-dimensions	III	RQ 1
Challenges related to new roles for patients and healthcare professionals as co-designers	II, III, IV, VI	RQ 2
Challenges related to patient representativeness in QI	II, III, IV	RQ 2
Influences on the relationship between healthcare professionals and patients during patient involvement in QI	IV, VI	RQ 3
Degree of patient involvement	I, II, III, IV, VI	RQ 3



## 5 DISCUSSION

*This chapter presents a discussion of findings in relation to the purpose and research questions.*

A current emphasis on patient involvement in healthcare is a means to strengthen the patient role (WHO, 2006; Batalden et al., 2015), and specifically, patient involvement in QI can be a way to achieve higher quality care (Bate & Robert, 2006; Renedo et al., 2015). However, the experiences and contributions of patient involvement in QI represent a new and unexplored area, both in practice and in literature (Wiig et al., 2013). This thesis provides practical experiences and explores contributions and challenges of patient involvement in QI. In addition, the aim of this thesis is to inspire change in care processes. The three research questions raised are discussed in relation to the findings in this thesis and earlier research.

### 5.1 How can patient involvement in QI influence quality in healthcare?

Overall, the findings in this thesis support earlier research suggesting that without a patient perspective on care based on patients' experiences, healthcare professionals will miss important improvement areas (Bate & Robert, 2006). This thesis illuminates that patients and healthcare professionals experience different kinds of problems in care; therefore, patient experiences are valuable because they provide additional QI information otherwise not available to healthcare professionals. In addition, Boivin et al. (2014) showed that patient involvement in QI led to changed priorities for improvements. For example, patients were more eager than healthcare professionals to suggest improvements related to patient involvement in care. The findings in this thesis did not show differences in priorities of improvement areas; however, patients and healthcare professionals identified different improvement areas based on their experiences. In the usual care encounters between patients and healthcare professionals, systematic documentation of experiences that could contribute to improving healthcare does not typically occur (Armstrong et al., 2013). Patients in the studies in this thesis said that when they talked about their experiences in ordinary care meetings with healthcare professionals, they felt as if they were complaining instead of contributing to improvements. Patient involvement in QI uses patients as experts by virtue of their experience to identify improvement areas, instead of viewing patients' reported experiences as complaints (Tritter & McCallum, 2006). This research indicates that a high degree of involvement affects improvements, which adds evidence to earlier research (Carman et al., 2013).

Difficulties in changing routines and existing organizational structures can pose barriers to a patient focus in healthcare (Lord & Gale, 2014). However, the findings in this thesis showed that patient involvement in QI overcame existing gaps between organizational functions. For example, the maternity and neo wards in the neo project increased their collaboration because of the improvement project. Renedo et al. (2015) argued that patients often call for more inter-organizational collaboration in their improvement suggestions. One contributing factor also may be involvement of several stakeholders (Van de Ven, 2013), which supports QI with multiple perspectives of improvement areas in healthcare. In this case, healthcare professionals from different wards collaborated with the patients in the QI. In addition, at SkaS, healthcare professionals had several years of education about improvement knowledge (Batalden & Stoltz, 1993) and the desire to have a process orientation at the hospital-wide level (Paper V). The circumstance in which need for improvement comes from several different directions can be valuable and help overcome existing gaps between organizational functions, such as wards. Having the same goals from multiple directions lends a greater impact to patient involvement in healthcare (Carman et al., 2013). This emphasis on non-hierarchical, multidisciplinary collaboration between and among healthcare professionals and patients is also one of the four

key elements in organizational structure that can support successful patient involvement (Renedo et al., 2015).

Involving patients and healthcare professionals in QI can increase the sustainability of the improvements (Freire & Sangiorgi, 2010). The AR approach (Papers I–V) provided opportunities to share experiences and results from QI in a way that would likely not be feasible in ordinary QI. The spread of the EBCD project results supported a sustainability of the improvements. As the involved patients and healthcare professionals talked about these improvements in different conferences and papers, the research approach strengthened the results as well (further discussed in Paper IV). These findings are consistent with Robert (2013), who argued that combining EBCD and AR supports learning in different healthcare contexts, and the spread and sustainability of the QI.

The findings in Paper III, suggest that quality dimensions in healthcare may be expanded with additional sub-dimensions. These were sub-dimensions patients mentioned as related to their own capacity for handling their care and how they were coping with their family situation. As presented in Table V, improvements in the research projects affected both technical and functional quality. For example, training nurses in how to handle patients with diabetes could be categorized as technical quality. As an example of functional quality, patient involvement led to improved collaboration between wards at the hospital. One could assume that patient involvement would affect only service aspects, such as comfort, but there were examples of improvements related to both better experiences and better medical care. This finding indicated patients' important contributions to healthcare quality, also mentioned in earlier research (Vincent & Coulter, 2002; Jaques, 2012).

Previously, quality dimensions were argued to be based on patients' experiences of care as delivered by healthcare professionals (Dagger et al. 2007). Dimensions of healthcare quality have been commonly measured by how healthcare professionals do their tasks, instead of how healthcare professionals and patients collaboratively achieve higher quality care from a patient perspective. Despite the fact that healthcare systems intend to involve patients in care decisions and activities today, the measures of quality continue to focus on professionals (Lord & Gale, 2014). Therefore, quality measured from a viewpoint of co-creation (McColl-Kennedy et al. 2012) is interesting. In addition, Lillrank (2015) argued that patient experience should be seen as a type of quality in healthcare, and it is still relevant to question who defines quality, as Donabedian (1988) argued.

## 5.2 What are the challenges with patient involvement in QI?

Challenges related to patient involvement in QI are mainly related to new roles for patients and healthcare professionals when collaborating with QI.

This research, especially Paper IV, identifies challenges for patients with a high degree of involvement in QI. The challenge is to become familiar with new ways of acting and a higher degree of involvement than in the traditional passive patient role (Kettunen et al., 2002). Patients highly involved in QI as co-designers felt that healthcare professionals took them seriously in that new role. Earlier research also shows that patients were stimulated to critically reflect on their usual patient role (Renedo et al., 2015) during involvement in QI. This new role greatly differed from the usual one in a care meeting. Armstrong et al. (2013) suggested that the role of co-designer may help change the traditional patient role.

In addition, a regard for other diverse patient roles (Legnick-Hall, 1995) in healthcare can be beneficial when working with QI. Patient roles related to care as a production process may

seem old-fashioned, but the roles of supplier and participant (co-creator of value) is interesting and can be supported by the new patient role as co-designer. Carman et al. (2013 p. 228) stated: “We are in the midst of an important and potentially transformative shift related to patients’ roles in healthcare.” Cornwell and Gaventa (2000 p. 50) described patient roles as moving from mere users and choosers to makers and shapers. Preparing for these new roles is important, as the future patient probably will demand a role with more responsibility. Healthcare professionals will create value with patients, instead of for them.

Furthermore, Papers II–IV illuminated that the co-designer role was also new to healthcare professionals. Renedo et al. (2015) argued that it is often unclear to healthcare professionals how to involve patients in QI. Previously, healthcare professionals identified and worked on improvement areas without involving patients (Bate & Robert, 2006), as healthcare professionals’ dominance was strong (Luxford et al., 2011). Therefore, the focus on developing care from a patient view based on patient experiences (Freire & Sangiorgi, 2010) was not as easy as it seemed. In fact, healthcare professionals found it harder to take on the new co-designer role than patients did. One reason could be that healthcare professionals have a deeply rooted desire to do their best for their patients. When patients talked about experiences that did not feel good; the healthcare professionals felt that they had failed and wanted to improve the situation. Lord and Gale (2014) noted that healthcare professionals tended to emphasize the value of their professional knowledge over patient-identified outcomes. In addition, Tritter and McCallum (2006) argued that focusing on professional development in relation to patient involvement was just as important as focusing on recruiting patients for QI. Papers II–IV support earlier research concerning the need for healthcare professionals to leave their comfort zones (Donaldson, 2008) in order to involve patients in QI. Luxford et al. (2011) argued that there must be a change in healthcare professionals’ mindsets when increasing patient involvement in care. In some cases, healthcare professionals underestimate patients’ ability to contribute to care (Armstrong et al., 2013). However, after completing QI with patient involvement, healthcare professionals often found the experience rewarding (Crawford et al. 2002), a finding that also appeared in the research in this thesis. The requirement for new roles for patients and healthcare professionals makes co-design both challenging and powerful (Donetto et al., 2015).

One fear during the EBCD projects in this research was that the wrong patients would be included, a fear that Lord and Gale (2014) and Renedo et al. (2015) also identified. The healthcare professionals in the neo and diabetes projects were anxious about whom to involve. They argued that a small number of patients might not be representative of all patients. They also were anxious about the patients’ personalities. However, the studies included no patient selection: All patients were invited. These arguments about representativeness were no longer relevant for the healthcare professionals after study completion. Perhaps this anxiety is connected to the prevailing medical context that evidence from randomized control studies is a guiding principle for truth (Renedo et al. 2015). Although the literature includes discussions of the uncertainty of which patients to involve (Lord & Gale, 2014; Renedo et al., 2015), the representativeness of healthcare professionals is not discussed as much (Tritter & McCallum, 2006). Study results do not indicate a difference in this concern between groups of patients who had an acute disease and those with a chronic disease. Chronic patients will continue their contact with healthcare professionals; those with acute diseases are less likely to do so.

Batalden and Davidoff’s (2007) definition of QI in healthcare includes both patients and relatives. Dent and Pahor (2015) also mentioned family contributions. The EBCD projects in this thesis were mainly conducted in pediatrics, an area that has not been studied often in relation to patient involvement in QI. Although young children cannot speak for themselves, parents can represent them and themselves. Older children were invited to participate in the

diabetes project, but none chose to do so. The patients' social networks, including families, are important for quality of care. Family-centered care as a concept for patient involvement has positive effects (Kuo et al., 2011; Kuhlthau et al., 2011; McColl-Kennedy et al., 2012). Recruiting participants for EBCD projects was sometimes difficult. Future patients probably will make demands on healthcare quality and want to be involved in their own care at higher degrees than today (Kettunen et al., 2002; Naidu, 2009).

### 5.3 How does patient involvement in QI affect the relationship between patients and healthcare professionals?

The relationship between healthcare professionals and patients is affected by patient involvement in QI (Tritter & McCallum, 2006). Since the relationship is built on a traditional way of handling care (Freire & Sangiorgi, 2010), change is not easy (Tritter & McCallum, 2006; Carman et al., 2013), a finding supported by both healthcare professionals' and patients' experiences (Paper IV). Developing these relationships between patients and healthcare professionals may move power from healthcare professionals to patients (Renedo et al., 2015). Patient involvement in QI can strengthen the patient's role in healthcare (Crawford et al., 2002; Boyd et al., 2012). From a healthcare professional's viewpoint, patient involvement can seem to give all the power to patients (Tritter & McCallum, 2006); however, the intention is to build equality in the power relationship between patients and healthcare professionals. When patients and healthcare professionals meet each other in QI, their roles are more equal than in an ordinary care meeting (Crawford et al., 2002; Kettunen et al., 2002; Tritter & McCallum, 2006; Naidu, 2009; Boyd et al., 2012).

Overall, EBCD projects established an arena with a different climate, making it possible for patients to speak up about things that could be improved. This different climate was interesting because the intention of ordinary care meetings is to work in equal partnership with patients (Coulter, et al., 2008; Eldh et al., 2010; Abrahamsen Gröndahl et al., 2011). In fact, Normann (2001) took that idea a step further, suggesting that the patient creates the value, and healthcare professionals are only invited to support that creation once in a while. In general, a paradigm shift in healthcare (Snyder & Engström, 2016) seems to be occurring toward patients as equal partners with healthcare professionals. However, a strengthened role for the patient may create feelings of less control and power for healthcare professionals (Tritter & McCallum, 2006), which could be one explanation for the slow adoption of patient involvement in QI.

### 5.4 Additional discussions

Focusing on patient involvement in QI relies on contextual factors (Pettigrew, 1987). Pettigrew (1987) discussed organizational factors from both inner and outer contexts. Inner contexts may be a hospital's specific cases of patient involvement, and outer contexts may include WHO and the Swedish patient law. The trend in Swedish healthcare today is to increase patient involvement, which probably was an impetus for the projects in this thesis and contributed to the organizations' interest in including a patient focus in QI. Discussions in Carman et al (2013) pointed to the importance of healthcare organizations' intentions to encourage patient involvement as a central factor to achieve improvement goals, as well as societal and political influences.

Discussing QI in research and practice encourages reflective dialogues that promote learning and further development of patient involvement in QI. Reflective dialogues concerning contextual factors raise awareness regarding the forces that combine to produce improvements

in healthcare, as they give meaning to QI in every unique situation (Batalden & Davidoff, 2007; Bate, 2014). The AR agenda in the QI projects in this thesis led to extended reflective dialogues that supported understanding and insights with participants. Especially valuable in this thesis was the close collaboration with participants in the research projects. Learning occurs when understanding, insight, and explanations are connected with AR (Coghlan & Brannick, 2008; Reason & Bradbury, 2009). During the steps of EBCD, dialogues were included that were in line with the AR approach, so the two supported each other (Paper IV). The iterative cycles of learning and action in AR, EBCD, and QI tools like the PDSA productively reinforced each other.

Collaboration with patients enriches research during the generation of knowledge (Gillard et al., 2012). During the research in this thesis, one of the papers was co-written with one of the project participants, the father of a child with diabetes. Co-writing the paper became a way to allow collaboration in third-person inquiry of the experiences of patient involvement in QI. The collaboration was fruitful in many ways; for instance, the father had earlier experiences as a researcher and could draw upon multiple competencies as a co-writer.

## 5.5 Limitations

As with any research process, this work had limitations. As mentioned earlier, the AR process is similar to QI (Coghlan & Brannick, 2006), which is why I selected it as a suitable approach for the research in this thesis (papers I-V). However, a case study approach could have been an alternative. AR and case studies share many similarities, but also some differences. The main argument for choosing AR instead of case study is that AR fits the dual purpose of improving healthcare for patients and simultaneously conducting research in a collaborative learning process. This thesis includes studies of several QIs, which in one way makes the research wide and shallow. On the other hand, I explored patient involvement in QI from different perspectives and levels in the organization, which could be seen as an in-depth study of the subject. In addition, empirical material from the studies remains to be interpreted.

Five of six appended papers in this thesis are based on QI in healthcare at one hospital, mainly in care of women and children; therefore, the generalizability is limited, which often is the case in AR. On the other hand, examining several projects at the same hospital provides familiarity with the context, an important consideration when studying QI. In addition, as an IAR, the familiarity I had with the context could have masked things for me, and an IAR may be biased toward showing positive outcomes in the organization. I sought to address these limitations through collaborative reflections with other participants in the studies and with the external researchers, as well as with multiple methods for generating empirical material (triangulation). Findings from the included papers support each other and are coherent with earlier research, which seems to validate the studies.

In the EBCD projects, patients were represented by their parents, which raises the possibility that the perspectives of patients and their relatives could differ. However, newborn babies cannot speak for themselves. The children with diabetes were invited to participate but chose not to, which indicates that other forms of involving children in QI may have to be developed. Families are important when involving patients in healthcare in general (Kuo et al., 2011), and therefore, their involvement in QI is important as well.

The fact that there were only two EBCD projects studied (paper I-IV) with few participants could also be a limitation. In some situations, the participants had difficulty attending meetings, which made the groups small in some reflection dialogues. This limitation was offset by the fact that the projects were long-term, which made it possible for me to go back to sources in

the organization to verify analyses and interpretations of the progress. Also, the findings in the studies were supported by similar studies in other contexts in earlier research. Another aspect that may outweigh this limitation is the use of multiple methods for collecting empirical material, although tools used during the QI with a positive effect – the Kano model and emotional mapping – have been tested only in a few contexts and cases.

Technical problems with the web-based questionnaire occurred in the study described in paper VI. Some participants could not finish the survey, and data was lost. The respondent rate could have influenced the results; however, the statistical tests showed a significant interaction effect between studied variables.

## 6 CONCLUSION

*This chapter summarizes the conclusions and contributions of the thesis.*

The purpose of this thesis was to explore contributions and challenges of patient involvement in QI in healthcare. To work with quality management based on principles, practices, and tools earlier developed from the manufacturing industry is becoming a common approach in healthcare, as is greater patient involvement in healthcare. In turn, patient involvement in QI is an important feature for healthcare, but the field has yet to yield many practical examples and research (Armstrong et al., 2013; Lord & Gale, 2014; Dent & Pahor, 2015). Based on findings from studies included in this thesis, quality can be created through collaboration among patients, their families, and healthcare professionals. Healthcare organizations' QI agendas need to include a move away from the view of healthcare professionals as giving care and patients passively receiving it (McColl-Kennedy, 2012) toward the idea of co-creating care with a common goal. Patient involvement in QI makes a difference.

The conclusions of this thesis can be clustered into three areas: contributions that influence quality; challenges of new roles; and decreased power asymmetry in the relationship between patients and healthcare professionals.

The main findings indicate that patient involvement influenced quality in healthcare in several ways through contributions to additional quality dimensions of care. First, patients' experiences pointed out improvement areas that healthcare professionals had not previously recognized. Second, patient involvement in QI projects helped to fill existing gaps between organizational functions, supporting a view of care from a patient-process perspective. Third, patient involvement contributed to an extended view of quality dimensions in healthcare. Furthermore, practices and tools related to QI were illuminated as valuable when working with patient involvement. These contributions add new knowledge concerning patient involvement in QI.

The main challenges related to patient involvement in QI were related to new roles for patients and healthcare professionals. Patients are becoming co-designers of care in collaboration with healthcare professionals, instead of simply passive recipients. This challenge argues for the criticality of dialogues in healthcare about the patient role and the changes in the roles of healthcare professionals.

Patient involvement in QI had a positive influence on the patient-professional relationship in healthcare. As the patient role was strengthened, the relationship became more equal. This shift in power could challenge prevailing roles and relationships, and may have a wider influence on the relationship between patients and healthcare professionals in ordinary care meetings.

The research in this thesis contributes to the theoretical field of improvement science in healthcare, to the methodology of AR and its use in combination with patient involvement in QI, and with practical examples of improved care for patients that can be valuable for healthcare professionals.



## 7 FUTURE RESEARCH

*This chapter illuminates potential areas for future research.*

Explorations and discussions of the contributions and challenges of patient involvement in QI are eliciting new potential areas for future research. As a newly researched area, patient involvement in QI is ripe for the study of several important issues.

One potential area to study is how to gauge the degree of patient involvement that may be most beneficial to a QI effort. A high degree of patient involvement may not be required for all improvement initiatives. Also, additional research on involvement by various patient groups could be interesting. Are there differences in experiences between patient groups with chronic or acute care? Are there any differences between patient ages and genders? Which patients want to join? Do we miss important information if certain groups of patients do not participate? How does it affect QI projects that patients contribute in their spare time, often unpaid, while healthcare professionals contribute during paid work time? These questions also highlight the importance of inviting patients as co-designers in the planning step of patient involvement in QI and as co-researchers in AR, a focus that could be interesting to explore.

The EBCD projects described in the literature often aimed to improve the experience from a patient's point of view. It would be interesting to study how EBCD projects could affect the work environment for healthcare professionals. Perhaps a stronger focus on the work environment also could be valuable when working with patient involvement in QI.

The question of how to measure patients' perceptions of quality is an important area for further study, especially if the patient acts a co-creator of value with healthcare professionals. In paper III, patients illuminated areas related to perceived quality that were not included in current sub-dimensions of quality. Further studies could explore if there are different sub-dimensions connected to specific patient groups, such as those defined by gender, age, or diagnosis.

In addition, research is needed in the development of the patient role in healthcare, specifically the requirements that involvement in QI places on the patient. How does involvement in QI affect a patient's involvement in his or her own care? Also, the evolution of the healthcare professional's role is interesting to explore.

Clearly, there seems to be a distinctive patient focus in healthcare and a global emphasis on patient involvement. However, patient involvement is not clearly defined, nor is it clear how and when to apply it. Definitions of concepts related to patient involvement seldom focus on patient involvement in QI, but rather, focus on involving patients in their own care. More studies are needed to support healthcare professionals to manage the challenges and contributions of involving patients in QI in healthcare.



## 8 PERSONAL REFLECTIONS

My personal journey through the doctoral process has been a long and winding road, during which various schools of thought have inspired me. I began with a strong focus on QM and improvement science as the main and only theoretical field, but soon realized there was more to consider related to QI. Later, several other fields influenced my thinking, such as action research, service management, and design thinking. I have tried to glean valuable crumbs of learning in each area that I have visited during the journey, but I have always returned to the field of quality management, or more particularly, the emerging science of improvement in healthcare with the belief that the field can be developed further. We still have much to learn.

The grounding principle of “the customer in focus” has affected me considerably. During my 32 years in healthcare, I have always thought that things could be improved from the patient’s point of view. Somewhere inside me I have had the patient in focus even if I was unaware of any guiding principles for QM thirty years ago. During my years as improvement facilitator, I often used the patient as a neutral departure for QI, which unified healthcare professionals around a common focus, instead of focusing on their diverse professions for QI.

I first heard about EBCD when visiting National Health Service NHS at Luton and Dunstable University Hospital in the UK. The possibility of involving patients in QI felt absolutely right, and I directly started to plan such an initiative at SkaS. Later, as we completed the first project and spread the good news, I thought the new practice of working with QI would spread like wildfire. But, oh so wrong I was! Many still find it difficult to adopt this way of working with QI. However, I will not give up, and perhaps research evidence will prompt action. My memories of the QI projects with patient involvement are flooded with feelings of joy and pride, power and learning. Together we became stronger, and I hope others will experience this as well.

What is quality? What is value in healthcare, and for whom? Many times I have been intrigued by these questions. If a high value yields better quality and better quality leads to higher value for the patient – which is the chicken and which is the egg? Who can best define quality? And how? The questions are many and the answers are few. The more I learn, the more confused I become. Currently, I rest in a situation in which I feel there can be many answers to questions, depending on who chooses the questions and the perspective taken when answering them. Many of the challenges to patient involvement in healthcare can at the same time act as contributions.

Becoming a little familiar with action research (AR) has provided a fortune of new thoughts of how to construct reality and how it can be viewed and assessed in collaboration with others. Sometimes I have thought that I would have chosen another research approach, because AR looks easy, but was very hard to do. However, I think that I have learned a lot. I would not refuse AR projects in the future. I enjoyed AR because it reminded me of my earlier experiences of facilitating QI projects, and I was very fond of the idea of making improvements while doing research. On the other hand, the most difficult thing for me during the doctoral process was to divide two things that I felt were the same. I wonder if this has to do with my background as a midwife. To be a healthcare professional means being taught to work according to evidence and proven experience. For me, this means that theory and practice are closely linked. During my doctoral work, I was forced to split these two into theoretical and practical implications or contributions, which was very hard for me. Maybe that’s why AR fit

so well for me, because in AR, theoretical, methodological, and practical issues overlap all the time.

I look forward to new challenges and new things to learn!

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