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# UPGRADING CHRONIC CARE

Exploring challenges in rheumatology care management

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*Till mamma*

## ABSTRACT

**Introduction:** The literature on chronic care describes a gap between what patients need and what healthcare provides. In rheumatoid arthritis, major medical advances have taken place in recent years which have made it possible to successfully treat more patients. However, these advances have led to organizational challenges in the management of healthcare delivery.

**Aim:** To explore the challenges in rheumatology care management by studying users' perceptions of the Feed Forward System (FFS) principles (Study I), simulation modeling as a tool for chronic care improvement (Study II and Study IV), and a way to test new chronic care processes (Study III).

**Method:** Qualitative and quantitative research methods were used to explore the challenges faced by providers and their patients at Swedish rheumatology clinics. Methods include interviews, a focus group discussion, questionnaires, a meta-analysis, and simulation modeling. Content analysis was used to analyze qualitative data.

**Findings:** Patients became more involved in and informed about their own care when they used the FFS. Providers said that it offered an overview of past treatments and their effects, as well as support for treatment decisions (Study I). Simulation modeling provided a way to test the effects of moving from time-centric to need-centric processes in rheumatology care (Study III). Simulation modeling was also shown to support healthcare improvement by visualizing the effects of planned changes, communicating these changes to management, and engaging providers to explore and test innovative solutions (Study II and IV).

**Discussion:** Feed Forward Systems and simulation modeling represent an upgrade of how to manage the challenges inherent to rheumatology care. FFS encourage patient empowerment, self-management, and shared decision making, as well as support learning for patients and providers alike. Simulation modeling helps manage complex problems and facilitates learning for providers and managers. This is enabled through the shared features of FFS and simulation modeling: (1) the transformation of data into knowledge, (2) a mutual communication platform for multiple stakeholder involvement, (3) provision of real time feedback that enables action in clinical practice, and (4) self-correction that generates learning opportunities.

**Conclusion:** The introduction of FFS and simulation modeling has implications at the clinical level and the patient level of rheumatology care. Upgrading chronic care where it is delivered, at both levels, can contribute to improvements in care management – changing the healthcare system from within.

## LIST OF PUBLICATIONS

1. **Hvitfeldt H**, Carli C, Nelson EC, Mortenson DM, Ruppert BA, Lindblad S. Feed forward systems for patient participation and provider support: adoption results from the original US context to Sweden and beyond. *Qual Manag Health Care*. 2009 Oct-Dec;18(4):247-56.
2. **Forsberg Hvitfeldt H**, Aronsson H, Keller C, Lindblad S. Managing health care decisions and improvement through simulation modeling. *Qual Manag Health Care*. 2011 Jan-Mar; 20(1):15-29.
3. **Forsberg Hvitfeldt H**, Glaser D, Aronsson H, Ernestam S, Lindblad S. Comparing outpatient department systems: Moving from time-centric to need-centric processes.
4. **Forsberg Hvitfeldt H**, Glaser D, Aronsson H, Lindblad S, Keller C. From in-silico to in-reality: The value of simulation in healthcare improvement.

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## LIST OF TERMS AND ABBREVIATIONS

ABM	Agent Based Modeling
AQR	Added Quality Requirements
CCM	Chronic Care Model
CMP	Chronic Management Processes
CRP	C-Reactive Protein
DAS28	Disease Activity Score for 28 joints
DES	Discrete Event Simulation
DHMC	Dartmouth-Hitchcock Medical Center
DIKW	Data Information Knowledge Wisdom
EHR	Electronic Health Record
ESR	Erythrocyte Sedimentation Rate
EQ-5D	Euro Quality in Five Dimensions
FFS	Feed Forward System
ICCC	Innovative Care for Chronic Conditions framework
ICT	Information and Communications Technology
MD	Medical Doctor
MS	Management Science
MQR	Minimum Quality Requirements
OR	Operations Research
OTS	Open-Tight Special
PDSA	Plan-Do-Study-Act
PSDSA	Plan-Simulate-Do-Study-Act
RA	Rheumatoid Arthritis
RN	Registered Nurse
SD	System Dynamics
SSM	Soft Systems Methodology
SRQ	Swedish Rheumatology Quality register
TNF	Tumor Necrosis Factor
VV&T	Verification, Validation and Testing
WHO	World Health Organization

## MY JOURNEY

She was crying from the pain and she was frustrated not being able to get up from the chair in the waiting room. She was no more than twenty-five, much younger than the other patients and her anxious mother stood next to her trying to help her.

This was one of my first experiences with *chronic care and rheumatology* as I conducted my Master's thesis in medical informatics, that later was transformed into Study I. As a student I realized early on that my interest was not in coding or building ICT systems, but rather in understanding how they were used and perceived by the user. This is what I had the opportunity to do at the rheumatology clinic - studying patients' and providers' experiences in using a *Feed Forward System*.

Since then, rheumatology has continued to be the context of my research. Prior to my doctoral studies, I worked as a project manager for the Swedish Rheumatology Quality register (SRQ). During two years I visited 23 rheumatology clinics and met with over 200 healthcare professionals. This great opportunity allowed me to observe the daily care and challenges in rheumatology.

I was introduced to *simulation modeling* when trying to find ways to manage one of these challenges: *access*. As I learned more about simulation modeling I realized it is difficult to find information and cases on this practice in Sweden. This difficulty inspired me to perform Study II. Study III allowed me to work with and explore a real problem in a virtual reality as I tried to improve access. The *clinical use and the value* of the simulation model was always important and guided Study IV in which I explored the model's ability to support *health care improvement*.

Reconnecting to informatics, both Feed Forward Systems and simulation modeling are methods for the collection and management of data in order to inform patients, doctors, and organizations on how to improve care and its delivery. The title of this thesis suggests that chronic care can be improved using informatics and ICT tools, hence the *upgrade*. The upgrade is not simply a technical one since it aims to empower patients and providers in their respective roles when interacting, generating knowledge from testing, evaluating the effects of improvement initiatives, and managing the complex reality they are part of.

This was a short summary of my journey and the pieces that form this thesis. To illustrate the patient perspective on the challenges and developments, the past and the present within rheumatology, a patient journey follows next.



## THE PATIENT JOURNEY

*First, my feet hurt every time I got out of bed. I blamed it on dancing in high heels. Then my feet started to hurt every time I got up from a chair. I didn't want to acknowledge the pain or the problem. When I could no longer use my arms, I realized something was very wrong...*

Carina was only 27 years old when she was diagnosed with rheumatoid arthritis. The day of her diagnosis, in May 1989, was the last time she would wear high heels. Carina and her husband have two daughters and her youngest was only about one year old when the diagnosis was made. At first the doctors did not understand what was wrong with Carina. It was almost a year after her symptoms first appeared that a rheumatologist made a correct diagnosis.

With the first appearance of these symptoms Carina did not want to admit that something was wrong. Three years after her first meeting with the rheumatologist, she still did not want to admit she had the disease. The other patients in the waiting room were old ladies, and she was not one of them. Carina thought something else was causing her pain. She still refused to admit to her family that she was very ill, especially because she did not want her daughters to suffer.

When Carina finally understood that her disease was a reality, she began gathering all the information she could. With no internet, she brought home all brochures she could find, talked to other patients with rheumatoid arthritis, and contacted the patient association. Working with her family, planning carefully, and taking analgesics, she was able to cope with the disease. However, many friends did not realize how ill she was. She tried to work but was not able to drive to and from work because of the pain.

When her rheumatologist transferred to another hospital, Carina felt *frightened and isolated*. There was no one she could call for advice or care if she felt worse. Lack of *access to care was scary*. When she later found a new doctor and a nurse who were readily accessible, she was greatly relieved. After ten years of illness, on sick leave from work and on medication that provided no relief, Carina had the opportunity to try new medications that had been recently approved for use. "It was magic!" as Carina exclaimed. She felt energetic again and could engage more fully in her daughters' lives.

Now, Carina meets with her rheumatologist every 4 to 5 months. When she arrives at the clinic she uses the Feed Forward System. She recognizes it is important that the doctor understands her disease and gives her the proper prescriptions. Since she understands that there are variations in the severity of her disease, she knows she must adapt her behavior accordingly. Using the printed summary from the Feed Forward System, she can discuss her condition with her doctor. As she says, "I am the expert on me." Carina wishes more patients would use this system as a support for the *important meetings with healthcare*. She states: "The summary details what we have done, what has been decided, and empowers me until the next meeting."

# 1 CHRONIC CARE CHALLENGES

I will introduce this thesis with descriptions of chronic care complexity and its challenges. Especially, I will focus on the intersection between patients and chronic care and illustrate the importance of the needs of patients. I will use the case of rheumatology to exemplify patient needs with focus on the areas of *patient access* to care and the *interaction between patient and provider*. By provider, I refer to the healthcare staff working with patients. For each of the two areas I will suggest approaches to manage present challenges. These approaches constitute the upgrade. The contexts are *the clinical level and the patient level*.

Chronic illnesses are increasingly common and cause great suffering (Shortell et al., 2009, WHO, 2002). Because of the many patients who suffer from chronic illnesses, there is a need to consider the quality of chronic care, which is both complex and costly (Shortell et al., 2009, Ovretveit et al., 2008, Harrington, 2003, Bohmer, 2009). Many of the challenges in modern healthcare are present in chronic care (Yazdany and MacLean, 2008). Inadequacies in treatment as well as the asymmetry between patients' needs and the design of the healthcare delivery system are some of the challenges facing chronic care (Bodenheimer et al., 2002, Wagner et al., 2001).

To a great extent, healthcare involves processes for acute and episodic illnesses rather than care for chronic illnesses (WHO, 2002, Wagner et al., 2005). Effective chronic care requires customized care with follow-up visits focusing on the patients' needs and illness severity (McCorkle et al., 2011). The evidence shows that education and health self-management can improve outcomes for chronically ill patients who have a lifelong relationship with health care (McCorkle et al., 2011, Bodenheimer et al., 2002). The increasing number of patients with chronic illnesses calls for action to assure care is provided at the right time for the right patient and to enable patients to manage their own health. If chronic care is improved, it will benefit a great number of patients (Wagner, 1997).

## 1.1 THE CASE OF RHEUMATOLOGY

Rheumatoid arthritis (RA) is a chronic condition. It is the most common inflammatory arthritis, affecting nearly 1% of the general population worldwide (Firestein and Kelley, 2009, Cecil et al., 2012). Globally, this means that about 70 million patients are suffering from RA. The prevalence of the condition is two to three times greater for women than for men. RA can occur at any age, but its onset between the ages of 45 and 65 is most common (Firestein and Kelley, 2009, Cecil et al., 2012). RA is associated with increased mortality and patients often suffer from pain, stiffness, reduced muscular power, weakness, and fatigue (Firestein and Kelley, 2009).

In the past decade, the setting of rheumatology has changed drastically. Since 1999, new treatments have become available, such as Tumor Necrosis Factor (TNF) inhibitors. These RA treatments have had substantial effect on reducing the symptoms of the

disease. For many patients, quality of life has improved (Firestein and Kelley, 2009, Klareskog et al., 2009). However, these new achievements are associated with increased costs, in particular pharmaceutical costs. For example, the annual national costs of antirheumatic pharmaceuticals in Sweden alone is about 1600 MSEK (SRQ, 2011)<sup>1</sup>. In 1999 the same figure was 60 MSEK annually.

With more treatment opportunities available, more patients can be cared for. This is discernible in rheumatology care as well as in the complexity of treatment opportunities and combinations (SRQ, 2011). There are many diverse challenges in rheumatology care such as the search for appropriate quality of life indicators, the need to follow these indicators longitudinally, the necessity of adherence to treatment guidelines, the disparate quality of care (Yazdany and MacLean, 2008), the problem of uncoordinated, ineffective and even unnecessary treatments (Harrington, 2008), delayed referral processes, limited access, inadequate routines for follow up visits (Newman and Harrington, 2007, Harrington, 2003), and staff shortages (Gartner et al., 2012).

The main challenges, that have been reported in Swedish rheumatology care are excessive patient waiting times and staff shortages (Eriksson et al., 2011). Traditional solutions have been attempted in Sweden to minimize or eliminate such problems. These solutions include staffing on a national level (Eriksson et al., 2011), internationally advanced access scheduling (Newman and Harrington, 2007), immediate access clinics (Gartner et al., 2012), and referral management (Harrington, 2003).

Despite the recent innovations in rheumatology care, Harrington suggests that chronic care has been unable to satisfy the demands of society and of patients (Harrington, 2003). Since the goal of health care delivery is to satisfy such demands (Wagner et al., 2001), chronic care requires customized procedures aligned with each patient's biological variation and disease fluctuation. To accomplish this there is a need to improve processes and systems. However, it has been acknowledged that there is a need to expand knowledge and to increase research initiatives in order to redesign rheumatology care (Harrington, 2008, Harrington, 2003). In summary, upgrading chronic care and rheumatology is needed to meet the various needs of the many patients.

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<sup>1</sup> Swedish currency rate October 2011:1 SEK = 6,44 USD/9,02 Euro (Swedish Riksbank).

## 2 UPGRADING CHRONIC CARE

It is recognized that new drugs and new therapies are not the sole solutions to better healthcare. The organization of healthcare is considered to be of great importance as well (Fulop, 2001, Bohmer, 2009). As described in the previous chapter, there are several challenges within chronic care and rheumatology care. This chapter will further explore two of these challenges that are the main areas of the thesis: *patient - provider interaction* and *patient access to care*. According to the Chronic Care Model (CCM), which I use to position the four studies in a wider context, the two main areas fold into the subjects of Delivery System Design and Productive Interactions. First, I will give a short background to the concept of improvement and models in chronic care that describe the foundation of the approaches I suggest to manage the challenges posed.

### 2.1 IMPROVEMENT

Healthcare quality improvement initiatives are the measures aimed at improving patients' health, bettering healthcare operations, and advancing professional development (Batalden and Davidoff, 2007). Such improvement proposals have had different names and forms over the years, including TQM (Total Quality Management), CQI (Continuous Quality Improvement), Lean, Six Sigma, and BPR (Business Process Reengineering) (Chassin and Loeb, 2011).

Due to the complex initiatives and the numerous contextual factors, the effects of these initiatives on healthcare quality have been debated (Blumenthal and Kilo, 1998, Kaplan et al., 2010, Thor et al., 2010). However, the evidence suggests that healthcare quality improvement initiatives can prevent illnesses, assess treatments, and support patients with chronic illnesses (Ovretveit et al., 2008). Thus, it seems that improvement can contribute to the upgrade of chronic care, but attention must be paid to the known challenges of improvement.

The ability to design and implement change is necessary in order to improve healthcare. While improvements require change, not all changes result in improvements. Therefore, an improvement requires an alteration in the performance of an operation, the generation and awareness of positive differences in contrast to previous results, and a sustainable impact (Langley, 2009). A model that ties all these parts together is the well-known model for improvement, Plan-Do-Study-Act (PDSA) for testing and implementing change (Langley, 2009, Shewhart and Deming, 1986).

The PDSA model has been used in rheumatology care improvements (Harrington and Newman, 2007, Newman and Harrington, 2007). The concept of the PDSA cycle is to start with the aim, and the appropriate measurements and then to develop a plan to test a change (Plan), perform and implement the test in reality (Do), observe and learn from the consequences and effects of the change (Study) and finally to determine what modifications should be made in order to inform the next cycle (Act).

### 2.1.1 Models and frameworks in chronic care improvement

There are various evidence-based models and programs for managing chronic care (Ovretveit et al., 2008). Ample research on chronic care improvement stems from the work of Edward Wagner, creator of the Chronic Care Model (CCM). The CCM is a conceptual model based on evidence for improving the care of patients with chronic illnesses (Wagner et al., 2005, Wagner et al., 2001). The CCM is built upon the following components: self-management support, delivery system design, decision support, and clinical information systems (Bodenheimer et al., 2002) (see Figure 1).

Related to the CCM, Wagner (1997) identifies success factors that aim to improve chronic care: (1) the use of plans and evidence-based guidelines, (2) reorganization of practice to meet patients' needs, (3) attention to the psychosocial needs of patients and appropriate behavior changes, (4) access to expertise, and (5) supportive information and communication technologies ICT (Wagner, 1997). The studies of this thesis will in particular focus on numbers 2, 4 and 5.

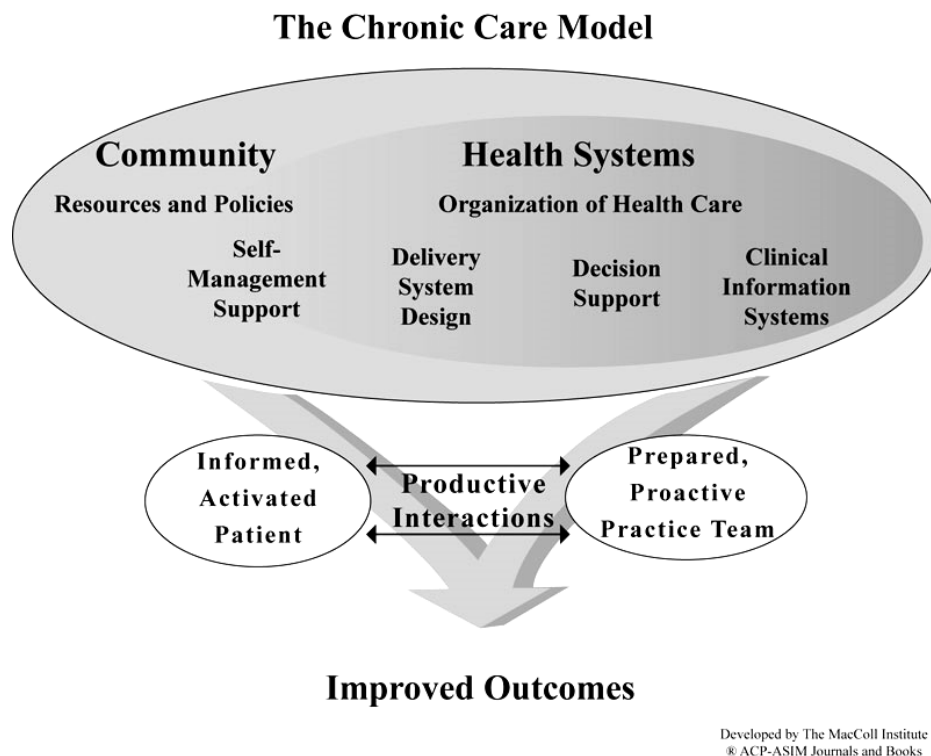


Figure 1. The Chronic Care Model (CCM).

Due to the increasing number and growing cost of chronic illnesses, the CCM was, with the assistance of the World Health Organization (WHO) updated in an effort called the “Innovative Care for Chronic Conditions” (WHO, 2002). The new model, the Innovative Care for Chronic Conditions (ICCC) Framework was a redesign of the CCM to suit an international context and a variety of healthcare systems (Epping-Jordan et al., 2004, Nuno et al., 2011). Evidence of the effect of the ICCC Framework is more limited than the evidence of the effect of the CCM (Nuno et al., 2011, Wagner

et al., 2001). The CCM focuses on the need to re-organize healthcare systems, whereas the ICC Framework emphasizes coordination and integration (Nuno et al., 2011).

Since the focus of the four studies (Studies I, II, III and IV) presented in this thesis is the upgrade and redesign of chronic care, I will use the CCM as a conceptual model to position the studies. The main areas of my research according to the CCM are within the areas of *Health Systems* and *Productive Interactions*. Study I mainly concerns the productive interactions between patient and provider. Study II presents work on different levels in the healthcare context with a focus on *Delivery System Design*. Study III and Study IV deals with delivery system design and new perspectives on decision support with close connections to the providers' work.

Care Management Processes (CMP) includes actions developed to improve the quality of care for patients with chronic illnesses (Shortell et al., 2009, Casalino et al., 2003). Several of these actions are related to the work of this thesis. CMP comprises the use of disease registries to identify patients with chronic illnesses, development of patient education programs to help patients better manage their illnesses, use of nurse care managers for the sickest patients with the most complex needs, provision of feedback to doctors on their performance, and reminders and decision support information for providers and patients at the time of care (Shortell et al., 2009, Wagner et al., 2001, Wagner et al., 1996). The use of CMP has proved effective in improving healthcare (Shortell et al., 2009).

The next sections present an overview of the main areas of the thesis: Productive Interactions exemplified by patient-provider interaction and Delivery System Design with a focus on health care access in rheumatology care. These two areas are the challenges that I have had the opportunity to research and that are important to both patients and health care providers. The approaches of the FFS and simulation modeling will be described in further detail and connect to the respective challenge.

## **2.2 PRODUCTIVE INTERACTIONS**

The following section takes on the next action step after granted access to healthcare, the patient-provider interaction, referred to as Productive Interactions in the CCM. This is also the first main area of this thesis. Patients with chronic illnesses manage their health every day and should not be considered only as receivers of care. Instead, they are also co-producers of care. This observation has implications for a new patient-professional partnership, involving collaborative care and self-management education (Bodenheimer et al., 2002).

### **2.2.1 Patient-Provider interaction**

The basis for how patients can contribute to their own care (i.e., self-management) until the next visit is established in the interaction between patient and provider during the clinical appointment. Education, communication, participation, motivation and shared decision-making are factors in this interaction (Daltroy, 1993, Teutsch, 2003). The outcome of the interaction plays an important part in patient satisfaction (Teutsch, 2003).

Patient engagement is considered to involve: informing patients, teaching them skills, and building their self-confidence so that they can engage in self-management (McCorkle et al., 2011). It is imperative that patients are well-informed so that they are prepared to participate in setting care goals and in planning how to achieve them (Daltroy, 1993, Wagner et al., 2005).

There is a considerable body of research on patient-provider interaction. However, research has also found that still more investigation is required. For example, there is a need to learn how the patient and the provider can be equally active in their meetings (Pilnick and Dingwall, 2011). Patient centered care is an important area of health care in the 21<sup>st</sup> century but the impact on patient health outcomes varies (Pilnick and Dingwall, 2011). Moving from patient centered care towards empowering partnering has been advocated in chronic illness where co-creation and cooperation are emphasized (McWilliam, 2009).

Educational programs have been shown in the past to be efficient but few patients participated (Daltroy, 1993). Research also describes a mismatch about patient information: what the patient seeks is not necessarily what the provider offers. Moreover, patients with chronic illnesses have different information needs than patients with acute illnesses (Daltroy, 1993). The research also recommends various patient-provider interaction tasks related to their communication. For instance, it is recommended that providers give specific (rather than general) instructions and present organized and summarized information in easily readable formats (Daltroy, 1993).

Patient self-management is an important aspect of chronic care. A randomized controlled trial performed by McCorkle et al. (2011) describes the benefits of self-management in oncology patients. It has been found that patients who are capable of self-management can solve problems, make decisions, use resources efficiently, form partnerships with providers, and take action (McCorkle et al., 2011). In short, self-management allows patients to become more active in their own care which can help shape the interactions with healthcare (Bergman et al., 2011, Wagner, 1997).

Shared decision-making is a joint collaboration between patient and provider in making decisions on future actions, such as treatment plans, and connects to patient centered care and patient empowerment (Whitney et al., 2004). It is acknowledged as an important part of the patient-provider interaction that also stresses the need for sharing information (Elwyn et al., 2000). Past research in shared decision making has focused on situations where there is more than one choice available and the importance of achieving a mutual agreement between patient and provider (Whitney et al., 2004, Frosch and Kaplan, 1999). Recent research also include situations where there is only one choice and when agreement is not reached, stressing the importance of information and communication (Whitney et al., 2008).

Information and Communications Technology (ICT) can facilitate the processes that are the basis for the interaction between patient and provider. A shared patient-provider

language is one such communication tool (McCorkle et al., 2011). Advances in ICT have also greatly benefited the area of chronic care. Many patients use the Internet for self-management support and for communication with healthcare, with other patients, and with various healthcare authorities (Dickerson et al., 2006). Moreover, disease/illness registries, with their real time decision support, have been identified as essential communication tools (Wagner, 1997). In summary, ICT can improve chronic care management by engaging patients in the care process (Marchibroda, 2008).

## 2.2.2 Feed Forward Systems

If you search for the term feed forward in PubMed you will find many areas of application such as physiology and gene regulation. If you Google the same term you will find many examples of application in computing and neural networks. The most suitable general description is “*Feed forward is the modification or control of a process by its anticipated or predicted results or effects*” (Brown and Little, 1993)<sup>2</sup>. Feed forward is not a new term but the application to be described here is novel. A suitable application of this definition in the context of rheumatology care management would be the use of the FFS aims to capture patient data at an early stage, in order to facilitate decision-making in later stages.

### 2.2.2.1 FFS in rheumatology

FFS represents ways to arrange a process in which principles can be applied with the help of ICT to capture data, on which the decision making process can be based. The first ICT using FFS was developed at the Spine Center at the Dartmouth-Hitchcock Medical Center (DHMC), in 1999. The aim of that system was to create a common language (Weinstein et al., 2000). This common language enables patients and providers to communicate better about the patients’ current health status, their treatments, and their response to therapy (Nelson et al., 2003, Nelson et al., 2000, Nelson et al., 1998, Nelson et al., 1996). The FFS process is illustrated in Figure 2.

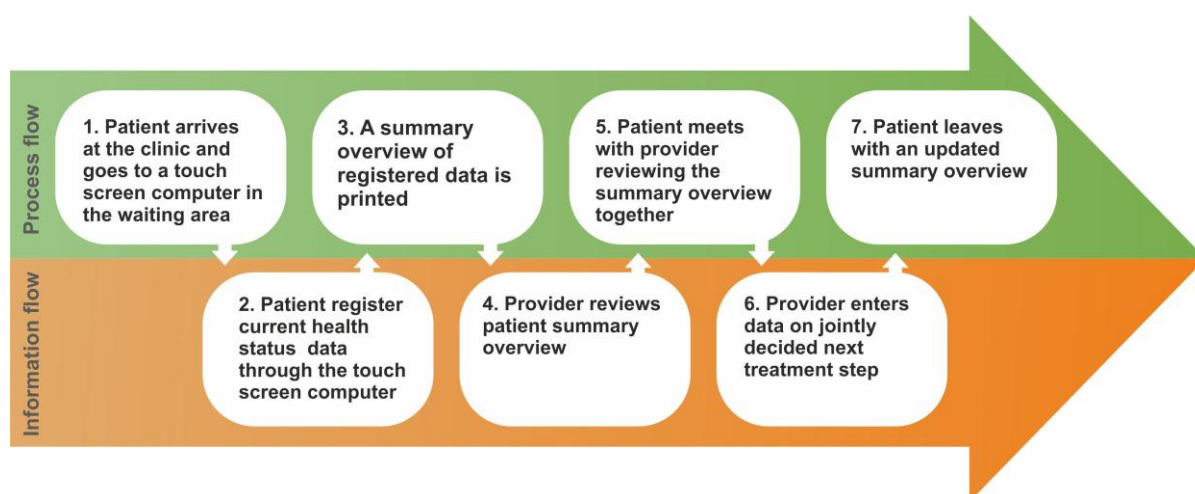


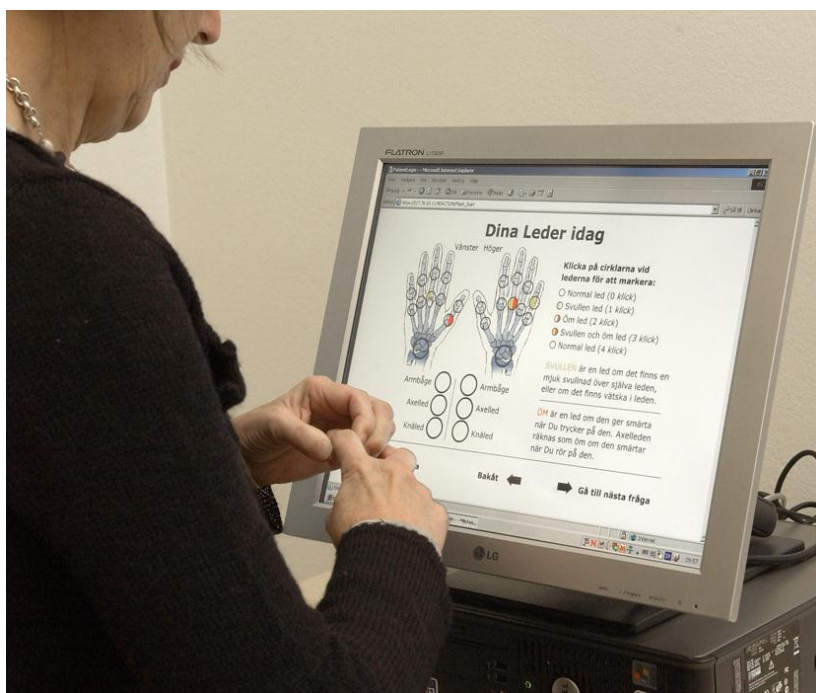
Figure 2. The FFS process as applied to the rheumatology care context.

<sup>2</sup> Page 929.



In 2003, the Swedish Rheumatology Quality register (SRQ) implemented an ICT based on FFS with online access. Instead of collecting all patient data during the patient-provider visit by asking questions, some patient data are collected from the patient prior to the visit. Data can either be collected at the clinic while waiting for the provider or from the patients' home via a patient portal online (e.g. [www.1177.se](http://www.1177.se) or [www.vardguiden.se](http://www.vardguiden.se)).

Similar systems have been reported in rheumatology care contexts with the main aim of comparing the accuracy of patients' reported health status via standardized paper questionnaires and computerized questionnaires (Richter et al., 2008, Greenwood et al., 2006). Conclusions revealed that computerized questionnaires accessed from a touch screen computer can generate results comparable to those of the paper version.



**Figure 3. Patient entering data on swollen and tender joints using the touch screen in the Swedish rheumatology setting.**

The Swedish FFS process begins when patients fill out an electronic self-administered health survey prior to their visit (see Figure 2). This is done using a touchscreen computer in the waiting area to enter data on their pain, swollen and/or tender joints, performance of daily activities, health-related life quality (using EQ-5D), and ability to work (see Figure 3). The data is compiled in an overview with all other information obtained in previous visits (see Figure 4).

The overview uses color codes to illustrate the value of DAS28 using red for a higher DAS followed by yellow, green, and white. With this data, providers can prescribe treatment and medication. The printed overview is shared between patient and provider during the visit and functions as a basis for shared decision making. The treatment that

is agreed upon is entered into the system and is thus accessible to both patient and provider to complete the overview.

Year	2012	2012	2012	2012	2012	2012	2012
Day Month	16-Jan	17-Jan	22-Jan	24-Jan	02-Feb	28-Feb	18-Apr
Årskontroll							
Allmänna variabler							
Score	/40	20/40	20/40	/40	/40	20/40	30/40
Global health	60	26	20	26	76	26	42
SR	30	10	20	10	34	19	5
Doctor's judgement	High	Moderate	Low	None	Maximal	Moderate	Low
EQ5D	0.877	0.77	0.77	1	1	0.896	0.737
CRP	25	10	3	10	45	12	2
RA							
HAQ	1.38	1.25	0.88	1.25		1.00	0.88
Pain	55	44	35	44	80	20	27
Swollen joints 28	8	3	0	0	12	2	1
Tender joints 28	8	3	1	0	14	1	0
DAS28	5.6	3.43	2.94	1.98	6.6	3.38	1.99
DAS28CRP	5.35	3.64	2.3	2.19	6.47	3.2	2.22
NSAID	COX2	COX2	COX2	COX2	COX2	COX2	COX2
CORT					PRE	PRE	
CORT dose					15 /1d	10 /1d	
LARM 1	MTX	MTX	MTX	MTX	MTX	MTX	MTX
LARM 1 dose	22.5 /1v	22.5 /1v	22.5 /1v	22.5 /1v	22.5 /1v	22.5 /1v	20 /1v
LARM 2							
LARM 2 dose							
LARM 3							
LARM 3 dose							
LARM 4							
LARM 4 dose							
Monitored month					0	0	2
Monitored drug					HUM	HUM	HUM
Drug dose					40/2v	40/2v	40/2v

Figure 4. The printed patient summary overview showing entered data and DAS28 (Disease Activity Score for 28 joints) over time.

### 2.3 DELIVERY SYSTEM DESIGN

Delivery system design involves access. The following text highlights the importance of access for patients with RA and simulation modeling as a way to deal with access.

#### 2.3.1 Access

In the report, *Crossing the Quality Chasm* (IOM, 2001), the Institute of Medicine, in the US, stated that timely care is an essential factor in the treatment of all patients, regardless if they suffer from acute or chronic illnesses. Delayed access to care may cause not only patient dissatisfaction, but also worsened illness or injury or lead to unnecessary visits with healthcare providers (Newman and Harrington, 2007, Murray, 2000). Access is an essential factor that can be studied in many different ways (Aday and Andersen, 1974, Vissers and Beech, 2005, Allder et al., 2011, Martin et al., 2003, Randolph, 2005, Murray, 2000).

Based on these different studies of access I chose to define access in the contexts of this thesis as the *availability of healthcare services to patients based on their individual needs in a timely manner*. According to the framework for studying access developed

by Aday and Andersson (1974) there are several components that contribute to the totality of access. Using their framework, the component I have chosen to focus on in this thesis is *Healthcare* whose characteristics include resources (volume and distribution) and the organization (entry and structure) (Aday and Andersen, 1974). The organization aspect refers to the process of gaining entry to the system (access) and structure can be referred to the processes after entry, i.e. the patient–provider interaction (Aday and Andersen, 1974).

Patients with suspected RA require prompt access to specialty care due to the narrow window of opportunity for treatment that is available. This window is open only for 3-6 months after the disease onset and is when treatment has the potential to generate best effect (Lard et al., 2001, Nell et al., 2004).

### **2.3.2 Access in the context of rheumatology**

Hence access for this group of patients is important and treatment within the window is recommended in guidelines. Patients with a confirmed diagnosis of RA also require prompt access to care since many of them receive aggressive treatments with TNF inhibitors that require follow-up. Long waiting times to specialists care are one obstacle to access. An Estonian study concluded that the traveling distances to specialists, as well as the long waits for specialist appointments, caused patients to consult general practitioners instead of specialists (Polluste et al., 2011).

The literature shows various strategies to improve access in rheumatology care. These include referral management (Harrington, 2003) and immediate access clinics (Gartner et al., 2012). It has also been suggested that rheumatology nurses may care for certain groups of patients who do not require an immediate appointment with a doctor. These nurses may give patients information and make telephone follow-up calls (Gartner et al., 2012, Wagner, 2000).

### **2.3.3 Open clinic**

The concept of Open clinic or patient driven access was tested in a randomized controlled trial during six years. Patients in the intervention group, with low DAS28, were given direct access based on their individual needs and not offered any routine follow up visits. The clinical and psychological status of the patients in the intervention group was evaluated after six years. They performed as well as the patients in the control group whose visits were initiated by a rheumatologist (Hewlett et al., 2005). When patients reach a lower DAS28 they can enter the Open clinic process and contact their rheumatologist when needed.

### **2.3.4 Tight clinic**

Another approach is the Tight clinic or tight control that aims to intensify treatment management for patients suffering from RA with a high DAS28. A randomized controlled trial aiming to compare tight control of the disease activity with routine outpatient care showed that patients in the tight control group achieved a greater response to

treatments and a decrease of disease activity than those in the control group (Grigor et al., 2004). Recent findings support frequent appointments as suggested in the Tight clinic, which is now recommended for patients with RA (Bakker et al., 2011). Belonging to the Tight clinic implies that the DAS28 is high. In this case, patients will meet with their rheumatologist with tight time intervals in order to evaluate treatment effects and adjust treatment plans to lower DAS28.

In both Open and Tight clinics, the Disease Activity Score for 28 joints (DAS28) was used to evaluate patients treatment response. DAS28 is a composite measure of the individual patient's number of swollen and tender joints, ESR (Erythrocyte Sedimentation Rate) or CRP (C-reactive protein) and global health (Wells et al., 2009). A low DAS28 reflects low disease activity or remission; a high DAS28 reflects high disease activity.

Access is an important aspect of rheumatology. The advantages of using Open and Tight clinics are the improved access and the opportunity of improved patient outcomes. Combining these concepts, simulation modeling could be a valuable tool to assess its impact on a clinical level.

### **2.3.5 Simulation modeling**

When thinking about simulation, computer games, weather forecasts, or flight simulators often come to mind. Essential aspects in all types of simulation involve testing, training, and learning to prepare for reality (Slovensky and Morin, 1997, Sterman, 2006). In healthcare simulation, people usually refer to practical training in surgical skills, acute care, or virtual patients. Access, patient flow, resource allocation and staff scheduling are examples of areas where process simulation has been applied (Aharonson-Daniel et al., 1996, Elbeyli and Palaniappa, 2000, Hung et al., 2007, Vermeulen et al., 2009, Elkhuizen et al., 2007).

Simulation modeling stems from Operations Research (OR), an area of research concerned with solving operational problems (Hillier and Lieberman, 2010). OR, sometimes used synonymously for Management Science (MS) (Hillier and Lieberman, 2010), aims to improve operations within organizations by using system models (Hillier and Lieberman, 2010, Pidd, 2003, Pidd, 2004b, Fulop, 2001). Different quantitative approaches and mathematical tools (e.g., statistics and decision modeling) are used in OR. These tools can also be used to improve healthcare (Fulop, 2001).

Simulation modeling allows creating and testing prototypes of changes before they are implemented in reality. It offers safe environments for testing and learning where time and space can be compressed (Slovensky and Morin, 1997, Sterman, 2006). It also can function as a systems analysis tool (Reid et al., 2005) making it possible to imitate or replicate an already existing system (Robinson, 2004, Slovensky and Morin, 1997). This is of particular importance when one is interested in looking at a complex system such as healthcare with its many components and interactions (Slovensky and Morin, 1997, Sterman, 2006).

### 2.3.5.1 Simulation methods

There are three multi-paradigm simulation modeling methods of relevance to this thesis; System Dynamics (SD), Agent Based Modeling (ABM), and Discrete Event Simulation (DES). Other methods identified in Study II such as Monte Carlo and Markov modeling are not of relevance to this thesis discourse. The three major methods are compared in depth in Study II but to understand some of their similarities and difference I present a short overview here.

In the 1950s the American computer engineer, Jay Forrester, founded the method, which is called System Dynamics (SD). This methodology is used to understand the structure, dynamics, and behavior of complex systems (Sternan, 2000). SD, which has its roots in differential equations (Gilbert and Troitzsch, 2005), emphasizes the importance of feedback control and delays (Pidd, 2003). SD cases often span several organizational boundaries and take on the macro view (Taylor and Lane, 1998, Gilbert and Troitzsch, 2005). This method has been applied in many areas of public health and social policy (Homer et al., 2007, Homer et al., 2004, Homer et al., 2008, Homer and Hirsch, 2006).

Agent Based Modeling (ABM), which was introduced in the 1990s, is a fast growing simulation method. ABM models agents and their interaction with each other and with their context (Gilbert and Troitzsch, 2005). ABM involves autonomous but rule-based agents, for example, people, hospitals, cars, and companies and is a popular method in studying complex social phenomena (Deguchi et al., 2006, Arai et al., 2005). ABM has been used, among other things, to examine human behavior and to study the spread of human immunodeficiency viruses, influenza, and the health and safety of populations (Anderson et al., 2007, Lee et al., 2008).

A frequently used simulation method for healthcare processes is the process-centric method called Discrete Event Simulation (DES), stemming from the 1960s. DES represents the components of a system and their interactions (Banks, 1998) that are often used for local and clinic decisions (Taylor and Lane, 1998). These components or objects are called *entities* and represent important features of a given system, i.e. patients, doctors or nurses. Groups of entities are named *classes*. The entities will change *state* during the simulation run, for example from referred patient to hospitalized to discharged (Pidd, 2003). DES looks at specific points in a given process (e.g., patient-provider meetings) and at the chronological sequence of events (Chase and Jacobs, 2006, Gilbert and Troitzsch, 2005, Robinson, 2004). The state of the system observed and simulated is updated as each event takes place. Events changes the state of the system representing how the real system changes over time (Law and Kelton, 2000).

DES, which has been used at various levels of healthcare, focuses on a variety of problems such as patient flows, resource allocation, and staffing scheduling (Günel and Pidd, 2010) is a suitable tool to evaluating and improving system performance (Mustafee et al., 2010). Questions suitable for testing in a simulation model begin with

*what if*, which allows for a wide variety of experimentation in healthcare. Examples of such questions are: *What if we hire another nurse? What if we have to cut the budget by 10 %? What if we had another three beds or two more examination rooms?* (Pidd, 2004a, Robinson, 2004).

## **2.4 SUMMARY**

In this section I have attempted to describe the challenges of chronic care, specifically in the context of rheumatology care. Two challenges have emerged, explicitly patient access and patient–provider interaction. A number of improvement methods and conceptual models exist all of which have their strengths and limitations. To meet the challenges of rheumatology, the approaches of FFS and simulation modeling are proposed. These approaches can form an upgrade and potentially contribute to the improvement of rheumatology at the clinical level with implications for both patients and healthcare providers.

## 3 AIM AND OBJECTIVES

### 3.1 GENERAL AIM

The general aim of this thesis is to *explore challenges in rheumatology care management*. This involves exploring users' perception of two ICT systems based on Feed Forward System principles, exploring simulation modeling as a tool in chronic care improvement and using simulation modeling to test new chronic care processes.

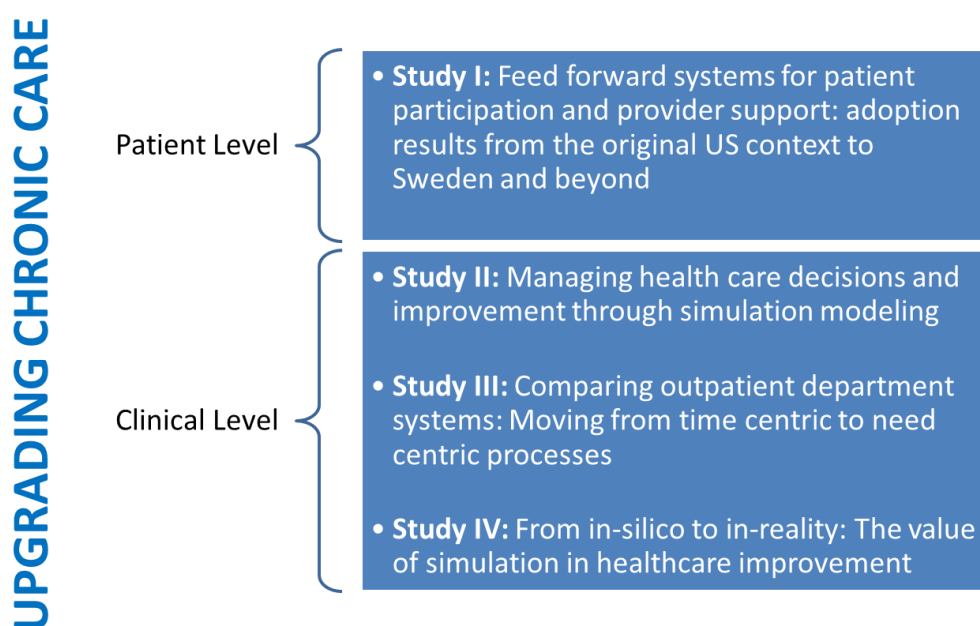
#### 3.1.1 Specific objectives

The specific aims and objectives of the four studies included in this thesis are to:

- Identify and describe the essential properties of FFS and explore patients' and providers' perceptions in two different healthcare contexts, the U.S and Sweden (Study I)
- Investigate the experience and potential value of simulation modeling when used in healthcare decision making and assess the quality of identified evidence (Study II)
- Compare two approaches to health care delivery in a rheumatology outpatient clinic in a simulation model (Study III)
- Describe the experience of using simulation modeling as a tool in healthcare improvement, and explore one method to investigate the value of simulation modeling (Study IV)

## 4 OVERVIEW OF THE THESIS

The four studies in this thesis can be seen as contributing to exploring rheumatology care at two different contextual levels, that of the patient and the clinic (see Figure 5). The thesis begins with identifying how FFS can be used to support patient provider interactions (Study I). To effect changes at the clinical level (e.g., managing access to care and waiting times), the attention in Study II turns to simulation modeling as a method to test proposed changes before they are implemented in reality. This study poses the following questions: How can simulation facilitate decision making in health care? What has been learned from the implementation experiences?



**Figure 5. Overview of the thesis.**

The feasibility of simulation models is explored and compared in the wider context of healthcare (Study II) and in the specific context of rheumatology care (Study III). Keeping in mind the issues of care access and waiting times, in Study III simulation modeling is applied in the context of rheumatology care. The goals of this study are to understand how to deal with the ever-increasing health care demands and with the need for health care to be designed to match the varying biological processes and patient needs and to ensure access.

The knowledge gained in Study II and Study III is then applied in order to move from a simulation model to real world change. In Study IV, the simulation model developed in Study III was applied but now in a new clinical context. The goal is to describe the experience of simulation modeling in healthcare improvement and its potential value.



## **5 METHODS**

Multiple methods were used in order to explore challenges in rheumatology care management and test ways to deal with them. This section describes the study context and design.

### **5.1.1 Study context**

The study context of this thesis is rheumatology care in Sweden. Three rheumatology clinics were selected: Karolinska University Hospital, Solna, in Stockholm (Study I and Study III); Sahlgrenska University Hospital in Göteborg (Study I); and Sunderbyn Hospital in Luleå (Study IV). Study I also includes data from the Spine Center at the Dartmouth-Hitchcock Medical Center (DHMC) in the United States.

Sweden has 20 counties and 290 municipalities. The counties are responsible for the organization of health services that are financed by taxes and are controlled by national government policies and guidelines (Swedish Association of Local Authorities and Regions, 2012, Anell, 2005). Public producers mainly provide these services, although the number of private producers, also publicly financed, is increasing (Anell, 2005).

### **5.1.2 Swedish Rheumatology Quality registry (SRQ)**

The Swedish Rheumatology Quality registry (SRQ) is a specialty oriented, multicenter, practice-based, longitudinal database in place since 1995. It is used for patients with rheumatic diseases who meet certain formal diagnostic criteria including a core set of rheumatoid arthritis-related outcome measures (Arnett et al., 1988, Felson et al., 1993). All 64 rheumatology units in Sweden use the SRQ to follow the progress of patients (n=42 700) over time.

The web version of SRQ, which was launched in 2003, uses real time, standardized data provided by patients and doctors. DAS28 is used as a measure of individual patients' disease activities and treatment responses. The purpose of the SRQ is to improve the care of patients and to support self-management. It is also used to track quality improvement and to support research (SRQ, 2011).

## 5.2 STUDY DESIGN

Table 1 presents an overview of the four studies including study design, data collection, study focus, and data analysis.

Study	Study Design	Data Collection	Study Focus	Data Analysis
I	Qualitative and quantitative	Interviews and questionnaires	FFS*	Qualitative content analysis and Fisher's exact 2-tailed test
II	Meta-analysis	Database search	Implementation experience and value of simulation modeling	MQR and AQR**
III	Discrete Event Simulation	Review of medical record, quality register and clinical process data	Open Tight clinic	Descriptive statistics
IV	Qualitative	Focus group discussion and interviews	Simulation modeling workshop	Qualitative content analysis

**Table 1. An overview of methods used in each study. \* FFS = Feed Forward Systems \*\* MQR = Minimum Quality Requirements, AQR = Added Quality Requirements**

### 5.2.1 Study I

Study I uses both qualitative and quantitative methods. The research team developed a questionnaire and interview guides that were then used in a small pilot (n=10) study in Sweden. Data from that pilot were not used in the data analysis. After minor adjustments, the questionnaire and interviews were used at Karolinska University Hospital and Sahlgrenska University Hospital. The questionnaire and interview guides were then translated for use at the DHMC Spine Center in the second part of this study. DHMC researchers made minor additional adjustments to the questionnaire and interview guides.

Patients were asked to participate in the study when they entered the clinics. All participation was voluntary. Patients were informed that their data would be treated with confidentiality. Informed consent was obtained verbally. Patients who agreed to participate in the study completed a questionnaire after using the Feed Forward System (FFS). After meeting with the healthcare provider, the patients participated in brief interviews on how the FFS affected their visit. In Sweden, there was some difficulty finding an opportunity to meet with the patients. The healthcare providers caring for the patients who had participated were also asked to participate in the study. All healthcare providers agreed to be interviewed.

The interview audio recordings and the field notes from both settings were transcribed. Data were then processed using content analysis; as the data were condensed, coded, and categorized, themes were identified (Krippendorff, 2004, Graneheim and Lundman, 2004). Fisher's exact 2-tailed test was used to compare questionnaire response patterns among patients in both settings. The value of P of less than .05 was used as the threshold for statistical significance.

In the search for the essential properties of the FFS, the following indicators were used in the questionnaire and the interviews: acceptance (perceived ease of use), use (actual use), and utility (perceived usefulness). Properties were classified as essential if they enabled reinforcing loops favorable to patients, providers, or to both, in clinical encounters.

### 5.2.2 Study II

Study II was a meta-analysis that included a literature search. The following search terms were used: *modeling, health care, decision and simulation* (with the search operator AND for all the four search terms). Six electronic databases were searched (PubMed/MEDLINE, Web of Science, Cumulative Index to Nursing and Allied Health Literature, SveMed+, PsycINFO, and Business Source Premier).

Selection criteria were established prior to conducting the literature search. Articles should: (1) have a focus on simulation modeling in healthcare associated with a case, (2) describe the use of simulation as a decision-support tool, (3) be written in English, and (4) be electronically or locally accessible. A total of 148 articles were identified in the search (including five articles from experts in the field). Forty-seven articles were excluded as they did not meet the selection criteria (see Figure 6).



**Figure 6. Flowchart of the meta-analysis process.**

**MQR: Minimum Quality Requirements, AQR: Added Quality Requirements.**

The remaining 101 articles were read in full. Of these, 42 articles were excluded as they were not relevant to the study aims. An independent researcher performed an inter-reliability test by reading a sample of the retrieved articles and applying the same selection criteria. The researcher's result was consistent with the research team selections (94%). The retrieved material was further analyzed using the Minimum Quality Requirements (MQR) and the Added Quality Requirements (AQR).

### 5.2.3 Study III

In Study III, a simulation model was built using Discrete Event Simulation (DES) that depicted a rheumatology outpatient department. DES was chosen as a method in order to perform a comparison of two systems (Standard and Open-Tight) involving different processes. Rheumatology specialists, a modeler, and the researchers performed the iterative building of the simulation model. Processes were observed and data obtained during two months at a rheumatology clinic that was selected as the model clinic. Data from the clinic and the SRQ were used to validate and verify the model. Data on the

number of patients on various waiting lists, the number of discharged patients, and the number of patient visits (by specialist and by day) were retrieved from the EHR (Electronic Health Record).

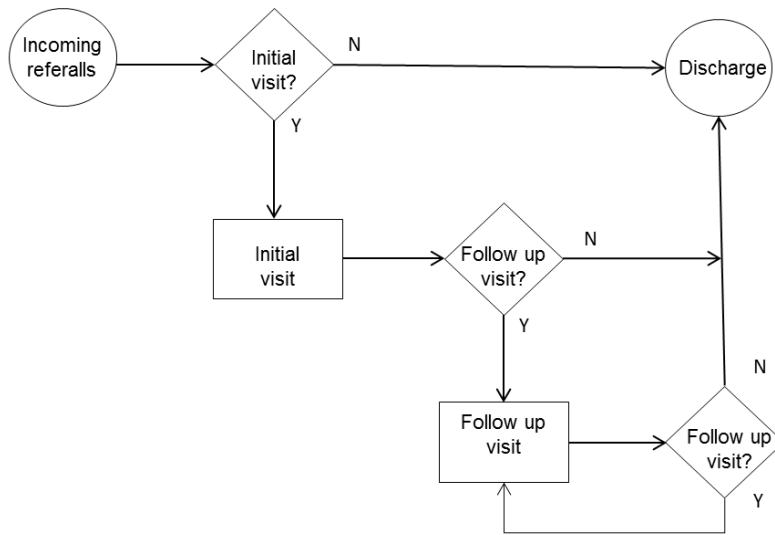
Two specialists helped to map the processes based on brief observations at the clinic. Process maps of the clinic's standard clinic processes (see Figure 7) and the intervention processes of the Open-Tight system (see Figure 8) were implemented into the simulation model using software AnyLogic™ version 6.5 (XJTechnologies, 2012). The SRQ annual reports provided data on the variations in the DAS28. The rules and logic according to the two different systems were retrieved from the articles describing Open and Tight clinics and were complemented by data from the model clinic where needed. Further rules and logic were then implemented into the model.

The DAS28 value controls if the patient should go to the Open or the Tight clinic. If DAS28 is  $\geq 3.2$  the patient belongs to the Tight clinic and if DAS28 is  $< 3.2$  the patient belongs to the Open clinic. Patients who cannot belong to either Open or Tight due to systemic diagnosis, for example, enter a separate process called Open-Tight Special (OTS). When patients belong to the Open clinic they are scheduled for regular follow up appointments with a nurse based on treatment.

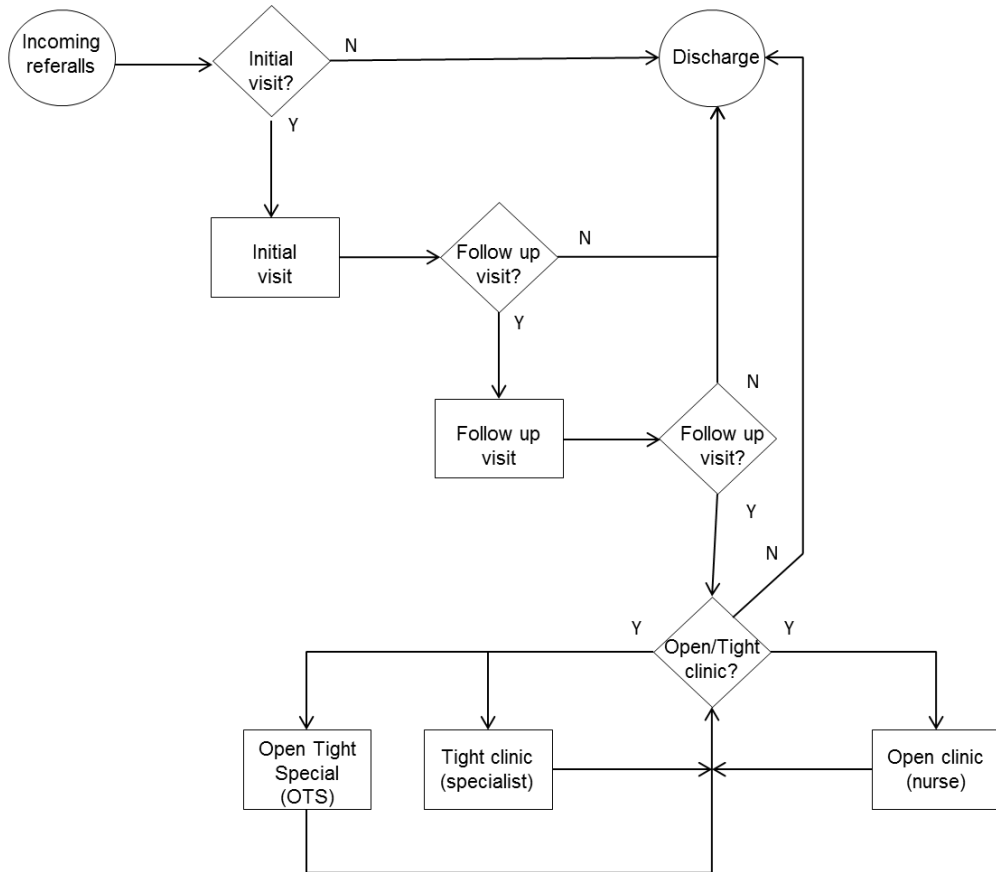
Appointments in the Tight clinic are scheduled with tight time intervals. When patients in the Tight clinic reach low disease activity they are invited to join the Open clinic and vice versa. Acute appointments are incorporated into the model and can occur if a patient experiences sudden decreased health status. Acute appointments are scheduled as soon as possible and occur randomly and equally frequent in both the Standard and Open-Tight system. In the Open-Tight system both doctors and nurses perform visits, whereas only doctors perform visits in the Standard clinic. The three initial visits are always performed by a doctor in order to follow up treatment responses.

To implement the actual waiting times and number of patients on the waiting lists, the simulation model uses a warm up period. To compare the Standard and the Open-Tight system, the same patients enter both systems to follow their process of care. Given that the same patients, irrespective of clinical process, have the same disease diagnosis and prognosis, the comparison is strict.

Our initial simulation setting tested different staffing variations to see their effects, especially the effects on the areas of our main interest. A staffing setup of 8 doctors in the Standard clinic (based on the staffing at the studied clinic) and 5 doctors and 3 nurses in the Open-Tight system was chosen. The cost for each resource was estimated and set per working hour (see parameter table 11.7 in Appendix). The model was simulated for ten years with a focus on a time period of four years in which the average resource utilization is greater than 80 %. Data obtained from the simulations were analyzed using descriptive statistics.



**Figure 7. Process map representing the Standard processes at a rheumatology clinic.**



**Figure 8. Process map representing the processes of the Open-Tight system.**

#### **5.2.4 Study IV**

In Study IV, a focus group discussion as well as individual interviews were used to describe how providers experience the use of simulation modeling for decision support in healthcare improvement. The model developed from Study III was loaded with data from the clinic at Sunderbyn Hospital and a process for telephone consultations was added.

Purposeful sampling was used to select providers familiar with process improvement to participate in a workshop about simulation and how simulation can be used to improve rheumatology care at their clinic (Patton, 2002). Seven participants (four doctors and three nurses) were considered a representative sample. The ages and clinical experiences of the participants varied.

The focus group discussion was preceded by a simulation workshop in the clinical setting. During the workshop, the participants received a short introduction to simulation modeling and a demonstration of the model. The participants were given time to discuss their ideas or questions, which were then simulated in the model.

Ten weeks after the workshop, interviews were conducted with two of the providers at the clinic, one nurse and one doctor. Interviews were conducted by telephone and also audio recorded. The interview questions were developed prior to the simulation workshop and some questions were added afterwards.

### **5.3 DATA COLLECTION**

The data collection methods are described next as a complement to the methods described above.

#### **5.3.1 Interviews**

Interviews are a method widely used in social sciences research. They involve a structured dialogue with a purpose (Kvale, 1996, Robson, 2002). Interviews were conducted in both Study I and Study IV. In Study I, the respondents were patients and providers. In Study IV, the respondents were providers. The interviews, which were conducted at the clinic (in Study I) and by telephone (in Study IV), lasted between 15 minutes and one hour.

In Study I only the interviews conducted in English were audio recorded. Handwritten notes were taken on the interviews conducted in Swedish. In Study IV all interviews were audio recorded. Semi-structured interview guides were used in all interviews. In Study I, the provider interviews were somewhat shorter in the US setting due to system differences. For example, the question on potential users was removed since all patients already used the system. All interviews were transcribed verbatim and subjected to a qualitative content analysis.

### **5.3.2 Questionnaires**

Questionnaires are often quantitatively designed and allows the researcher to collect data in a standardized form (Robson, 2002). The research team prepared the questionnaire that was first used in Study I in the Swedish setting. The questionnaire was then adapted for use in the US setting to suit the context and how the FFS was used within the clinic. Since the routines at the US clinic differed from the Swedish one regarding if patients had the opportunity to review their printed overview, this question was moved to the patient interview thus making the interviews different between the settings.

The questionnaires, which were designed to complement the interviews, were given to the participating patients after they had completed the FFS input in order to obtain their opinions and accounts of their experiences. The patient questionnaire consisted of both closed and open-ended questions. Open-ended questions are useful because patients may give unexpected answers (Fowler, 2009). Response categories included 5-point Likert ratings, yes/no answers, and free text as appropriate for the items. Patients could write general comments at the end of each question and also at the end of the questionnaire.

### **5.3.3 Focus group discussion**

Focus groups discussions, also known as group interviews, are used to investigate experiences, attitudes, and emerging ideas in a group (Krueger and Casey, 2000, Pope et al., 2002). The use of focus group discussions began in the 1920s as an area of market research (Robson, 2002). As with individual interviews, a focus group discussion should have a purpose and a structure (Krueger and Casey, 2000, Robson, 2002).

In Study IV, a focus group was assembled at the clinic. This was an environment in which the respondents were comfortable. During the hour of the focus group discussion, two researchers, who were the moderators, audio recorded the discussion and took notes. It is necessary to have moderators since the strength of the focus group research method can also be its weakness if not well managed. The moderator has a multifaceted role which is to facilitate the discussion, manage the group dynamics, and create a sense of security and openness in the participants (Krueger and Casey, 2000, Morgan, 1997, Fern, 2001, Robson, 2002).

The focus group discussion in Study IV consisted of a homogenous group. The group members shared a common professional background and had similar work experiences. Simulation modeling was new to all of them. While facilitating communication, homogeneity in groups may also lead to groupthink (Robson, 2002). The moderators tried to ensure that all participants had the chance to speak by initially asking all of them to answer the same question.

## 5.4 DATA ANALYSIS

The following sections describe the main data analysis methods used.

### 5.4.1 Content Analysis

Qualitative content analysis was used to analyze data in both Study I and Study IV. Content analysis is a commonly used method of analysis in the social sciences (Dixon-Woods et al., 2005, Krippendorff, 2004). While there are different definitions of content analysis, Krippendorff's definition is used here: "A research technique for making replicable and valid inferences from texts to the contexts of their use" (Krippendorff, 2004)<sup>3</sup>.

Data analysis was inductive in both Study I and Study IV as patterns and codes were searched for (Patton, 2002). Of the three distinct approaches to content analysis defined by Hsieh and Shannon (2005), the conventional approach was used. This approach is suitable for analysis of phenomena in which few theories have been proposed or little research exists (Hsieh and Shannon, 2005). The preparation, data collection, and data analysis followed three general steps; (1) the preparation phase, (2) the organizing phase, and (3) the reporting phase (Elo and Kyngäs, 2008). The focus group discussion and the interviews were transcribed verbatim.

Two researchers read the transcribed focus group discussion and individual interviews repeatedly in order to immerse themselves in the data. The analysis focused on manifest content. During data abstraction condensed meaning units were created and labeled with codes (Graneheim and Lundman, 2004). Finally, categories were created, followed by sub-categories (Graneheim and Lundman, 2004). These categories and sub-categories were content groups that shared a certain commonality (Krippendorff, 2004). In Study I, the amount of data was richer allowing themes to be created. In Study IV, the analysis concluded with categories.

### 5.4.2 Meta-analysis

Meta-analysis (also called meta-study or meta-synthesis) is a research method used to synthesize data from previous primary research (Dixon-Woods et al., 2005, Robson, 2002). All such syntheses involve interpretation (Dixon-Woods et al., 2005), and most meta-analysis involves pooling quantitative data in order to perform statistical analysis on larger cohorts (Greenhalgh, 2006). Meta-analysis can also be of a qualitative nature and can be used in combination with literature reviews (Robson, 2002). Paterson (2001) uses the term *meta-study* to refer to this qualitative version of meta-analysis.

Webster and Watson (2002) define a literature review as the creation of a knowledge foundation for the purpose of advancing the current state of knowledge, developing theory as well as identifying knowledge gaps. Greenhalgh (2006) defines a systematic review as an overview of primary research including defined objectives and a transpar-

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<sup>3</sup> Page 18



ent description of the method and the material. The steps in a systematic literature review and a meta-study or meta-analysis share similarities including the retrieval and analysis of literature plus the contribution of novel knowledge (see Figure 6). A meta-study has a clearer focus on analyzing, developing, and testing theory in qualitative research, whereas literature review aims to advance the knowledge within a certain research field (Levy and Ellis, 2006, Paterson, 2001). This difference is illustrated in Study II through the combination of the PDSA improvement model with the simulation model as described in Figure 9.

The Minimum Quality Requirements (MQR) were applied to evaluate the quality and rigor of the evidence in the 59 articles. As stated by Fone et al. (2003), MQR are the minimum requirements needed in publications of simulation modeling research. To further research the question on implementation experiences and the potential value of simulation modeling, the MQR were complemented with the Added Quality Requirements (AQR) (see Table 2).

Minimum Quality Requirements (MQR)	Added Quality Requirements (AQR)
1. Aim	
2. Objective	
3. Model specification	3. 1 Modeling method specification (DES/SD/ABM/Monte Carlo/ Markov/Combination/Other)
4. Parameter data	4.1 Amount of variable data
5. Assumptions	
6. Validation	6.1 Verification 6.2 Sensitivity analysis 6.3 Empirical data
7. Results	
8. Area: <ul style="list-style-type: none"> <li>• Hospital scheduling and organization</li> <li>• Infectious and communicable diseases</li> <li>• Cost of illness and economic evaluation</li> <li>• Screening</li> <li>• Miscellaneous</li> </ul>	8.1 Abstraction level
	9. Generalizability/transferability
	10. Experience of decision support and implementation

**Table 2. Minimum Quality Requirements (MQR) and Added Quality Requirements (AQR) used to analyze retrieved articles.**

The MQR and the AQR were checked against the retrieved material. The purpose of this step was to determine if the different quality requirements were mentioned, but not how often or to what degree they were met.

## 5.5 ETHICAL CONSIDERATIONS

According to the Swedish law (SFS, 2003:460), approval from the relevant ethics committee is required to conduct research that implies physical or physiological influence on the participants. All studies were performed and approved by The Regional Ethical Review Board at Karolinska Institutet, Sweden. Protocol: 2009/895-31/5.

For the interviews, questionnaires and the focus group discussion in Study I and Study IV, all participants gave their informed consent. They were also informed about the voluntary nature of their participation and their right to withdraw at any time. Data are presented so that individual participants remain anonymous, and quotations used in reports do not include information that could identify the participants. Recorded interviews and paper questionnaires are copied and safely stored at multiple locations. Data needed to validate simulation models were extracted from SRQ, an EHR and hospital administration systems. Data were analyzed on a group level. Data from the SRQ are found in public annual reports, and therefore no approval was needed for their use.

## 6 FINDINGS

The findings presented here are shown per study.

### 6.1 STUDY I

*Feed forward systems for patient participation and provider support: adoption results from the original US context to Sweden and beyond*

The aim of Study I was to identify and describe the essential properties of the FFS and to explore patients' and providers' perceptions of the FFS in two different healthcare contexts – the United States, where the system was developed, and Sweden, where the system was subsequently adopted for use in clinical settings. Eighty-eight patients participated in this study (US clinic n=44, Swedish clinics n=44). In addition, 13 providers from the US clinic and 6 providers from the Swedish clinics participated. Women comprised 55% of the patients at the US clinic and 70% of the patients at the Swedish clinics.

All participating providers at the Swedish clinics were doctors. In the US clinic, 9 of the providers were doctors, 2 were physiotherapists, and 2 were nurse practitioners. Most of the patients rated the FFS as excellent to good (United States: 84%, Sweden: 96%,  $P < .001$ ). Many patients valued the opportunity to enter data in the system prior to their clinical visit (United States: 41%, Sweden: 61%) (see Table 3). Patients appreciated that the FFS was quick, easy, and efficient. The overview helped the patients track their progress and identify important topics to discuss with the providers.

Questions from patient questionnaire	Patients at US clinic in % (N = 44)	Patients at Swedish clinics in % (N = 44)	P value
<i>Familiarity with use of computers:</i>			<0.01
Very familiar	34	27	
Familiar	27	59	
Not familiar	39	14	
<i>Willingness to enter data prior to appointment:</i>			<0.1
Yes	41	61	
No	45	23	
Have no computer	14	16	
<i>Overall impression of the system:</i>			<0.001
Excellent	14	30	
Very good	45	66	
Good	25	0	
Fair	9	2	
Poor	7	0	

**Table 3. Patients' perceptions of the use of the FFS (by country setting).**

The patients commented about areas where they thought the FFS could be improved. They said that some questions were repetitive, there were ergonomic problems with the

workstation where the FFS was set up, extra time was needed to complete the FFS, and there were not given sufficient information before using the FFS.

The providers reported that most patients rated the FFS as positive. They reported that the system facilitated provider decision making and follow-up, that it promoted better communication, and that it acted as a quality control instrument.

*The system makes it possible for  
the provider and me to talk about  
the important issues*

Patient

However, the providers also noted several drawbacks with the FFS. They reported that extra time was required to use the FFS, and data sometimes had to be entered twice since the FFS and the EHR were not connected with each other. Nevertheless, half of the providers stated that the FFS saved time, useful for managing data and for supporting their decisions.

The essential properties of the FFS that the providers identified included the involvement of patients in structured data collection before the clinical visit and the generation of an overview of data that enabled decision support for doctor. These properties enabled patient involvement through engagement, education, and communication with the providers.

*Hidden information that the patient  
has may unexpectedly surface*

Provider

In summary, Study I provided feedback to system developers to use in making improvements to the ICT. While implementing some system improvements, I turned my attention to another challenge in rheumatology care management – patients’ access to care. The research team had been introduced to simulation modeling as a way to test improvements before their implementation; this is the tool I chose to use. Before creating models, I searched the literature on the effects of simulation modeling in healthcare. This literature search later became the meta-analysis performed in Study II.

## 6.2 STUDY II

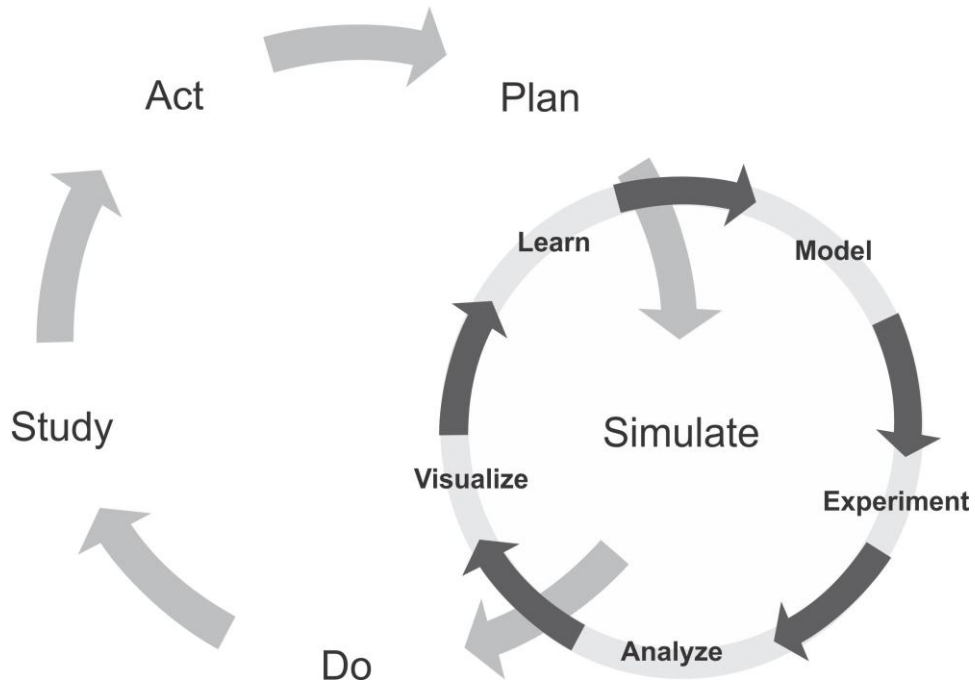
### *Managing health care decisions and improvement through simulation modeling*

The first aim of Study II was to investigate the experience and value of simulation modeling when used in healthcare decision-making. The second aim was to evaluate the quality of the evidence found in the research. Many models have been developed for numerous challenges, but there is little understanding of what happens after a model has been developed and provided to the stakeholder. This meta-analysis focused on simulation modeling when used as a tool for decision support in health care. Fifty-nine articles were included in this analysis, all of which were published between 1988 and mid-2009. Most of the articles were journal articles. They originated from 12 different countries, mainly the United States, Canada, the United Kingdom, and the Netherlands.

In order to meet the research questions, we created, specified and used the Added Quality Requirements (AQR) to analyze the articles. Most published articles on simulation modeling fulfill many of these quality requirements. Sixty-two percent of the 59 articles scored 10 or more (on the 13 AQR). When information was lacking in the articles, it most frequently related to validity, verification, sensitivity analysis, generalizability or transferability, decision support, and the implementation experience. The most common topic in the articles dealing with simulation modeling in healthcare was *hospital scheduling and organization*. The second most common topic was the description of models for *infection and communicable diseases*. Discrete Event Simulation (DES) was found to be the most used simulation method identified on the micro and meso levels. On the macro level, SD (System Dynamics) was the method most frequently used.

Only 14 studies (24%) offered descriptions on implementation and decision-support experiences. The articles that did report these findings state that simulation modeling can enable informed decisions, develop system knowledge, determine critical factors for the development of an organization, supply scenario analysis and options to choose from, help understand complex problems, and facilitate communication and the formation of plans and directions for future work. Through instant feedback on innovations and changes, analysis of different plausible scenarios, collaboration and communication around a shared view of a system and understanding how complexity works, simulation modeling aids decision making in health care.

The meta-analysis of the findings led to the conceptualization of a model for simulation and improvement which was arrived at through the merger of the model for simulation with the model for improvement (the Plan-Do-Study-Act cycle). The PSDSA (Plan-Simulate-Do-Study-Act) model is an attempt to enable further applications of simulation modeling and increase its full use in healthcare (see Figure 9).



**Figure 9. The PSDSA (Plan-Simulate-Do-Study-Act) model: a fusion of the conceptual model for improvement (the PDSA cycle) and the model for simulation.**

Understanding how simulation and improvement can be combined led naturally to questions about how simulation can be used to test hypothesis on how to improve access to care.

### 6.3 STUDY III

#### *Comparing outpatient department systems: Moving from time-centric to need-centric care processes*

The aim of Study III was to compare two approaches to healthcare delivery in a rheumatology outpatient clinic using a simulation model. Simulation studies performed in the context of rheumatology are scarce, but the concept of outpatient department has been studied via simulation modeling quite frequently (Elkhuizen et al., 2007, Rohleder et al., 2007, Huarng and Lee, 1996, Chand et al., 2009).

DES and the simulation software AnyLogic™ (XJTechnologies, 2012) were used to construct a simulation model that depicted a rheumatology outpatient department. The model is a comparison of time-centric care (Standard system) with need-centric care (Open-Tight system).

When the simulation model is operating, there are certain model outputs in focus:

1. Number of patients in the clinical processes at any point in time
2. Discharged patients from the Standard system and from the Open-Tight system
3. Completed initial and follow-up visits for the Standard system and for the Open-Tight system
4. Resource utilization of doctors, nurses, and rooms in the Standard system and in the Open-Tight system
5. Waiting times for planned initial and follow-up visits in the Standard system and in the Open-Tight system
6. Number of patients waiting for planned initial and follow-up visits in the Standard system and in the Open-Tight system
7. Costs of the Standard system and of the Open-Tight system

In accordance with the aim of this research, the factors of primary interest were the resource utilization, costs, and waiting times. The data from two of the simulated years and resources were sent to 8 doctors (doctors) in the Standard system and to 5 doctors (doctors) and 3 nurses (registered nurses) in the Open-Tight system.

The results from the simulation model showed that there is higher utilization of resources by the doctors in the Open-Tight system because of the fewer number of doctors. The general high resource utilization is due to that doctors and nurses are allowed to begin new visits close to the clinics' closing times. The length of waiting times for initial visits is similar in the two systems, but the length of the waiting time for follow-up visits in the Open-Tight system is longer (see Table 4).

	<b>Standard</b>	<b>Open-Tight</b>
<b>Resource utilization (mean)</b>	97.1%	109% (MD) 90.8% (RN)
<b>Waiting time in days (mean)</b>	IV = 0.07 FV= 8.0	IV = 0.5 FV MD = 12.8 FV RN = 5.2
<b>Costs in 1000 SEK (total)</b>	16 821	13 883

**Table 4. Summarized results from Study III. IV = Initial Visit; FV = Follow-up visit; MD = Medical Doctor (doctor); RN = Registered Nurse.**

The simulation includes holiday schedules that reduce the resources during summer and Christmas (July 1st to August 15th and December 24th to January 7<sup>th</sup>) to two doctors in the Standard clinic and one doctor and one nurse in the Open-Tight system. The model showed that waiting times increased and resource utilization decreased during the summer and Christmas holidays.

This work has resulted in a working model feasible to use when improving clinical processes in rheumatology care. Developments of the model and results are presented in the discussion (in chapter 7).



## 6.4 STUDY IV

### *From in-silico to in-reality – The value of simulation for healthcare improvement*

The first aim of Study IV was to describe the experience of using simulation modeling for healthcare improvement. The focus of the study was *how, for whom, and when* simulation modeling can support healthcare improvement. A second aim was to explore the use of focus group discussion as a method for evaluating simulation modeling.

Two elements were critical in this research: the experience with a simulation model in a clinical setting, and the use of a simulation model by healthcare providers. The importance of collaborative modeling and user interaction in all steps of simulation modeling was strongly emphasized. Such a model should reflect the reality, the needs, and the visions of the organization it is designed for. As far as the workshop design, a common complaint by the providers was that there was insufficient time allotted to fully understand the model, to become familiar with it, and to begin testing ideas. However, the testing of ideas caused some participants to think more about their work routines. As a result, some new ideas were created and some old ideas were rejected.

Using content analysis of the focus group discussion data, the following categories were identified: (1) model user, (2) model assessment, (3) model design, (4) model use, (5) benefit and value, (6) improvement work, (7) workshop design and (8) workshop outcome.

Categories are presented in the domains of *how, for whom* and *when* simulation modeling can be used. *How* relates to topics that simulation modeling can facilitate with and for whom concerns potential users of the simulation model. *When* refers to situations where simulation modeling could be beneficial. Concerning the *how* domain, simulation modeling was seen as a decision support tool because of its visualization of problems and potential solutions. Furthermore, simulation modeling can test ideas and methods of working as well as communicate planned improvements and their effects. It was observed that simulation modeling could benefit healthcare improvement by depicting problems and solutions, by generating new ideas, by inspiring colleagues, and by informing management of improvements and processes.

*By understanding that anything may  
be suggested, we can test many different  
things and start thinking outside the box.  
It is so easy to get stuck in patterns.*

Nurse

In exploring the *for whom* domain, the focus group discussants pointed out that simulation modeling can be used both at the clinical level and at the management level. However, the user needs to have an interest in and familiarity with simulation modeling.

Specific potential users, such as schedulers, nurse managers and heads of department, were mentioned.

On the topic of the *when* domain, the focus group discussants stated that simulation modeling was useful in assisting in the development and testing of their ideas in the clinics and in showing their work and results to managers. They also commented that simulation modeling could present the financial aspects of changes and their budget implications.

*Simulation is a tool for information and education.*

Doctor

The data analysis of the follow-up interviews revealed the following new categories: the (9) holistic view, (10) learning, and (11) organization. Simulation modeling can facilitate learning, both for the individual and the organization, when showing the effects of improvements connected to the holistic view. It was also noted that simulation modeling can advance the holistic view and can support improvement work and learning. Finally, Study IV established that the focus group discussion was a useful method for learning about how the participants experienced the use of the simulation model.

## 7 DISCUSSION

To better manage the challenges of chronic care, this thesis presents approaches for managing complexity, empowering patients and supporting learning for patients and providers. This thesis explores various challenges in providing care for patients suffering from chronic rheumatoid arthritis, specifically the challenges that arise in the interaction between the patients and their health care providers (patient level) and in patients' access to care (clinical level).

The two approaches – the Feed Forward System (FFS) and simulation modeling – together constitute a proposed upgrade that can support chronic care re-design. Both approaches are based on Information and Communication Technology (ICT) and facilitate gathering and managing data that can create an understanding and learning opportunity in the transformation of data and information into knowledge and action and finally to improvement.

### 7.1 FEED FORWARD SYSTEMS

The purpose of the FFS is to influence the outcome of a process before it has been initiated. In the context of rheumatology it aims to capture data from patients to facilitate the patient-provider interaction. Patients can review their personal data which has been recently entered in the system and can compare these data to data from previous entries. In this way, patients can easily follow the progress of their disease and the results of their treatments over time (Study I).

The subjective experience of pain and/or the inability to perform daily routines is turned into explicit, concrete, and measurable data points. This can enable the transformation from tacit to explicit knowledge and may create learning opportunities for patients (Nonaka, 1994). When single data points are viewed in comparison, they can inform decisions about future actions to take (Study I). As Carina stated in *The Patient Journey*, she is an expert on her body and how her disease affects her body. With the use of the FFS she can translate that knowledge in a way that is accessible and assessable for her doctor.

Study I shows that by using the FFS, patients are better prepared, informed, and involved in their own care. FFS allows patients and providers to use the same data and language when making joint decisions on future treatment. In this way, patients and providers may become empowered as they meet in the shared decision making process. The interaction between patients and providers can be facilitated by the common language of the FFS that helps patients and providers to focus on what is important during the visit (Study I). The common language has previously been described as a vital part of the patient-provider interaction in chronic care (McCorkle et al., 2011).

The overview can also support communication on sensitive topics such as mental illness. Moreover, Study I showed that the FFS can help make patients become more active during their clinical visits. Such activity has been identified as an important factor in the patient–provider interaction (Pilnick and Dingwall, 2011). When patients become more involved and active this can enable self-management later on. For Carina, the overview has become a guide for her actions between her interactions with healthcare.

Monitoring the disease and regularly gathering data can help patients detect problems and act proactively (Bergman et al., 2011). By using the FFS from home, ICT can help patients communicate with healthcare by identifying when they are in need of care and eliminate unnecessary visits that could obstruct access for patients with a greater need of care.

Caring for patients with chronic diseases is a multifaceted task due to the vast amount of EHR information, treatment opportunities and combinations and patient preferences. The patient overview, which is generated by the FFS, is a record of what has been jointly decided during the clinical visits. It is compiled in a way that is useful to providers in the decision making process (Study I). The data in the FFS can support benchmarking between patient groups and clinics in improving quality of care (Study I). In particular, the overview illustrates how data can be transformed into information on treatment effects and then into knowledge on how to proceed based on the feedback.

Similar examples of the FFS and computerized questionnaires in the context of rheumatology have been reported elsewhere (Greenwood et al., 2006, Richter et al., 2008). The instant provision of results was appreciated (Greenwood et al., 2006) also valued in Study I. While some providers raised the concern that certain patient groups might find it difficult to use the FFS in Study I, findings from Greenwood et al. (2006) suggest that the use of the touch screen questionnaire can be acceptable regardless of the patients' age and previous experience with computer use (Greenwood et al., 2006). Similar to the findings of Study I, the instantly available data offers support for clinical decision making that can improve health care quality and support patient empowerment (Richter et al., 2008).

## **7.2 SIMULATION MODELING**

Study II suggests there are opportunities for simulation modeling to assist healthcare improvement in making informed decisions. This was reinforced in Study IV where focus group discussion participants saw the benefit of testing to see how changes can affect the whole. Also, Study III exemplifies how simulation modeling can support clinical process re-design when trying to improve access.

In a collaborative effort of mapping processes, gathering data, forming questions, modeling and testing changes in a virtual reality (as in Study II, Study III and Study IV) implicit knowledge and assumptions are made explicit. The simulation of models helps in the visualizing of interactions of processes and in the testing of different scenarios which can support informed decision making (Study II). Without risking the consequences of making changes and possible mistakes in real life, simulation modeling can support testing in a safe environment in order to explore different options before making decisions about which changes to implement.

Simulation modeling can be linked to healthcare improvement work when complemented by the PDSA cycle (Study II). The difficulties in planning and sustaining improvement work using the PDSA cycle (Baxley et al., 2011) may be alleviated by the use of the PSDSA model (Study II) (see Figure 9). The timing and placement of simulation modeling in the PDSA cycle was mentioned in Study IV, emphasizing the structure of the PSDSA model from Study II. Simulation modeling is suitable when initiating improvement work. It is in the start-up phase when planning different changes that simulation modeling can help refine the changes to actually be implemented. Healthcare improvement initiatives can be iteratively tested in silico instead of in reality, and launched when the model presents output that meets the desired goals and improvements (Study II).

The ability to test in safe environments, defined as “micro worlds”, has been proposed as an essential element in organizational learning (Senge, 1994). A similar concept called virtual worlds allow decision-makers to use a safe and low cost laboratory for testing and rehearsing (Sterman, 2006). Effective learning depends on instant feedback without time delays, which in turn can support change in mental models (Sterman, 2006). Learning opportunities and the generation of new insights from simulation modeling has previously been acknowledged as *intangible products* (Pidd, 2004a).

Simulation modeling is recognized as a way to capture complex relations within a system (Slovensky and Morin, 1997) also shown in Study II. Simulation modeling can advance understanding by displaying the cause and effect of changes in the healthcare context where many processes, stakeholders, decisions and systems interact, adding to the complexity of healthcare (Sterman, 2006, Bar-Yam, 2005, Eldabi, 2009, Slovensky and Morin, 1997). The possibility to view how changes cause effects in a larger context and over a longer time span, illustrates how data put into a model can be transformed into actionable knowledge. This knowledge may assist providers and managers in improving healthcare.

Simulation studies performed in the context of chronic care most often involves the System Dynamics method (Homer et al., 2007). Simulation research in rheumatology is scarce, but outpatient departments have been studied using simulation modeling quite frequently (Elkhuizen et al., 2007, Rohleder et al., 2007, Huarng and Lee, 1996, Chand et al., 2009). Study III showed that simulation modeling suits the challenges of rheumatology when trying to improve access to care. The use and capture of evidence from

clinical trials into the model to propose clinical re-design, demonstrates the power of simulation modeling in performing research. This is one of the factors contributing to the proposal of simulation modeling as the third branch of science after theory and experimentation (Pool, 1992).

Despite the many reported simulation modeling projects, little has been written about their real life implementation or value in improving healthcare (Brailsford et al., 2011, Fone et al., 2003). This aspect was obvious in Study II, where only 24% of the retrieved articles mentioned implementation or decision support experiences. Instead, articles of simulation modeling projects tend to end when the simulation model is completed, without any real change being effected (Study II). Study IV was intended to illustrate the use and potential value of simulation modeling at the clinical level.

This knowledge gap is acknowledged as one of the most important issues in the research on Operations Research (OR) in healthcare services (Brailsford et al., 2011, Eldabi, 2009). To resolve this issue, research focus has often been on the barriers of implementation of simulation modeling which has revealed these to include healthcare culture and incentives, costs of simulation software, and poor availability and quality of data (Brailsford, 2005, Eldabi, 2009).

### **7.3 FROM DATA TO DECISION**

The two approaches described above, FFS and simulation modeling, represent two different ways of transforming data into knowledge that can inform decisions. This movement is explained by the Data Information Knowledge Wisdom (DIKW) model. The model originates from the 1930s and was further developed by the systems theorist Russell Ackoff in 1989 (Rowley, 2007). The model has previously been applied within the areas of knowledge management, information management, information systems (Rowley, 2007) and in nursing informatics (Matney et al., 2011).

The components of the DIKW model starts with *data* that is the raw material and presentations of symbols (Fricke, 2009). *Information* represents processed, relevant or useful data (Fricke, 2009) and allows answers to questions of who, what, where and when (Rowley, 2007). The collection of information and understanding that allows instructions to be created represents *knowledge* (Fricke, 2009, Rowley, 2007). *Wisdom* is the least often defined or used part of the model (Fricke, 2009, Rowley, 2007). The meaning of wisdom varies and includes contextualizing information, knowing why, evaluating and understanding (Rowley 2007), applying know-how (Fricke, 2009), and experiences (Matney et al., 2011).

The DIKW model, applied to this thesis can be used to illustrate how data in the patient overview is transformed into knowledge. It can also show the transformation of information into knowledge when using simulation modeling. The combination of instant feedback, provided by the FFS and simulation modeling can contribute to informed decisions.

## 7.4 CHALLENGE MEETS UPGRADE

The developments in rheumatology as described in the introduction have created organizational challenges. With more treatment possibilities, more patients can be treated more effectively. Patients with a controlled disease activity still require surveillance of their heavy drug treatment. The volume and diversity of patients' needs pose challenges to the healthcare delivery system and to patient access.

Feed Forward Systems and simulation modeling represent an upgrade of how to manage the challenges inherent to rheumatology care. This is enabled through the shared features of FFS and simulation modeling. Both approaches share the *ability to transform data into information and knowledge* through the use of instant feedback. From data, gathered systematically over time using the FFS, patterns can be identified that provide *feedback in real time* and that can be used to inform the next action step. Instant feedback and real time data can help *render action into reality* (Neuhauser et al., 2011), which can be accomplished by the use of simulation modeling for providers and managers.

Another similarity concerns the *multiple stakeholders involved*. FFS is best used by patient and provider jointly, as shown in Study I. Simulation modeling can be used by the provider, who suggests an improvement for testing, by the manager who can make the decision to implement it, or by the providers who will implement the improvement in practice. FFS and simulation modeling form a *mutual communication platform* that creates a space for joint sharing of views. Feedback from the FFS and from simulation modeling can create *opportunities for self-correction* at an early stage in the process of either deciding on the next treatment step or making improvements to launch into reality.

## 7.5 METHODOLOGICAL CONSIDERATIONS

Qualitative and quantitative research methods have been used to fulfill the aim of this thesis. Data were collected by means of interviews and a focus group (Study I and Study IV), questionnaires (Study I), and simulation modeling (Study III). In quantitative research, the terms validity, reliability and generalizability are relevant. However, in qualitative research, these issues are addressed by the concept of trustworthiness, which includes credibility, transferability, dependability, and confirmability (Marshall and Rossman, 2006, Creswell and Creswell, 2007, Lincoln and Guba, 1985).

When constructing questionnaires, important factors to be considered are sampling, question design, reliability, and validity (Fowler, 2009). The questionnaire and interview guides in Study I were translated from Swedish to English, however without a back translation which is considered practice and important in maintaining reliability of the instrument. Reliability refers to the accuracy of the measuring instrument or procedure whereas validity concerns the degree to which a study accurately reflects or assesses what the researcher is attempting to measure (Robson, 2002). Instead of back

translation, the questionnaire in Study I was pilot tested to obtain useful information on wording, question design, question order, and scale, which potentially increased the reliability.

Study IV is limited by the fact that only one focus group discussion and two interviews were conducted. The workshop focus group method used to introduce simulation modeling to healthcare providers had certain limitations. Feedback from the focus group revealed, for example, that the lack of time resulted in inadequate understanding and application of the model. Also, the participants were new to simulation modeling as a method. The importance of developing and explaining the model's logic step-by-step and to respond to questions and problems (Pidd, 2004, Aharonson-Daniel et al., 1996, Alkaabi et al., 2006, Cochran and Bharti, 2006) is recognized. Study IV was a pilot study in the sense of exploring how focus group discussions could be used in studying the experience of using simulation models at the clinical level.

In performing a meta-analysis, there are many possible limitations to manage, for example, in the selection of databases, search terms, and selection criteria as well as in the interpretation of findings. Perspectives on the research context and culture where the researchers are situated can influence the terms and databases used in the literature search (Anagnostou et al., 2011). To deal with these matters the research team aimed for transparency of the entire research process. In addition, tasks that might be subject to interpretation were checked.

*Dependability* refers to consistency in the research process in terms of data collection and data analysis (Graneheim and Lundman, 2004). In Study I and Study IV, data were collected in similar ways for all participants. Since data collection periods were quite short in both studies, time or seasonal biases cannot be excluded. *Confirmability* refers to the corroboration of the findings. The research team performed data analysis jointly highlighting the topic of objectivity of the research process. The research team's efforts permitted a review of each other's work that confirmed evidence of similarities, identified differences, and led to new interpretations (Sandelowski, 1993, Graneheim and Lundman, 2004).

### 7.5.1 The simulation modeling journey

*All models are wrong but some are useful*  
George E P Box (Box and Draper, 1987)<sup>4</sup>

Study III provided challenges that are described further here. Of the several important steps in the simulation modeling project, I focus here on the steps for the *validation*, *verification* and *testing* of the model.

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<sup>4</sup> Page 74.



The intent of simulation modeling is not to reflect all aspects of reality since such a portrayal is neither possible nor desired (Pidd, 2004a, Gilbert and Troitzsch, 2005). Nevertheless, the verification, validation, and testing of models is of great importance (Gilbert and Troitzsch, 2005, Banks, 1998). Banks (1998) names this process VV&T (Verification, Validation, and Testing). Verification refers to the construction of the model in a reliable manner; validation refers to the construction of the model so that it reflects a real life system; and testing refers to the process of checking for errors and inconsistencies (Banks, 1998, Robinson, 2004, Gilbert and Troitzsch, 2005). To increase the chances of successful model implementation, model credibility is important. Such credibility includes model validity, stakeholder participation and the use of respectable methods and analysts (Steins et al., 2010).

Study III, which involved access to data from multiple sources, required close cooperation with healthcare providers, researchers, and modelers on the project team. This cooperative strategy aimed to verify and validate the simulation model created. The strategy also permitted constant checking of the model output against model input for various scenarios. The research team was thus able to test model data against real life data in an iterative testing sequence.

Despite the strong emphasis on the validation and verification process, this is the step most often lacking in the research articles of the meta-analysis (Study II). The consequences of the failure to verify and validate model data can, of course, lead to misleading model output. Hence, it is essential to eliminate errors early in the process (Banks, 1998). The built-in compiler in the simulation software detects coding errors whereas logical errors are detected when running the model and when presenting model output to researchers. Logical errors can be difficult to spot in complex models. The designed user interface helped us visualize and detect some errors in our model.

Study III revealed the difficulties in simulation modeling, with its VV&T processes. Further testing after the completion of Study III resulted in the development of a new version of the simulation model. The second version of the simulation model was developed as part of new clinic assessments aided by the availability of new data about the use of DAS28 over time (SRQ, 2011). The same staffing arrangement as in the first version was used and modifications of the second version of the model (see parameter table in Appendix) included four changes.

First, the clinic's open hours from those in the first model were changed. This change meant that the providers at the clinic would no longer initiate new visits in the 35 minutes before the clinic's closing time. The second change related to the intervals between nurse visits in the Open clinic that previously were set using a triangular distribution (2, 8, and 14 months). The new and constant value, which rheumatologists thought was more accurate, was set to 12 months. The third change involved the criterion for the Open-Tight clinic that is based on DAS28 and was changed from 3.2 to 3.4. The fourth change dealt with the fact that patients remain at the same time intervals, irrespective of the DAS28 progression in the Standard system. Thus, patients whose condi-

tion deteriorates, in reality begin at step one in the time interval series that controls the time between visits.

The second version of the model simulated twelve years, with a warm-up time of seven years that was excluded from the analysis. The warm-up time was chosen based on when resource utilization in the Standard system reached a steady state. In the output analysis, the steady state of the model was defined as the point when the average resource utilization in the Standard setting does not change more than 1% per year. The new results are presented in Table 5.

Results from the developed model show that resource utilization is lower in both systems (Standard and Open-Tight). Waiting times for the initial visit are similar to the first model. However, for follow up visits, the waiting time is longer in the Standard system and lower in the Open-Tight system. Costs are lower in the Open-Tight system (as revealed in Study III) because, as expected, the resource utilization is lower and the doctors and nurses share the work load.

Second version of model	Standard	Open-Tight
Resource utilization (mean)	94.1%	88.3% (MD) 74.6 % (RN)
Waiting time in days (mean)	IV=0.1 FV=44	IV=1.0 FV MD=11.6 FV RN=0.8
Costs in 1000 SEK (total)	11 188	7 467

**Table 5. Summarized results from the revised version of the model in Study III. The simulation includes holiday schedules. IV = Initial Visit, FV = Follow-up visit, MD = Medical Doctor, RN = Registered Nurse.**

The experience of working with the simulation model used in Study III has resulted in the development of a business model useful for future simulation projects. The business model is based on the experience of the research team and the literature, mainly the Soft Systems Methodology (SSM), which Peter Checkland originally developed (Checkland, 1981). The core features of this business model are joint workshops and meetings with organization representatives that develop an understanding of challenges, questions, expectations, data, processes, and delivery formats. These features will be used in the planning, execution, implementation, and evaluation of the simulation model in future projects.

## **8 CONCLUSIONS**

Feed Forward Systems and simulation modeling represent an upgrade of how to manage the challenges inherent to rheumatology care. The FFS encourages patient empowerment, self-management, shared decision making and support learning for patients and providers alike. Simulation modeling is an approach to managing complex problems and facilitating learning for providers and managers.

This is enabled through the shared features of FFS and simulation modeling: (1) transformation of data into knowledge, (2) a mutual communication platform for multiple stakeholder involvement, (3) provision of real time feedback that enables action in clinical practice, and (4) self-correction that generates learning opportunities.

### **8.1 IMPLICATIONS FOR PATIENTS AND CLINICS**

Beginning at the patient level, patients and providers can use a common language offered by the FFS. This allows patients to be more involved in and informed about their care. The patient overview supports the providers in making informed decisions on future treatment.

At the clinical level, simulation modeling can be used as a tool for improvement when testing the effects of rheumatology care process re-designs. Simulation modeling can also support improvement by visualizing the effects of planned changes, communicating these changes to management, and engaging healthcare staff to explore and test innovative solutions. In other words, the introduction of the FFS and simulation modeling has the potential to help providers and patients to change the healthcare system from within.

### **8.2 FUTURE RESEARCH**

Several ideas and questions have emerged during this journey of exploration and some areas where research opportunities have been identified are the following:

- The effect of simulation modeling in a setting where simulation modeling has been used for learning
- The effects of using FFS and simulation modeling in other chronic care settings
- The impact of FFS on patients' health outcomes
- The implementation aspects of FFS and of simulation modeling
- Developing coaching and simulation as a part of healthcare improvement

In summary, the upgrade proposed in this thesis need to be continually developed through practice and research if we are to manage the challenges of chronic care to match the needs of patients like Carina.

## 9 ACKNOWLEDGEMENTS

*The goal is the journey*

I am very grateful for this journey that has given me new friends and colleagues, many new insights, and that has taken me to so many exciting places. I have had the opportunity to watch healthcare up close and to experience the daily processes of rheumatology care. I have met many amazingly dedicated people – healthcare providers, patients, researchers and enthusiasts, all determined to make a difference. I have read, learnt, tested, taught and even created a movie. All these experiences have made my journey an incredible one.

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# 11 APPENDIX

## 11.1 STUDY I

### 11.1.1 Patient questionnaire Swedish settings

Denna enkät är framtagen för att fånga upp patienters åsikter om RA-registret för att på så sätt kunna förbättra registret för användarna. Med termen system avses RA-registret.

1. **Hur är ditt helhetsintryck av systemet (RA-registret)?** (Ringa in det alternativ som passar bäst)

Mycket bra   Bra   Medel   Dåligt   Mycket dåligt

Kommentar: \_\_\_\_\_

---

2. **Var systemet lätt eller svårt att förstå?** (Ringa in det alternativ som passar bäst)

Mycket lätt   Lätt   Medel   Svårt   Mycket svårt

Kommentar: \_\_\_\_\_

---

3. **Var det lätt eller svårt att förstå hur du skulle gå vidare i systemets olika delar?** (Ringa in det alternativ som passar bäst)

Mycket lätt   Lätt   Medel   Svårt   Mycket svårt

Kommentar: \_\_\_\_\_

---

4. **Skulle du uppskatta möjligheten att kunna registrera dina data hemifrån alt från jobbet?** (Ringa in det alternativ som passar bäst)

Ja   Nej   Har ej tillgång till dator

Kommentar: \_\_\_\_\_

---

5. **Upplivede du något/några problem vid användandet av systemet?** (Ringa in det alternativ som passar bäst)

Ja   Nej

Om du upplivede några problem, vilket/vilka var det? \_\_\_\_\_

---

**6. Vill du registrera något annat än det som systemet erbjuder?**  
(Ringa in det alternativ som passar bäst)

Ja

Nej

Om ja, vad vill du i så fall registrera? \_\_\_\_\_

---

**7. Vill du registrera på något annat sätt än det som systemet erbjuder?**  
(Ringa in det alternativ som passar bäst)

Ja

Nej

Om ja, hur vill du i så fall registrera? \_\_\_\_\_

---

**8. Är diagrammen lätta eller svåra att tolka?**  
(Ringa in det alternativ som passar bäst)

Mycket lätt    Lätt    Medel    Svårt    Mycket svårt

Kommentar: \_\_\_\_\_

---

**9. Vilka fördelar har systemet?**

» \_\_\_\_\_  
» \_\_\_\_\_  
» \_\_\_\_\_

**10. Vilka nackdelar har systemet?**

» \_\_\_\_\_  
» \_\_\_\_\_  
» \_\_\_\_\_

**11. Är du van vid att använda datorer?**  
(Ringa in det alternativ som passar bäst)

Mycket    Medel    Lite    Inte alls

**12. Vilket år är du född?** \_\_\_\_\_

*Tack för din medverkan!*

### 11.1.2 Patient questionnaire for U.S. setting

*Questionnaire* (Please mark the choice that corresponds with your opinion.)

**1. What was your overall impression of the computer based Health Survey?**

Excellent      Very Good      Good      Fair      Poor

**2. Was the Health Survey easy or difficult to understand?**

Very Easy      Easy      Ok      Difficult      Very Difficult

**3. Was it easy or difficult to understand how to move forward in the Health Survey?**

Very Easy      Easy      Ok      Difficult      Very Difficult

**4. Would you like the chance to complete the Health Survey prior to your appointment using your home or work computer?**

Yes      No      Do not have access to a computer

**5. Did you experience any problems completing the Health Survey process?**

Yes      No

If yes, please define the problem: \_\_\_\_\_

\_\_\_\_\_

**6. Is there other information that you think the Health Survey should ask about?**

Yes      No

If yes, please describe the information: \_\_\_\_\_

\_\_\_\_\_

**7. Would you like to be able to complete the Health Survey in any other way (than by computer?)**

Yes      No

If yes, please list options: \_\_\_\_\_

\_\_\_\_\_

**8. Would you like to complete the Health Survey before your appointment using the internet?**

Yes      No



**9. How familiar are you with using computers?**

Very Familiar    Familiar    Not Familiar

**10. Please list advantages and disadvantages of the system**

Advantages

- \* \_\_\_\_\_
- \* \_\_\_\_\_
- \* \_\_\_\_\_
- \* \_\_\_\_\_

Disadvantages

- \* \_\_\_\_\_
- \* \_\_\_\_\_
- \* \_\_\_\_\_
- \* \_\_\_\_\_

**Comments:**

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**Demographic Information:**

Age \_\_\_\_\_

**Gender: Female                      Male**

*(Please circle one)*

**Occupation** \_\_\_\_\_

*Thank you for your participation!*

**11.1.3 Patient Interview guide, Swedish settings**

1. Hur uppfattar du läkarens åsikt om systemet?
2. Hur påverkar systemet läkarbesöken? Underlättar de eller ej?
3. Tror du systemet kan påverka kontakten mellan dig och läkaren?

**11.1.4 Provider Interview guide, Swedish settings**

1. Hur länge har du arbetat med RA-registret?
2. Har systemet påverkat dina arbetsrutiner? Om ja i så fall hur?
3. Är arbetet med systemet värt besväret?

4. Hur påverkar systemet besöksrutinen?
5. Vad tror du det finns för långsiktiga effekter av systemet?
6. Vad tror du skulle ske om alla patienter använde sig av systemet?
7. Kan du tänka dig någon situation där RA-registret inte ska användas?
8. Vad gör du om RA-registret inte fungerar? Hur påverkar detta ditt arbete?
9. Finns det något i RA-registret som du skulle vilja ändra på?
10. Känns systemet säkert?
11. Hur uppfattar du patienternas åsikt om systemet?
12. Tror du registreringen kan påverkas om patienten registrerar hemifrån?
13. Vilka fördelar har systemet?
14. Vilka nackdelar har systemet?

#### **11.1.5 Patient Interview guide, U.S. setting**

1. What do you think was the provider's opinion of the computer-based Health Survey?
2. How did the computer-based Health Survey affect your visit? Is it different from other visits you have experienced?
3. What influence or impact do you think that the computer-based Health Survey had on the interaction between you and your provider?
4. Did your provider show you the answers to your Health Survey? If yes, was it helpful?
5. Did you find the diagrams and results easy or difficult to interpret?

#### **11.1.6 Provider Interview guide, U.S. setting**

1. What is your occupation?
2. Do you use the system in your daily work?
3. For how long have you worked with the system?
4. Is the work with the system "worth the effort?"
5. In your opinion, what are the long term effects of the system?

6. Is there any situation where the system cannot be used?
7. Is there anything in the system that you would like to change?
8. What is your impression of the patient's opinion of the system?
9. What advantages does the system possess?
10. What disadvantages does the system possess?

## 11.2 STUDY III

Parameter table used in Study III with updated simulation setting for the second version of the simulation model. Parameters in *italics* represent change made from the initial settings.

Category	Parameter	Parameter description	Default set value(s) Differences in italic	
			Initial setting	Second version setting
Patients and resources	Patient referral inflow	Average patient referral inflow per day	4	4
	Number of available examination rooms	Available examination rooms in the outpatient department	10	10
	Number of nurses in service	During regular working weeks, summer and winter holiday period	0 in Standard, 3 in OT. During holidays, 1 in OT.	0 in Standard, 3 in OT. During holidays, 1 in OT.
	Number of doctors in service	During regular working weeks, summer and winter holiday period	8 in Standard, 5 in OT. During holidays, 2 in Standard and 1 in OT.	8 in Standard, 5 in OT. During holidays, 2 in Standard and 1 in OT.
	Working hours for the clinic, summer and Christmas schedule	Open hours for the clinic.	8:30-12:00 pm 1:00- 4:00 am (Mon-Fri). Summer (July 1st to August 15th) and Christmas (December 24th to January 7th)	8:30-12:00 pm 1:00- 4:00 am (Mon-Fri). Summer (July 1st to August 15th) and Christmas (December 24th to January 7th)
	Resource cost	Given in units per hour	Doctor 300 SEK/h Nurse 150 SEK/h Room 50 SEK/h	Doctor 300 SEK/h Nurse 150 SEK/h Room 50 SEK/h
Doctor time and priority	Doctor appointment duration	Defined as (min, avg, max), gives samples from uniform or triangular distribution	(30, -, 45) min	(30, -, 45) min
	Doctor appointment priority	Possible to prioritize for example Initial visits higher than Follow-up visits	No priority distinction between Initial visits and Follow-up visits	No priority distinction between Initial visits and Follow-up visits
	Time between doctor visits in Tight clinic	Defined as (min, avg, max), gives samples from uniform or triangular distribution	(1, 2.5, 4) months	(1, 2.5, 4) months

Open and Tight system settings	Time between doctor visits in Open Tight Special Clinic (OTC)	Defined as (min, avg, max), gives samples from uniform or triangular distribution	(3, 6, 12) months	(3, 6, 12) months
	Time between nurse visits in Open Clinic	Defined as (min, avg, max), gives samples from uniform or triangular distribution	(2, 8, 14) months	(12, 12, 12) months
	Health improvement between visits	Measured by DAS28, defined as (min, avg, max), gives samples from uniform or triangular distribution	(-4, 0, 4)	(-4, 0, 4)
	Criterion for discharge, $C_D$	Related to DAS28	2.6	2.6
	Criterion for Open or Tight, $C_{OT}$	Related to DAS28	3.2	3.4
	Exception to $C_{OT}$	Percentage of Open clinic patients sent to Tight and vice versa	5% / 15%	5% / 15%
	Probability to initial visit	Percentage of patients from referral to initial visit	82%	82%
	Probability to follow-up visit	Percentage of patients from initial visit called to follow-up visit	65%	65%
Simulation settings	Simulation time	Years to simulate, default setting, (range)	10 yrs (1-20)	8 yrs (1-20)
	Warm-up time	Years before the system is considered to be "warm" and results are analyzed, default setting (range)	2 yrs (0-5)	2 yrs (0-5)

## 11.3 STUDY IV

### 11.3.1 Focus group questions

- **Introduktion**
  - Berätta kort om er upplevelse av att arbeta med en simuleringsmodell
  - Berätta kort om hur det gick att arbeta med era frågor och arbete två och två
  - Var resultaten som ni fick fram förväntade eller såg ni något oväntat?
  - Till vilka frågor passar inte simulering?
  - Vad ser ni för fördelar med att arbeta med en simuleringsmodell jämfört med att testa i praktiken?
  - Vad ser ni för nackdelar med att arbeta med en simuleringsmodell jämfört med att testa i praktiken?
  - Upplevde ni några insikter eller aha-upplevelser under simuleringens gång?
  
- **Var och när**
  - Vilka frågor och områden tycker ni simulering kan passa bäst till?
  - Kan förbättringsarbete vara ett område och i så fall hur?
  - Vilka kan vara potentiella användare till simulering i hälso- och sjukvården?
  
- **Simulering och förbättringsarbete**
  - Hur skulle simulering kunna hjälpa er i ert förbättringsarbete?
  - Har denna workshop hjälpt er framåt på något sätt?
  - Kan simulering hjälpa er i ert framtida förbättringsarbete?
  
- **Värde och trovärdighet**
  - Kände ni att ni kunde lita på simuleringsmodellen?
  - Kände ni att simuleringsmodellen återspeglade er klinik och dess processer?
  - Beskriv/fundera öppet kring det potentiella värdet med simulering

### 11.3.2 Interview questions

1. Hur är läget generellt sett på kliniken, hur ser er arbetsbelastning ut nu och vid tillfället för workshoppen
2. Beskriv dina tankar efter workshoppen.
3. Har du och dina kollegor diskuterat workshoppen och simulering något efteråt?
  - a. Om ja/nej, vad eller varför inte tror du?
4. Har workshoppen lett till nya idéer, diskussioner på kliniken eller insikter/reflektioner?
  - a. Om ja/nej, vad eller varför inte tror du?
5. Har ni valt att göra något annorlunda efter workshoppen?
6. Om du får tänka dig en optimal simuleringsmodell, vad skulle den innehålla?
7. Hur skulle den kunna hjälpa dig i ditt arbete?
8. Vilka kopplingar ser du mellan simulering och förbättringsarbete?
9. Hur tror du att simulering kan bidra till lärande (individ och organisation)?
10. Hur skulle du berätta om simulering för någon som inte vet något om ämnet och som inte var med på workshoppen?