



UNIVERSITY  
OF SKÖVDE

DOCTORAL DISSERTATION

# BRIDGING THE INFORMATION GAP

Supporting Evidence-Based Medicine and Shared Decision-  
Making through Information Systems

**HANIFE REXHEPI**  
*Informatics*



BRIDGING THE INFORMATION  
GAP

Supporting Evidence-Based Medicine and Shared Decision-Making through Information  
Systems



DOCTORAL DISSERTATION

# BRIDGING THE INFORMATION GAP

Supporting Evidence-Based Medicine and Shared Decision-Making through Information Systems

HANIFE REXHEPI

*Informatics*



UNIVERSITY  
OF SKÖVDE

Hanife Rexhepi, 2018

*Title:* BRIDGING THE INFORMATION GAP

Supporting Evidence-Based Medicine and Shared Decision-Making through Information Systems

University of Skövde 2018, Sweden

[www.his.se](http://www.his.se)

*Printer:* BrandFactory AB, Göteborg

ISBN 978-91-984187-1-2  
Dissertation Series, No. 19 (2018)

*For my parents, Isme and Izet who raised me to love learning and inspired me to  
seek higher education*



## ABSTRACT

Practicing evidence-based medicine (EBM) and shared decision-making (SDM) along the patient process is important in today's healthcare environment, as these models of care offer a way to improve quality and safety of care, patient satisfaction, and reduce costs. EBM is the conscientious and judicious use of current best medical evidence in conjunction with clinical expertise. It also includes taking into account patient values and preferences to guide decisions about the care of individual patients. SDM offers a process that guides how a healthcare professional (e.g., a physician or a nurse) and a patient jointly can participate in a decision after incorporating the body of evidence (the options, benefits and harms) and considering the patient's values and preferences.

The degree to which healthcare professionals can practice EBM and SDM is dependent upon the availability of information about the patient (e.g., medical diagnosis, therapies as well as laboratory and administrative information) and medical evidence (such as medical guidelines). Patient information is a prerequisite for making decisions about the care of individual patients and it is evidence-based medical knowledge, clinical expertise as well as patient values and preferences that guide these decisions. Moreover, for patients to be able to communicate values and preferences as well as participate effectively in their own care, they need to have a basic understanding of their condition and treatment options, and the consequences of each. Hence, they need access to the same information streams—in “patient-accessible” form—as their physician(s) and care team throughout their journey (process) in healthcare. However, making the right decisions about the care of individual patients at the right time and place is a challenge for healthcare professionals. Due to interoperability issues, existing information systems do not support a seamless flow of patient information along the patient process. Healthcare professionals are therefore unable to easily access up-to-date information about the patient at the right time and place. The situation is complicated further by the fragmentation of medical evidence in different repositories and its presentation by diverse providers, each with unique ideas about how information should be organized and how search engines should function. Limited or no access to relevant patient information and the best medical evidence about the benefits and risks of treatment options can result in flawed decisions and, more seriously, the suffering of patients. The situation also affects SDM. If patients are not informed about their health condition, treatment options, benefits and risks or not given high quality information, e.g., because healthcare professionals do not have access to the best evidence, patients will be unable to assess ‘what it is important to them’, or they will make

inadequate decisions about key issues. Consequently, it is almost impossible to practice EBM and SDM in everyday clinical care.

For EBM and SDM to serve their purpose, healthcare professionals and patients need information systems that provide quick and trouble-free access to all-round information. They also need information systems that can influence the patient/physician relationship and facilitate their pursuance of shared goals in the healthcare process, taking into account both illness and personal experience. Hence, based on a qualitative approach, this thesis proposes recommendations regarding the redesign of future healthcare information systems in ways that will facilitate, rather than hinder, the access to relevant information. One important recommendation identified is that future healthcare information systems must support the core characteristics of EBM and SDM, in an integrated manner, and using the one without the other is not enough. However, such support requires the adoption of a process view on information system development based on the patient's process. A process-oriented approach with supporting information systems is thus vital for the support of an evidence-based practice where the patient is an important and active collaborator. Moreover, the challenges identified with regard to information system support are not exclusively technical. Organizational culture, and the attitudes of healthcare professionals to patient involvement are some of the biggest challenges facing healthcare organizations.

## SAMMANFATTNING

Målet för hälso- och sjukvården är en god hälsa och en vård på lika villkor för hela befolkningen. Tillgången till patientinformation och medicinsk kunskap samt patientens delaktighet i den egna vården är därför en nyckelfråga för att skapa förutsättningar för en sådan vård. Beslut om vård och behandling skall så långt som möjligt baseras på bästa tillgängliga kunskap och patientens önskemål. Evidensbaserad medicin (EBM) innebär att den professionelle väger samman sin expertis med bästa tillgängliga kunskap, patientens situation, erfarenheter och önskemål vid beslut om insatser. Shared decision-making (SDM) är ett arbetssätt för att öka patientens delaktighet i beslut som rör deras hälsa och vård. Behandlingsresultatet blir bättre om patienten är delaktig i vården. Det är dessutom lagstadgat att patienten och de närstående ska vara delaktiga i sin vård och behandling. För att möjliggöra delaktighet krävs det att de får god och anpassad information om sin vård och behandling, men också information om eventuella risker.

Att basera beslut på vetenskap och beprövade erfarenheter har dock visat sig vara svårt för vårdpersonalen. Det beror bland annat på att de har begränsad tillgång till informationssystem som stödjer en snabb och enkel tillgång till patientinformation över organisationsgränserna. Ytterligare en anledning är att befintliga informationssystem inte stödjer vårdpersonalen till att enkelt hitta, sovra och använda vetenskaplig kunskap i vården. Av den anledningen upplever vårdpersonalen svårigheter att vid sidan av patientarbetet hålla sig à jour med den ständigt växande vetenskapliga litteraturen, följa nya rön samt värdera resultatens tillförlitlighet och tillämpbarhet. Patientens elektroniska tillgång till den egna informationen är också begränsad, vilket påverkar deras möjlighet att aktivt delta i sin vård och påverka den utifrån sin roll. Utöandet av EBM och SDM försvåras följaktligen av avsaknad av patientinformation och medicinsk kunskap.

För att EBM och SDM ska kunna tjäna sitt syfte behöver vårdpersonal och patienter informationssystem som ger snabb och problemfri tillgång till allsidig information. De behöver också informationssystem som underlättar kommunikationen och samarbetet mot gemensamma mål genom hela patientprocessen. Genom att kombinera existerande forskning inom processorientering, EBM och SDM, har ett antal rekommendationer för utveckling av vårdens framtida informationssystem identifierats. En av dessa rekommendationer är att framtida informationssystem måste stödja samtliga kärnelement av EBM och SDM på ett integrerat sätt. Ett sådant stöd kräver dock att systemutvecklingen utgår från ett processorienterat synsätt där patientens process är i fokus. Vidare har denna forskning påvisat att de tekniska utmaningarna med vårdens

framtida informationssystem inte är de enda utmaningar som hälso-och sjukvården står inför. Den organisatoriska kulturen och vårdpersonalens syn på patientens delaktighet i den egna vården är några av de största utmaningarna som svensk hälso- och sjukvård står inför.

# PUBLICATIONS

Publications written as part of this thesis are listed below. Papers 2 and 4 were published prior to name change. Papers 3 and 5 have received the best paper award.

## PUBLICATIONS WITH HIGH RELEVANCE

1. Rexhepi, H., Åhlfeldt, R. M., & Persson, A. (2015). Towards effective and efficient information system support for healthcare processes: A healthcare practitioner perspective. *IADIS International Journal on Computer Science and Information System*, 10(1), 80-96.

I am the main author of this paper. For the purpose of this paper, I have had the sole responsibility to (1) analyze the data from the interviews and observations, and (2) write the paper. Feedback has been given by the co-authors. The process support system presented in this paper has been developed together with the co-authors.

2. Krasniqi, H., & Persson, A. (2012). Web-based Knowledge Portals in Swedish Healthcare-Overview and Challenges. *In Scandinavian Conference on Health Informatics 2012; October 2-3; Linköping; Sweden* (No. 070, pp. 9-12). Linköping University Electronic Press.

I am the main author of this paper. For the purpose of this paper, I have had the sole responsibility for (1) analyzing the knowledge portals and carrying out the interviews, (2) analyzing the empirical data and (3) writing the paper. Feedback has been given by the co-author.

3. Rexhepi, H., & Persson, A. (2017). Challenges to Implementing IT Support for Evidence Based Practice Among Nurses and Assistant Nurses: A Qualitative Study. *Journal of Electronic Commerce in Organizations (JECO)*, 15(2), 61-76.

I am the main author of this paper. For the purpose of this paper, I have had the sole responsibility for (1) analyzing the IT-based knowledge repositories and carrying out the interviews, (2) analyzing the empirical data and (3) writing the paper. Feedback has been given by the co-author. *This paper has been given the Outstanding Paper Award and has been invited to be submitted as a reworked full paper to a special issue of Journal of Electronic Commerce in Organizations (JECO) 15(2).*

4. Krasniqi, H., Åhlfeldt, R. M., & Persson, A. (2011). Patients' experiences of communicating with healthcare - an information exchange perspective. *In 15th International Symposium on Health Information Management Research (ISHIMR 2011)* (pp. 241-251). University of Zurich.

I am the main author of this paper. I have had the sole responsibility of analyzing and summarizing the collected data. I have also had the sole responsibility of writing the paper. Feedback has been given by the co-authors.

5. Rexhepi, H., Åhlfeldt, R. M., Cajander, Å., & Huvila, I. (2016). Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health informatics journal*, 1-10. 1460458216658778.

I am the main author of this paper. All authors of this paper contributed equally in the analysis of the data and had a joint responsibility for writing the paper. However, I have had the overall responsibility for writing the results section. *This paper has been awarded as the best Paper submitted to the International Symposium on Health Information Management Research 2015. It has also been invited to be submitted as a rework special issue article to the Health Informatics Journal 2016.*

6. Åhlfeldt, R. M., Persson, A., Rexhepi, H., & Wåhlander, K. (2016). Supporting active patient and health care collaboration: A prototype for future health care information systems. *Health informatics journal*, 22(4), 839-853.

I am an important contributor to this paper. I have had the sole responsibility of conducting the literature review. Moreover, together with the co-authors, I have been involved in developing the process support system presented in this paper. The paper has been co-written, meaning that the authors have had a joint responsibility for the writing.

7. Rexhepi, H. (2015). Process-oriented information systems: A key to evidence based medicine. *IADIS International Journal on Computer Science and Information System*, 10(1), 64-79.

I am the sole author of this paper. It has also been my sole responsibility to further develop the process support system so that it fulfills the purpose of this research.

8. Rexhepi, H. (2016). Information Systems for the Practice of Evidence-Based Medicine and Shared Decision Making. *In 10th European Conference on Information Systems Management: ECISM 2016* (p. 258). (pp. 258-270).

I am the sole author of this paper. It has also been my sole responsibility to further develop the process support system so that it shows how EBM and SDM can be supported.

# CONTENTS

1. INTRODUCTION .....	1
1.1 Research problem .....	3
1.2 Research question.....	9
1.3 Delimitations .....	10
1.4 Thesis structure .....	11
2. THEORETICAL BACKGROUND.....	15
2.1 Evidence-based medicine and shared decision-making .....	15
2.1.1 The connection between evidence-based medicine and shared decision-making .....	23
2.2 Process orientation – an overview.....	24
2.2.1 Process orientation in healthcare.....	25
2.2.2 The patient process.....	26
2.3 Knowledge management in evidence-based healthcare.....	28
2.3.1 Basic concepts of knowledge management.....	29
2.3.2 Knowledge management .....	32
2.4 Knowledge management and organizational processes .....	35
2.5 Other related research.....	38
2.6 An analysis of the relationship between EMB, SDM, process orientation and knowledge management .....	44
3. METHODOLOGY .....	51
3.1 Research paradigm and research approach .....	51
3.1.1 Case study research .....	53
3.2 Research process.....	53
3.2.1 Literature review.....	55
3.2.2 Case studies .....	57
3.2.3 Qualitative analysis in the case studies .....	67
3.3 Trustworthiness of the research .....	69
4. RESULTS .....	75
4.1 <b>RQ 1A:</b> What challenges are healthcare professionals facing? .....	76
4.1.1 <b>Paper 1:</b> Towards effective and efficient information system support for healthcare processes: A healthcare practitioner perspective .....	76
4.1.2 <b>Paper 2:</b> Web-based knowledge portals in Swedish-healthcare – Overview and challenges.....	79
4.1.3 <b>Paper 3:</b> Challenges to implementing IT support for evidence based practice among nurses and assistant nurses: A qualitative study.....	79
4.2 <b>RQ 1B:</b> What challenges are patients experiencing with regard to accessing information about their own care and engaging in decisions?.....	80
4.2.1 <b>Paper 4:</b> Patients´ experiences of communicating with healthcare – An information exchange perspective .....	81
4.2.2 <b>Paper 5:</b> Cancer patients´ attitudes and experiences of online access to their electronic medical records: A qualitative study .....	82

4.3	<b>RQ 1C:</b> What recommendations can be identified for the development of future information systems .....	83
4.3.1	<b>Paper 6:</b> Supporting active patient and healthCare collaboration: A prototype for future healthCare information systems .....	83
4.3.2	<b>Paper 7:</b> Process-oriented information systems – A key to evidence based medicine .....	84
4.3.3	<b>Paper 8:</b> Information systems for the practice of evidence based medicine and shared decision making .....	85
5.	<b>SYNTHESIZED RESULTS</b> .....	91
5.1	Supporting the core characteristics of EMB and SDM in an integrated manner .....	92
5.1.1	A process-oriented approach .....	93
5.1.2	From repositories of health information to interactive tools .....	93
5.1.3	Current and relevant information integrated into the current context .....	97
5.1.4	Enable a combination of access, communication, creation and capture of medical knowledge.....	99
6.	<b>CONTRIBUTIONS AND FUTURE WORK</b> .....	105
6.1	Contributions to research and practice .....	105
6.2	Future work.....	108
7.	<b>APPENDIX</b> .....	111
	<b>A</b> Interview guide – case study one.....	111
	<b>B</b> Interview guide – case study two .....	114
	<b>C</b> Interview guide – case study three.....	117
8.	<b>REFERENCES</b> .....	125
9.	<b>THE PAPERS</b> .....	141







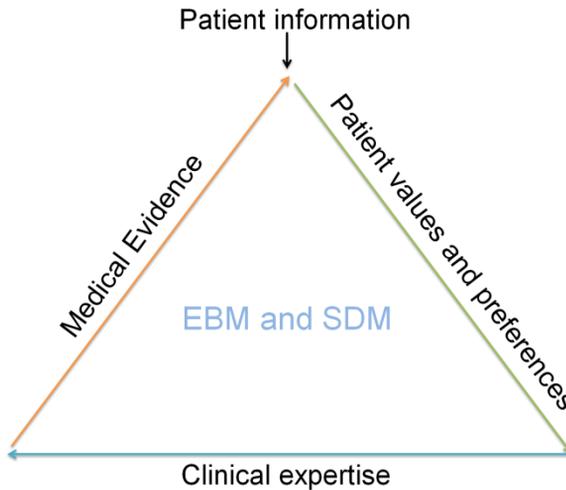
# CHAPTER 1

## INTRODUCTION

Practicing evidence-based medicine (EBM) and shared decision-making (SDM) along the patient process is important in today's healthcare environment, as these models of care have the potential to improve the quality and safety of care. EBM is the conscientious and judicious use of current best medical evidence in conjunction with clinical expertise as well as patient values and preferences, in order to guide decisions about the care of individual patients (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996; Straus, 2010). These decisions can vary from simple ones (e.g., whether to prescribe an antibiotic for a patient with a sore throat that presents a red larynx, but no suppuration) to more complex decisions which involve more than one reasonable option (e.g., the patient has been diagnosed with Acoustic Neuroma and decisions on tests and treatment options available have to be made). Clinical expertise refers to healthcare professionals' cumulative experience, education and clinical skills that an individual acquires through clinical experience and clinical practice. The patient's own personal preferences and unique concerns, expectations, and values are brought to the patient encounter/patient meeting and must be considered. The best medical evidence, also called medical knowledge, is usually found in medical guidelines, systematic reviews and other clinically relevant medical research that has been conducted using sound methodology (Sackett et al., 1996).

Evidence-based medical knowledge does not, by itself, constitute the basis for making a decision; however, it can help support a healthcare professional in the decision-making process. There is sometimes an incorrect assumption that EBM refers to the use of research and clinical expertise alone. This has led to a common criticism that EBM ignores patients' values and preferences and promotes a cookbook—explicitly not its intention. Medical evidence, whether strong or weak, is never a sufficient basis for making a decision; a patient's values and preferences must balance this evidence. As emphasized by Straus (2010) “each patient brings to a clinical encounter unique preferences, concerns and expectations which must be integrated into clinical decisions if they are to serve the patient”. Hence, shared decision-making is central to evidence-based medicine and good patient care (Kambhampati, Ashvetiya, Stone, Blumenthal, & Martin, 2016). Hoffmann, Montori, and Del Mar (2014) define SDM as a process where a healthcare professional (e.g., a physician or nurse) and a patient jointly discuss the medical evidence, the options available, their benefits and harms, while considering the patient's condition and incorporating the patient's values, preferences and

circumstances into the decision-making. They further argue that medicine cannot, and should not, be practiced without up-to date evidence. Nor can medicine be practiced without knowing and respecting the informed preferences of patients. Hence, patient information (e.g., medical diagnosis, laboratory tests, diagnostic imaging reports, treatments, therapies, medical list, allergies, x-rays and administrative information such as appointments) is a prerequisite for making decisions about the care of individual patients and it is evidence-based medical knowledge, clinical expertise as well as patient values and preferences that guide these decisions (see figure 1). The full integration of these components into healthcare decisions enhances the opportunity for improved quality and safety of care.



**Figure 1:** *The core characteristics of EBM and SDM.*

The degree to which EBM and SDM can be practiced is thus dependent upon the availability of patient information (such as diagnosis, treatments, therapies, medication lists, etc.) and medical knowledge (such as medical guidelines) along the patient process. However, for patients to be able to communicate values, preferences and participate effectively in their healthcare, they need to have a basic understanding of their health condition, treatment options, and the consequences of each (Thom et al., 2016). Hence, they need access to the same information streams—in “patient-accessible” form—as their physician(s) and care team, throughout their journey (process) in healthcare (Reid, Compton, Grossman, & Fanjiang, 2005). A patient’s right to information and participation in decisions involving their healthcare is also emphasized in the Swedish Patient Act (SFS, 2014:821). The Patient Act states that healthcare professionals have a statutory responsibility to involve patients in making decisions about their own care, inform them about their health condition and treatment options, as well as the risks and benefits of treatments. The law also emphasizes that the patient should be provided with information in an understandable format, meaning that the information must be adapted to the patient’s particular circumstances and capabilities

(SFS, 2014:821). Hence, it is not an option for healthcare professionals in Sweden to not involve patients in their own healthcare, or to not inform them about their health condition and treatment options.

Furthermore, information systems play a crucial role in the practice of EBM and SDM by supporting the availability to information and the interaction between patients and their healthcare professionals so that decisions are informed by the best available medical evidence and reflect the individual patient's well-considered goals and concerns (Fowler, Levin, & Sepucha, 2011). However, current solutions of information systems are far from this perspective for various reasons. One of these reasons is the lack of efficient and comprehensive information systems throughout the healthcare delivery system. In fact, the design and implementation of information systems in healthcare have not yet achieved their potential to impact the delivery of healthcare services. During 2005 and 2006, The National Strategy for eHealth was developed, at the request of the Swedish Government, after national consensus was reached on the need to develop and introduce nationally coordinated information system support and more integrated information management. The objective was to improve and renew health and social care by putting the needs of the patient first (Swedish Ministry of Health and Social Affairs, 2006). Within six months, all of Sweden's county councils and regions had decided to adopt and implement the national strategy into their own activities. Although much has been accomplished during these years, such as the development of the Swedish National Information Structure and the National Interdisciplinary Terminology, the evidence base on the use and impact of information system support is still limited and inconsistent. Given the current situation regarding information system support in healthcare, implementing evidence-based practice where healthcare professionals and patients jointly participate in making decisions, is almost impossible to achieve in practice. However, information system constraints are just some of the many issues preventing the practice of EBM and SDM. Healthcare professionals and patients' attitudes and perceptions towards shared decision-making also affect the degree to which these models of care are incorporated into practice (Pollard, Bansback, & Bryan, 2015). Healthcare professionals also need skills, such as the ability to ask well-built clinical questions, knowing how to find and evaluate the evidence and how to engage patients in making decisions. However, without supportive technologies that improve access and sharing of information between patients and their healthcare professionals, the gap between empirical evidence and clinical practice is likely to expand which, in turn, may have a negative impact on the quality and safety of care.

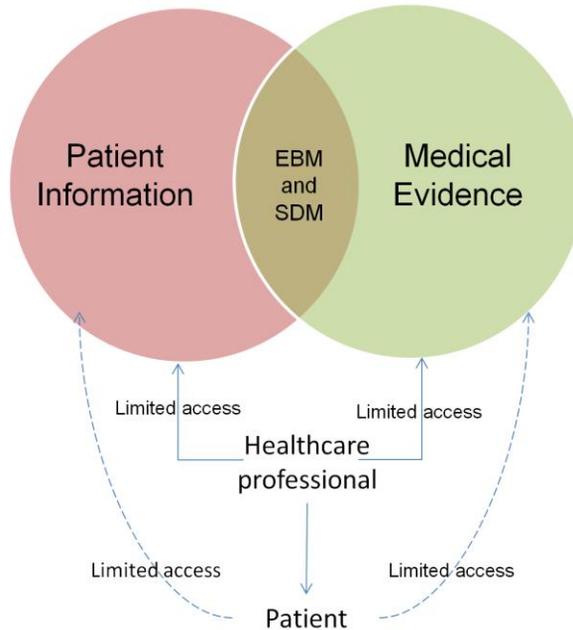
## 1.1 RESEARCH PROBLEM

As shown in the previous section, it is broadly accepted that decisions about the care of individual patients require the integration of research evidence and individual preferences. However, despite the justification that evidence-based medicine and shared decision-making may lead to better quality and safety of care, implementation remains limited in practice (Barratt, 2008). As noted in the previous section, availability to patient information and medical knowledge is a prerequisite for an evidence-based practice. However and unfortunately, much of the information about a patient (e.g., diagnosis, treatments, therapies, medication lists, etc.) and the latest medical knowledge is under-utilized at the point-of-care and point-of-need (see figure

2), due to the absence of efficient and comprehensive information systems throughout the healthcare delivery system. Many healthcare organizations today are experiencing the challenge of achieving a streamlined exchange of information between different healthcare providers, due to issues with information system interoperability (Furukawa et al., 2014; Morton et al., 2015). It is thus rare for current information systems, such as electronic health records (EHRs), to transmit patient information seamlessly, although this was a key selling point for digitizing healthcare records. This is particularly problematic in the care of patients with chronic or multiple conditions, as they require care from different healthcare providers in both health and social care. A healthcare provider refers to a government authority, county council and municipality with regard to health and medical services for which they are responsible (SFS, 2008:355). Each individual healthcare professional (e.g., physicians, nurses, physiotherapists and social care professionals) involved in the care of a patient generates information that is needed by the others. In such environments, collaboration and the coordination of activities, as well as the ability to easily share information in a uniform and transparent way, anywhere and anytime, as required by the patient process, are vital components in providing continuity of care (Bose, 2003; Iroju, Soriyan, Gambo, & Olaleke, 2013). However, due to interoperability issues, patient information is fragmented in the proprietary, heterogeneous EHRs of healthcare organizations. Consequently, vital information, stored in these systems, needed to present a clear and complete picture of a patient, cannot easily be accessed. All too often, healthcare professionals must proceed without knowledge of the problems addressed by other healthcare provider professionals, including services provided, medications prescribed, or preferences expressed in the previous healthcare setting (Ben-Tovim, Dougherty, O'Connell, & McGrath, 2008). If information is missing, it may be impossible to perform medical procedures, preparations may have to be omitted, or a previously booked procedure may be postponed or canceled. Pending procedures may then have to be re-scheduled, resulting in numerous phone calls and loss of time. In addition, if any test results are missing but urgently needed, it may be necessary to repeat tests or procedures (Reichert, 2011, p. 5). In the absence of such information, a complex set of patient flows emerges in which a patient's healthcare records, necessary for care, have to be printed and transmitted between and across healthcare providers. This often leads to a considerable administrative load for healthcare professionals and, in the case of emergency care, lifesaving information may be unavailable (Lenz & Reichert, 2007; Reichert, 2011). The printed copies of the healthcare record must then be integrated into the recipient's EHR, by adding a scanned version to the system or typing a summary in the system. This can entail problems related to inefficiency and the risk of making errors (Zwaanswijk, Verheij, Wiesman, & Friele, 2011). Poor communication and the incomplete transfer of information caused by issues with information system interoperability are among the major factors contributing to adverse events in medicine (Lenz & Reichert, 2007).

The patient is also an important link in the transfer of information between different healthcare providers. In the majority of care situations, the patient is the only common component between healthcare providers. By default, patients are given the added responsibility of recounting their patient information, both medical (e.g., medical notes, laboratory tests, diagnostic imaging reports, treatments, therapies, medical list, allergies and x-rays) and administrative (e.g., appointments) to various healthcare providers (Patel, Barker, & Siminerio, 2014). When patients have to recount their medical history, it can negatively affect the quality of care, especially if the patient does

not want to disclose certain information or communicates incorrect information. Despite the fact that patients play an important role in communicating their own healthcare information, they lack easy access to information regarding their own care.



**Figure 2:** Healthcare professionals have limited access to patient information and medical knowledge. The patient's access to information electronically is also limited, which means that healthcare professionals are usually their primary source to information.

In making decisions about patient care, healthcare professionals must also use current best evidence (explicit/documented medical knowledge) in conjunction with clinical expertise (tacit knowledge). Despite the broad availability of online evidence resources that can help answer questions raised by healthcare professionals, many of them remain unanswered (Del Fiol, Workman, & Gorman, 2014). A seminal 1985 study by Covell, Uman, and Manning (1985) revealed that internal medicine physicians raise two questions for every three patients seen in office practice. In 70% of the cases, these questions were not answered. More recent studies have reported similar results, indicating that there has been little improvement in the three decades since Covell's study was published. A review by Del Fiol et al. (2014) found that physicians are effective in finding answers to questions they pursue, however, roughly half of the questions are never pursued. One important technical reason is that existing information systems are not adequate enough to answer the clinical questions that arise. Best medical evidence is increasingly fragmented in different, technology-based information repositories (IT-based knowledge repositories) where the evidence is presented by diverse providers, each with unique ideas about how information should be organized and how search engines should function. Moreover, these IT-based knowledge repositories are

usually not comprehensive, nor are they integrated within EHRs. For healthcare professionals, this makes finding relevant medical evidence difficult while the patient is in the office and when decisions about the care of the patient are made. Hence, healthcare professionals must rely on experience and consultation with seniors, rather than on best scientific medical evidence. If the physician and/or nurse do not have access to the best medical evidence regarding the benefits and risks of the treatment options, then the decisions that they make with patients will be flawed and patients may suffer (Barratt, 2008). The situation also affects SDM, as the evidence must be shared with the patient. If patients are not informed about treatment options, the benefits and risks of each, or are not given high quality information, e.g., because the healthcare professional do not have access to the best medical evidence, they will be unable to assess ‘what it is important to them’, or make inadequate decisions about key issues (Elwyn et al., 2012). Consequently, it is almost impossible to practice EBM and SDM in everyday clinical care.

However, it is not only the healthcare professionals who are burdened by the situation with suboptimal information system support. A study by Patel et al. (2014) shows that one third of patients reported that they experience a gap in the exchange of information between healthcare professionals involved in their care or between themselves and their healthcare professionals (see figure 2). The study by de Silva (2012) reveals that patients are not always properly informed about their illness and the options for treatments, which has resulted in dissatisfaction with health services (de Silva, 2012). Similar results have been reported in Elwyn et al. (2012) and Joseph-Williams, Edwards, and Elwyn (2016). At a minimum, patients need access to information in the EHRs of their healthcare providers—their own diagnoses, medications, allergies, lab test results, visit summaries (Tang & Lansky, 2005). Coulter, Entwistle, and Gilbert (1999), the Swedish Ministry of Health and Social Affairs (2006), the Swedish Patient Act (SFS, 2014:821), Thom et al. (2016) and Hoffmann and Del Mar (2012) emphasize that patients cannot make informed decisions without having a basic understanding of their health condition and the likely outcomes with and without treatment. Nonetheless, many patients have limited or no access to this information. While not all patients want to play an active role in making decisions about their healthcare, most want their healthcare professionals to inform them about their current condition, treatment options, the likely benefits and harms of each, and take their preferences into account (Coulter, 2010; Mühlhauser, Albrecht, & Steckelberg, 2015). For example, Chiu, Feuz, McMahan, Miao, and Sudore (2016) in their study have shown that most of the older patients preferred to share decisions with their physician or to make decisions on their own. Unfortunately, it seems that, in some circumstances, healthcare professionals may assume that older adults, patients with limited health literacy, or low level of education, do not want to participate in treatment decisions and would prefer that the physician makes the decision based on evidence and clinical expertise (Politi, Lewis, & Frosch, 2013). In Sweden, a survey of 156 hospitalized elderly people found that 27.5 % (42 patients) were not asked for their opinion at all during decision-making or were encouraged to share the decision-making. About half of the patients did not feel they were well informed, and some (15 %) admitted they were afraid to ask questions about their healthcare (Ekdahl, Andersson, Wiréhn, & Friedrichsen, 2011). Most patients wanted to be given more information and to be involved in their healthcare without having to ask the physician. These results are worrying, given the legal requirements regarding the obligation of healthcare professionals to inform patients and involve

them in making decisions about their own care (SFS, 2014:821). Moreover, researchers in Norway found that patients believed that healthcare professionals “owned” the knowledge and decided what information should be communicated to the patient. However, patients wanted a dialogue about their health and struggled to be involved in decision-making (Aasen, Kvangarsnes, & Heggen, 2012). Similar results where physicians did not implement shared decision-making in practice have also been reported in Belgium, Germany and Australia (Butow et al., 2007; Leask, 2009; Pardon et al., 2011).

Furthermore, in an effort to help patients become more informed, cope with their diagnosis, understand their disease process and increase their participation in making decisions about their own care, an international movement towards providing patients with online access to their EHRs has been initiated. In the US, for instance, the OpenNotes initiative that gives patients access to their EHR began as a pilot and evaluation project that includes 105 volunteer primary care physicians and 19,000 of their patients (Delbanco et al., 2012; Walker, Meltsner, & Delbanco, 2015). The project started in 2010 and has since spread throughout the US. Similar schemes have been initiated in Australia (Pearce & Bainbridge, 2014), Finland (Kaipio et al., 2017), Canada (Wiljer et al., 2008), Denmark (Rahbek, 2013), Estonia (Tiik & Ross, 2010), the UK (Mold & de Lusignan, 2015), and Sweden (Erlingsdóttir & Lindholm, 2015). In Sweden, the county council of Uppsala gave all citizens over 18 years of age online access to their EHR through the eHealth service “Journalen” in 2012. The service, Journalen, was eventually launched as the national system in Sweden, accessible through a national patient portal. However, there are limitations and exceptions to patient access. Whether a patient has access to their EHR depends on whether they receive care from a public or private healthcare provider. If a patient receives care from a public healthcare provider, access depends on whether Journalen has already been implemented in that specific county council. Some private healthcare providers give their patients access to the EHR, even if that county has not yet implemented Journalen. However, it is also possible that the county has implemented Journalen, but specific private providers do not give access to their notes. Although the interface of Journalen is identical for all users, there are significant differences in how much information each healthcare provider gives access to. Such differences in information access mean that patients cannot participate in their own healthcare on equal terms. Hence, one can also question whether such differences imply that the Swedish healthcare system does not meet the requirement in the first paragraph of the Health and Medical Services Act, namely that care should be provided under equal conditions to everyone (SFS, 2017:30).

Moreover, the implementation process of the eHealth service, Journalen, has been long and fraught, necessitating legal changes and research to allay a series of concerns, raised mostly by clinicians. Clinicians have been concerned that online access to EHRs will increase their workload, and cause patients distress, confusion and anxiety if they misinterpret the medical entries written. This is considered particularly worrying if patients access their records during weekends and evenings, when healthcare professionals are not available to answer questions or deal with concerns (Erlingsdóttir & Lindholm, 2015). These concerns have also affected the uptake and impact of online EHRs. The problem with resistance is not confined to Sweden. Clinicians in many countries, such as the UK and US, have opposed efforts to allow patients access to their

records. Providing patients with online access to their own EHRs is, however, an important step forward for a more active patient. Although patients and their use of and attitudes towards online access to their EHRs have been studied to some degree, research so far has mostly focused on the healthcare professionals' perspective (de Lusignan et al., 2014; Erlingsdóttir & Lindholm, 2015; Grünloh, Cajander, & Myretteg, 2016; Wiljer et al., 2008). Hence, there is a need to further understand how patients, especially seriously ill patients, experience the online access to their EHR and whether it has any effect on SDM. Another unexplored issue is whether just making information in the EHR available to patients is sufficient, as it primarily involves a passive activity, or whether future healthcare information systems should shift from being passive archives for recording health information (as they are today) to being an active tool.

Furthermore, as well as giving healthcare professionals access to the current best evidence, the Internet is being used to help patients find information about health conditions and treatment. Today, health information is one of the most frequently sought topics on the Internet. Traditionally, healthcare professionals have been, and to some extent still are, perceived as the main providers of information to patients (McMullan, 2006). However, with the easy access and availability of information through the Internet, many patients are no longer satisfied with the role of passive recipient of health information. They want to have a more active role as fully informed patients and participants in the decision-making regarding their own healthcare (McMullan, 2006; Tan & Goonawardene, 2017). Nevertheless, similar to the problems experienced by healthcare professionals, some issues involved in the design of information sources for patients prevent them from finding relevant information at the point of need. For example, the medical evidence is fragmented and stored in different, IT-based knowledge repositories and presented by diverse publishers. Moreover, Fiksdal et al. (2014), in their research, have shown that most participants who used the Internet as a tool to find information about health and medical conditions experienced challenges with efficiently addressing their particular needs, given the vast amounts of information. This reflects the challenge in streamlining and personalizing information for a user base that is diverse, both in terms of individual background and need. Hence, they call for the development of new strategies and technologies for the provision of health information (Fiksdal et al., 2014).

Although there is a common view in research that both patients and healthcare professionals need easy access to patient information and medical knowledge, the information system solutions provided usually handle only one type of information category (e.g., patient information) and one user group (e.g., healthcare professionals). EBM and SDM, on the other hand, include a holistic perspective that involves at least two participants; the healthcare professional and the patient, and a two-way exchange of information; both patient information and medical knowledge. This raises the following questions: can patient information and medical knowledge be provided in a more compact and applicable form and can information systems improve the practice of EBM and SDM?

## 1.2 RESEARCH QUESTION

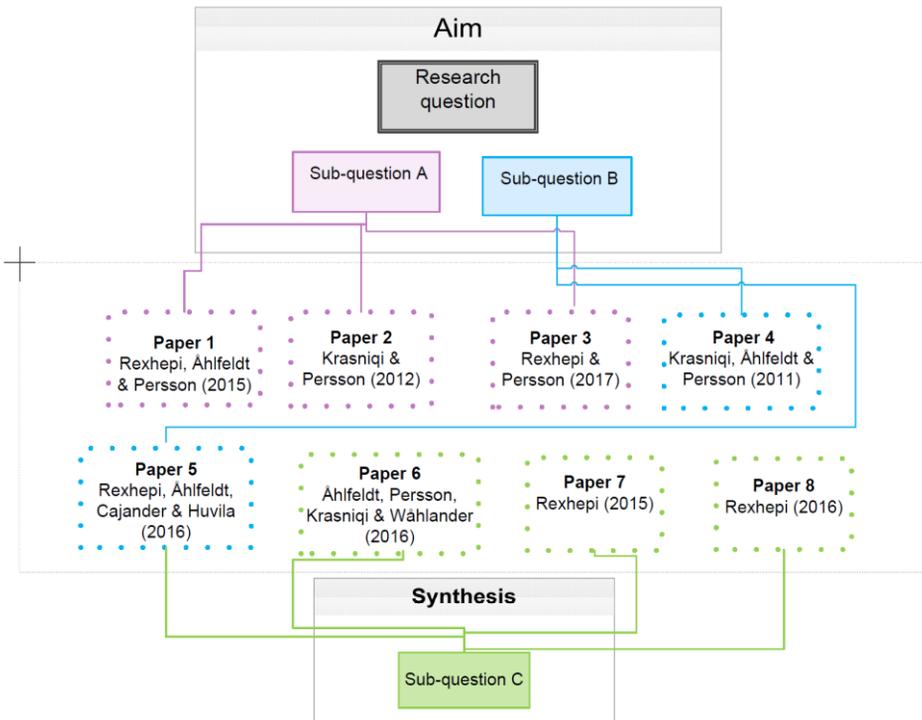
There is an increasing consensus among healthcare experts that information systems can significantly contribute to improving the quality and safety of care by timely providing both patients and healthcare professionals with patient information and relevant medical knowledge at the point of care. Nonetheless, information remains underutilized at the point of care and point of need. This raises the question whether information system solutions can support the practice of EBM and SDM by providing access to current and relevant high quality medical evidence and patient information in the context of patient care decision-making. Hence, this thesis aims to propose recommendations regarding how future healthcare information systems can be redesigned in ways that can facilitate, rather than hinder (1) the collaboration between healthcare professionals and patients and (2) the access to both patient information and medical knowledge along the patient process, and in so doing support the practice of EBM and SDM. Given this aim, the main research question is:

1. *How can future healthcare information systems support the communication between patients and healthcare professionals such that they easily and efficiently can collaborate in pursuing shared goals in healthcare with attention to both illness and personal experience?*

If viewed at a detailed level, the main research question can be divided into three inter-related sub-questions:

- a. What challenges are healthcare professionals facing when they try to apply evidence-based medicine in actual clinical practice?
- b. What challenges are patients experiencing with regard to accessing information about their own care and engaging in healthcare decisions?
- c. What recommendations, derived from theory and practice, can be identified for the development of future information systems that support the joint efforts of healthcare professionals and patients, along the patient process, in making healthcare decisions based on the current, best medical evidence available and the patient's values and preferences?

This thesis has resulted in eight published research papers. Each paper answers one or more of the research questions presented in the above (see figure 3).



**Figure 3:** The relationship between the research questions and papers included in the thesis.

### 1.3 DELIMITATIONS

Evidence-based medicine and shared decision-making is a process of lifelong, self-directed, problem-based learning in which caring for one's own patients, their values and preferences, creates the need for clinically important information about diagnosis, prognosis, therapy and other healthcare issues. The practice of EBM and SDM is dependent on approaches for training in how to formulate clear, answerable clinical questions, search strategies, grading the quality of evidence, communication skills, and methods for involving patients in decision-making. Information system support is, however, mainly identified as a way to significantly improve the provision of healthcare. Even though the non-technical approaches to EBM and SDM are vital, this thesis primarily focuses on the information system support.

Moreover, developers of healthcare information systems around the world endeavor to increase the quality of care by improving the availability of patient information and relevant medical knowledge. Although problems associated with highly decentralized healthcare and autonomous information systems are found in other countries, this work mainly focuses on the Swedish healthcare system. The delimitation derives primarily from the fact that legislation and regulations governing the process of patient information may vary between countries. Patient rights to prevent the distribution of private information and the right to electronically access information about their own

care may also vary between countries. For example, according to the Swedish Patient Data Act (SFS, 2008:355) [Patientdatalag], healthcare providers may gain direct access to each other's EHRs and other personal data that is processed for the purposes relating to care documentation. This act makes it possible for healthcare managers and private healthcare providers to develop different kinds of systems for the maintenance of composite records. Through the maintenance of composite records, accessibility to patient information is provided. However, taking into consideration respect for patients' self-determination and privacy, as well as that healthcare should, as far as possible, be formulated and implemented in consultation with the patient, the regulation gives patients the right to oppose the availability of information in their EHRs through the maintenance of composite records. Moreover, the Patient Data Act makes it possible for a healthcare provider to also give patients individuals direct access to their information electronically, such as to their EHRs. This rule does not constitute an obligation for a healthcare provider to give individuals direct access, but only the opportunity to do so.

It should however be emphasized that the problems identified in this thesis are by no means exclusively related to Swedish healthcare. In fact, these are challenges facing the health system worldwide.

#### 1.4 THESIS STRUCTURE

The thesis is composed of six chapters. Chapter 1 introduces the research area and research problem, followed by a presentation of the research questions. It discusses the problems facing the healthcare organizations, with regard to information systems support. The theoretical background chapter (Chapter 2) provides an overview of the main theories used, and how they relate to each other. This chapter concludes with a presentation of related research and an analysis of the relationship between EBM, SDM, process orientation and knowledge management. The methodology chapter (Chapter 3) presents the main method and data collection techniques used. It discusses the research approach applied to the research presented in this thesis and is followed by a presentation of the research process. The chapter concludes with reflections on the trustworthiness of the research.

Chapter 4 provides a brief summary of each research paper, focusing on aims and conclusions drawn. A synthesis of the results is given in chapter 5. The synthesis is based on a number of recommendations for the development of future healthcare information systems. The major findings of the research are concluded in chapter 6. Moreover, chapter 6 outlines the research contributions and presents suggestions for future work.



# THEORETICAL BACKGROUND



## CHAPTER 2

# THEORETICAL BACKGROUND

To understand how information systems can improve the quality and safety of care, EBM and SDM need to be scrutinized. More specifically, this chapter explains what EBM and SDM are and how they are connected. Furthermore, since evidence-based practice, where the healthcare professional and patient jointly participate in healthcare decisions, is dependent on the availability of patient information and medical knowledge, it is necessary to consider theories that can help to structure, provide and promote timely access to this information and knowledge. Hence, the theories Process Orientation and Knowledge Management (KM) are introduced and defined. Furthermore, a description regarding how these theories are related to EBM and SDM and why their consideration is important is given. Thereafter, other related research is presented.

### 2.1 EVIDENCE-BASED MEDICINE AND SHARED DECISION-MAKING

The concept of evidence-based medicine (EBM) has been defined as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al., 1996). The practice of evidence-based medicine means integrating individual clinical expertise with the best available medical evidence and the patients' values. Clinical expertise refers to the clinician's cumulative experience, education and clinical skills that the individual acquires through clinical experience and clinical practice. The best medical evidence (sometimes also called best research evidence) is usually found in medical /clinical guidelines, systematic reviews and other clinically relevant medical research that has been conducted using sound methodology. These guidelines include recommendations that can help healthcare professionals interpret existing evidence by providing recommendations for decision-making based on literature reviews and existing evidence (Lenz & Reichert, 2007). Sackett et al. (1996) define the best external clinical evidence as “the clinically relevant research, often from the basic sciences of medicine, but especially from patient centered clinical research into the accuracy and precision of diagnostic tests (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens. External clinical evidence both invalidate previously accepted diagnostic tests and treatments

and replaces them with new ones that are more powerful, more accurate, more efficacious, and safer”. Sometimes there is insufficient research evidence upon which to base decisions or the research evidence is inconclusive or of poor quality. In addition, sometimes there is research but it does not directly apply to the particular area. In these cases, the healthcare professional needs to use individual clinical expertise together with patient values and preferences to assess whether the research can be applied in the actual clinical context. In their early discussion of EBM, Sackett and colleagues (1996) argued that medical evidence can inform decisions about patient care, but cannot replace professional expertise and judgement. Clinical/professional expertise is used to determine whether the available evidence should be applied to the individual patient at all and, if so, whether it should be used to inform decision-making. It is important that all the evidence, even if it is in the form of medical guidelines, is professionally evaluated, because every patient context is unique. Sometimes the physician will need to draw on alternative sources of evidence other than research evidence alone. It is important to note that it is research that often – but not always – provides the strongest evidence upon which healthcare professionals base decisions. However, research evidence alone is not enough (Aveyard & Sharp, 2013). This is why the definitions of EBM include references to professional and clinical judgement as well as patient values and preference. As emphasized by Aveyard and Sharp (2013) “Where there is no reliable research evidence, the judgement of the practitioner and patient values and preference is the best evidence”. The practice of EBM is thus a multistep process involving five essential steps (see table 1): 1) converting information needs into answerable questions based on the patient or problem at hand; 2) finding the best evidence with which to answer the questions; 3) critically appraising the evidence for its validity and usefulness; 4) applying the results of the appraisal to clinical practice. However, before deciding whether that evidence can be applied to the patient, the patient’s own personal values and circumstances must be taken into account. The evidence regarding both efficacy and risks should be fully discussed with the patient, in order to allow them to make an informed decision. This approach allows a “therapeutic alliance” to be formed with the patient and is consistent with the fundamental principle of EBM: the integration of medical evidence with clinical expertise and patient values. 5) An evaluation of the approach in which one has to decide whether there is a need to improve on any of the four steps (Akobeng, 2005).

**Table 1:** *The practice of EBM is thus a multistep process involving five essential steps*

Steps in EMB		
1	<b>ASK</b> a specific clinical question	Form a relevant and answerable question based on the patient's case
2	<b>FIND</b> the best evidence with which to answer that question	Choose relevant resources (e.g. different library resources, national medical guidelines) and perform a search
3	<b>CRITICALLY APPRAISE</b> the evidence for its validity and usefulness	Examine the evidence e.g. the articles to determine the validity and applicability to the patient's case
4	<b>APPLY</b> the results into clinical practice/patient care decisions	Use the evidence in conjunction with clinical expertise, patients' values and preferences to make a decision about care.
5	<b>EVALUATE</b> the process/steps	Evaluate the performance of the steps 1 to 4 and review the patient's outcomes to determine if there is a need for improvement and if so, where

The full integration of these components, current best medical evidence, clinical expertise and patients' values, into clinical decisions thus enhances the opportunity for quality, and safety in medical care. If the most current, up-to-date evidence is not incorporated, healthcare quickly becomes outdated. Conversely, without clinical expertise, the practice of healthcare risks becoming tyrannized by evidence, as even excellent external evidence may be inapplicable to or inappropriate for an individual patient (Sackett et al., 1996; Siminoff, 2013). Nor can medicine be practiced without knowing and respecting the informed preferences of patients (Hoffmann, Montori, et al., 2014). EBM has often been criticized for ignoring patient values and preferences. An examination of the definition and steps of EBM quickly dismisses these criticisms. In line with current research, this thesis emphasizes that evidence is never sufficient for making decisions about the care of a patient. The patient's values and preferences must always balance the evidence, in order to achieve quality and safety in the provision of care. The practice of EBM is thus not a "one-size fits all". In other words, evidence alone is not enough; it should be supplemented with the judgement of the healthcare professional and the wishes of the patient. Aveyard and Sharp (2013, p. 12) emphasize:

There is also a third component – that the patient/client's preference must be acknowledged and their consent sought prior to the undertaking of any intervention. If all the best evidence and clinical or professional judgement pointed towards an intervention or therapy that the patient/client did not accept, then we should not carry it out (Aveyard & Sharp, 2013, p. 12).

The above statement highlights that all care delivered must be with the agreement or consent of the patient. Not only does the patient have a legal right to make his or her own decisions (in most countries), it has also been recognized that shared decision-making can have an important role in patient care (SDM). Internationally, shared decision-making is seen as a hallmark of good clinical practice, respecting patients' right to know that their informed preferences should be the basis of all medical actions (Elwyn, Tilburt, & Montori, 2013), and as a way of enhancing patient engagement (Hoffmann, Légaré, et al., 2014). Shared decision-making is applicable to most clinical situations, but is especially important in any situation with more than one reasonable option. Such a situation may include an option for screening or a treatment decision, when no option has a clear advantage and the possible benefits and harms of each option affect patients differently (Elwyn et al., 2014). In terms of models of the healthcare professional–patient relationship, SDM is often positioned as a “middle ground” between the paternalistic (i.e., healthcare professionals make the decisions) and the informed decision-making model (i.e., patients make the decisions) (Makoul & Clayman, 2006) (see table 2).

**Table 2:** *Models of the healthcare professional–patient relationship (Charles, Gafni & Whelan, 1999).*

	Paternalism	Shared decision-making	Informed
<b>Information transfer</b>	One way: From doctor to patient, minimum necessary for informed consent	Two way: doctor provides all medical information needed for decision-making, patient provides information about her preferences	One way: From doctor to patient, all medical information needed for decision-making
<b>Deliberation</b>	Physician alone, or with other physicians	Physician and Patient (plus potential others)	Patient (plus potential others)
<b>Decision about implementing treatment</b>	Physician	Physician and Patient	Patient

Shared decision-making, according to Charles, Gafni, and Whelan (1997, p. 682), is seen as a mechanism to decrease the informational and power asymmetry between healthcare professionals and patients by increasing the patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being. Supporting and involving patients in decisions regarding their healthcare help healthcare professionals and patients agree on a healthcare plan. When patients participate in decisions and understand what they need to do, they are more likely to follow prescribed treatments (Edwards & Elwyn, 2009). Previous research that studied outcomes with SDM has shown that many patients wish to be involved in the decision-making and, that doing so may increase patient satisfaction with care and satisfaction with treatment decisions (Baars, Markus, Kuipers, & Van Der Woude, 2010; Glass et

al., 2012; Hoffmann, Montori, et al., 2014; Mathews, Coleska, Burns, & Chung, 2016). Research regarding the implementation of SDM has also shown that SDM may reduce healthcare utilization, costs and improve treatment adherence (Rathert, Wyrwich, & Boren, 2013). Therefore, shared decision-making is increasingly advocated as an ideal model when faced with making decisions in the patient encounter. Although a more shared approach is advocated, such a shift to a more patient-centered approach in the context of clinical practice has been slower (Légaré & Witteman, 2013). Research suggests that lack of implementation may be due to barriers such as the time required to incorporate patients into the decision-making process, physicians' perceptions that the specific clinical scenario is inappropriate for SDM, or physicians' perceptions that the patient may be unwilling or unable to participate in the decision (Légaré & Witteman, 2013; Pollard et al., 2015). Although the potential benefits of SDM have been espoused in policy and research, there is to date no accepted definition of the concept. Instead, there is a wide range of definitions. For example, Hoffmann, Légaré, et al. (2014, p. 35) define SDM as "a consultation process where a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances". Hoffmann, Légaré, et al. (2014) further argue that shared decision-making is not a single step to be added to a consultation, but should be seen as a process that can be used to guide decisions about screening, investigations and treatments. Also Coulter (2012) sees SDM as a process, emphasizing that "shared decision-making is a process in which clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes, and uncertainties, together with decision support counseling and a system for recording and implementing patients' informed preferences" (Coulter, 2012, pp. 82-83). Shared decision-making thus, is an approach where healthcare professionals and patients make decisions together using the best available medical evidence, where patients are encouraged to consider available screening, treatment, or management options and the likely benefits and harms of each. In this approach, the healthcare professionals' role is to help patients become well-informed, help them develop their personal preferences for available options, and provide professional guidance where appropriate (Elwyn et al., 2014).

A similar but slightly different view of the concept is given by Charles, Gafni, and Whelan (1999) who suggest key characteristics of shared decision-making. According to the authors, these characteristics can be thought of as minimum or necessary criteria for classifying a healthcare professional-patient decision-making interaction as shared decision-making. The characteristics of SDM are;

1. **Information exchange:** Information exchange refers to the type and amount of information that is exchanged between a healthcare professional and patient and whether the flow of information is one or two-way. In a shared decision-making model, the information exchange is two-way (Charles et al., 1997). At a minimum, the healthcare professional must give the patient all the information that is relevant to making the decision. The types of information that the healthcare professional might communicate to the patient include the natural history of the disease, the benefits and

risks of treatment alternatives, the treatment procedure(s), potential effects on the patient's psychological and social wellbeing, and community resources and information that the patient could access about her disease (Charles et al., 1999, p. 654). This is primarily technical knowledge which most patients do not have. Without such information, the patient may have nothing to evaluate and deliberate about. The importance of providing patients with such information is also supported by current research. For example, Mathews et al. (2016), in their research, have shown that patients lack of knowledge about their illness may cause them to give their physicians full responsibility in the decision-making. They also found that as the patient educated themselves on the pathophysiology of Rheumatoid Arthritis and its treatment modalities they gained confidence and began pursuing a more collaborative role in their treatment decisions through SDM (Mathews et al., 2016). Moreover, information that the patient might communicate to the healthcare professional includes: medical history, values, preferences, fears about the disease, lifestyle, social context (e.g., work and family responsibilities and relationships), and current knowledge of various treatment options obtained from lay networks and/or other information sources. This is what Charles et al. (1999) refer to as primarily types of self-knowledge that the patient brings to the patient encounter and the healthcare professional typically has no way of knowing except through direct communication with the patient during consultations. The first type of information exchange thus ensures that all relevant treatment options and the benefits and risks of these alternatives are on the table; the second ensures that both the healthcare professional and patient evaluate these within the context of the patient's specific situation, preferences and values (Charles et al., 1997, 1999).

2. **Deliberation:** The deliberation stage of decision-making refers to the process of expressing and discussing treatment preferences. Charles et al. (1999) argue that a shared approach requires that each person is willing to engage in the decision-making process by expressing treatment preferences, in addition to whatever information they exchange. Studies by Nota, Drossaert, Taal, and van de Laar (2016) and Mathews et al. (2016) on decision-making have shown that patients felt they could more easily express and discuss treatment preferences when they were explicitly invited to do so by their physician, when they were taken seriously and listened to, and when the physician was open to answering questions. Thus, the healthcare professionals qualities such as being readily available, considering the patient's opinion, and explaining the disease and treatment in a way the patient understands can facilitate a trusting relationship between the patient and the healthcare professional. This relationship can then influence patients to transition from a paternalistic decision model to a shared decision model (Mathews et al., 2016).

Moreover, the process of shared decision-making requires at least two participants - healthcare professional and patient (i.e., it takes two to tango). Limiting the conceptualization of shared decision-making to include only a

healthcare professional and patient may not, in many cases, reflect the current realities of a patient process, which may involve other healthcare professionals. The patient's friends or family may also play an important role in the care process of the patient, e.g., a patient may require third parties to act on their behalf. Hence, the shared decision-making process requires at least two participants but may often involve more than two. Thus, if only one person makes the decision, the process is not shared. This is what distinguishes the shared decision-making model from paternalistic and informed models of decision-making.

Worth mentioning in this context is that not all patients want to participate in the shared decision-making process. This fact has not been researched enough and deserves much more attention because there are many different possible explanations. For example, some patients may state a preference not to participate in decision-making, which may reflect that they are simply not motivated to take an active role and would rather leave the decision-making to the physician. For other patients, a stated preference not to participate in decision-making may, according to Charles et al. (1999), reflect a situation specific response, e.g., a patient may not have enough information or skills. In this situation, an intervention, such as a decision aid, can provide information and help the patient structure the decision-making process. In still other instances, patients may express a preference for a passive role in decision-making, because they do not want to be perceived as a difficult patient or they have learned through previous interactions that a more active stance is not well received by healthcare professionals (Charles et al., 1999). More current studies have shown that some patients feel that they are not able to participate in the decision-making process, because of the physician not acknowledging their role in the decision-making. Other patients may feel that they have no choice. Unawareness of not having a choice is a known barrier for patient participation (Caress, Beaver, Luker, Campbell, & Woodcock, 2005; Fraenkel & McGraw, 2007) and previous studies have shown that patients are more motivated for SDM after being informed about the possibilities and benefits of it (Nota et al., 2016). Hence, for shared decision-making to occur, the healthcare professional and the patient must be willing to engage in the decision-making process. No matter how much the patient wants to participate, if the healthcare professional is not willing, then shared decision-making will not occur. Similarly, if the healthcare professional is willing but the patient is not, then the process will not be shared.

3. **Decision on the treatment to implement:** The final task in the decision-making process, according to Charles et al. (1999), is to choose a treatment to implement. Work towards reaching an agreement is done through the deliberation process. When a decision is taken, it does not necessarily mean both parties are convinced that it is the best possible treatment for this patient; instead, it means that both parties endorse it as the treatment to implement. For example, the healthcare professional may feel that another treatment would benefit the patient more, but endorses the patient's

choice as part of a negotiated agreement in which the patient's views are taken into account (Charles et al., 1997, p. 688). Through mutual acceptance, both parties share responsibility for the final decision. This is therefore an important characteristic and helps to distinguish shared decision-making from other models of decision-making.

SDM has also been described by other researchers, such as Elwyn et al. (2012), who propose a three-step model for clinical practice that resembles the model proposed by Charles et al. (1999). The model consists of three steps: choice talk, option talk and decision talk. In this process, the healthcare professional supports patients' to deliberate about their options throughout the process. Choice talk refers to the step of making sure that patients know that reasonable options available. The talk can be initiated by a patient or a healthcare professional before or during the patient encounter. According to Elwyn et al. (2012), this step does not necessarily have to be done face to face — an email, letter or a telephone call can also be effective. Option talk refers to providing more detailed information about options, while decision talk refers to guiding the patient in forming preferences, values and deciding what is best. Before taking a decision, patients will usually want time to study new information about the options and to consider their personal preferences and values, particularly regarding future situations that are unknown to them (Elwyn et al., 2012; Walter, Emery, Rogers, & Britten, 2004). Therefore, deliberation may, in part, be done outside the patient encounter, although patients often wish to consolidate their views with a trusted clinician and/or nurse. Recognizing this need to talk to others, at different times and places, and allowing time for it, is a cornerstone of effective SDM (Rapley, 2008).

The definitions of SDM given by, e.g., Coulter (2012), Hoffmann, Montori, et al. (2014) and Charles et al. (1999) emphasize the essence of shared decision-making, namely, the willingness of the healthcare professional and patient to share information and to jointly engage in the decisions informed by best evidence, not only about the risks and benefits but also patient specific values and preferences. Both parties thus need to be willing and able to not only share information but also accept responsibility for shared decision-making (Sheridan, Harris, & Woolf, 2004). In line with the definitions given by Hoffmann, Montori, et al. (2014), Charles et al. (1997) and Elwyn et al. (2014), this thesis considers shared decision-making as a process where a healthcare professional and a patient jointly participate in a healthcare decision after incorporating the body of evidence (the options, benefits and harms) and considering the patient's values, preferences, and circumstances. For such a process to take place, it is important that healthcare professionals make patients feel at ease with participating in the decisions about their healthcare. Healthcare professionals need to clearly and concisely present information to patients about their medical situation and the clinical evidence, such as existing treatment options, the benefits and risks of these alternatives, the treatment procedure(s), potential effects on the patients' psychological state of mind, etc. Patients must also be given the opportunity to communicate information to healthcare professionals, such as medical history, values, preferences, fears about the disease, lifestyle and current knowledge of various treatment options obtained from lay networks and/or other information sources. Moreover, in line with Elwyn et al. (2014) and Jordan, Ellis, and Chambers (2002), we therefore believe that the role of healthcare professionals in the shared decision-making process is not only to help patients become well-informed, but also help them understand the presented information and develop their personal preferences for available options, as well as provide professional guidance where appropriate. However, not all patients want to play an active role in

choosing a treatment or medication and would rather leave the decision-making to the healthcare professional. Therefore, according to Jordan et al. (2002), healthcare professionals must be adaptable and sensitive to the preferences and beliefs of individual patients. Many authors have also suggested that the presentation of evidence is a key component of SDM (Godolphin, 2009; Jordan et al., 2002; Ruland & Bakken, 2002). However, researchers such as Makoul and Clayman (2006, p. 306) argue that this must be considered as an ideal element because adequate evidence is available for only a limited number of clinical decisions. In situations where evidence is available, healthcare professionals need to be aware of the amount of patient-directed information material that is not balanced or omits relevant data. Hence, they need the necessary skills and resources to be able to synthesize information for their patients, when it is not readily available from other sources (Jordan et al., 2002). Moreover, while it has been suggested that agreeing upon a course of action is the appropriate result of SDM, some researchers argue that agreeing to disagree about a course of action is also acceptable within SDM (Makoul & Clayman, 2006), since a difference of opinion between healthcare professionals and patient may still exist at the end of the SDM process.

### 2.1.1 THE CONNECTION BETWEEN EVIDENCE-BASED MEDICINE AND SHARED DECISION-MAKING

The relationship between shared decision-making and evidence-based medicine is increasingly becoming recognized (Elwyn et al., 2014). Both EBM and SDM are essential to patient safety and healthcare quality. EBM is about using individual clinical expertise together with the best available, external clinical evidence and patients' values in making decisions about the care of individual patients. Shared decision-making provides a process that brings the evidence and clinical expertise into the consultation and incorporates it into discussions with the patient along with their values and preferences (Hoffmann, Légaré, et al., 2014). In other words, SDM is an important component to EBM. It is a way that enables evidence to be incorporated into clinical practice. Adopting a shared decision-making approach to consultations can reduce the unwarranted variation in care (Mulley, Trimble, & Elwyn, 2012) that may partially arise when a healthcare professional's individual clinical expertise dominates the decision-making, with insufficient consideration of both empirical evidence and patients' preferences (Hoffmann, Légaré, et al., 2014). Current research has also shown that healthcare professionals and patients typically overestimate the benefits of interventions and underestimate their harms. Adopting a shared decision-making approach can help to resolve this discrepancy between healthcare professionals and patients' expectations, since it requires that the evidence, such as benefits and risks, is carefully considered and discussed (Hoffmann, Légaré, et al., 2014). Consequently, shared decision-making may reduce the inappropriate use of tests and treatments (Stacey et al., 2011). SDM is thus a mechanism by which evidence, such as treatment options and their benefits and harms, can be explicitly brought into the consultation and discussed with the patient. Hoffmann, Montori, et al. (2014) emphasize that, "without SDM, EBM can turn into evidence tyranny. Without SDM, evidence may poorly translate into practice and improved outcomes. Likewise, without attention to the principles of EBM, SDM becomes limited because a number of its steps are inextricably linked to the evidence. For example, the discussions with patients about the natural history of the condition, the possible options, the benefits and harms of each, and a quantification of these must be informed by the best available research evidence" (Hoffmann, Légaré, et al., 2014, p. 1295). Hence, if SDM does not incorporate the evidence, the

preferences that patients express may not be based on reliable estimates of the risks and benefits of the options, and the resulting decisions not truly informed.

## 2.2 PROCESS ORIENTATION – AN OVERVIEW

The traditional way to structure an organization is through the formation of departments and vertically functional units consisting of individuals with a similar area of expertise (Gemmel, Vandaele, & Tambour, 2008). In this structure, the organization groups employees according to a specialized or similar set of roles or tasks. This makes it possible for employees, such as healthcare professionals, to become specialists in their field. However, the functional organization no longer fits into these current characteristics of the rapidly evolving and technologically deploying business world. During the last decade, there has been a transition from viewing an organization as a number of departments to focusing on the business processes being performed (Gemmel et al., 2008, p. 5). Healthcare organizations in general have also started to move from relatively functional and hierarchical structures to those focusing on processes and cross-functional teams (Vos et al., 2011). The focus on business processes implies a strong emphasis on how work is done within an organization, in contrast to a focus on what is done. It helps to see the whole rather than separate departments and their results (Hellström, Elg, & Lindmark, 2011). Mounting empirical evidence suggests that having a process orientation results in an enhancement of the customer view and products/services, a decrease in costs, faster functions (Harrington, 1991; Khosravi, 2016; Rentzhog, 1996) and increasing inter-organizational learning (Majchrzak & Wang, 1996).

In definitional terms, a process is a “structured, measured set of activities across time and place, with a beginning, an end, designed to produce a specified output for a particular customer or market” (Davenport, 2013, p. 5). A similar process definition by Harrington (1991) focuses on how input is converted into results. Deming (2000) extends the definition by also including who does what. This gives a broader perspective, which can be useful when improvement efforts are made. Moreover, Hammer and Champy (1993) discuss processes as a group of related tasks that together create value for a customer. The interrelated work tasks are initiated in response to an event that achieves a specific result for the customer of the process. Moreover, the definition by Hammer and Champy (1993) emphasizes one of the important characteristics of a process, namely, the customers who are the recipients of the defined outcomes of the process.

A similar definition is presented by the Reijers (2006) and Harrington (1991). They define a process as a collection of activities that take one or more kinds of input and create an output that is of value to an internal or external customer. This definition puts emphasis on the input and output behavior of a business process that should result in some value to the customer. The definition of the process as “a collection of activities” is however abstract, since it neither implies the ordering of activities nor does it provide any other explanation regarding how the activities in the process are executed (Weske, 2010). However, in the aforementioned definition of business process by (Davenport, 2013), the relationship of process activities is emphasized and considered, since the term “activities across time and place” is used.

Processes can be divided or categorized, with respect to their function in an organization. An organization's primary processes, also called core processes, consist of the broadly-defined set of processes that together meet the organization's overall business concept. In the healthcare sector, this is the interaction between patients and healthcare professionals. Primary processes thus reflect the organization's core business, in other words, its main source of living. Support processes are not directly involved in fulfilling the organization's business idea, but provide the core processes with the necessary supporting resources, such as employees, equipment, facilities, and materials. Support processes are, however, just as important to the success of the organization as core processes. Another important process is the management process which includes actions that managers should take to support the organizational processes (Rentzhog, 1998). Generally, in developing the healthcare organizations, process orientation has become important and valuable, both presented conceptually and confirmed empirically (see, e.g., Elg, Stenberg, Kammerlind, Tullberg, and Olsson (2011). In such efforts, the patient and the patient's process become an important starting point (Elg et al., 2011).

### 2.2.1 PROCESS ORIENTATION IN HEALTHCARE

Traditionally, the healthcare organization has a functional organizational structure. Within this organizational design, individuals with a similar area of expertise are grouped into independently controlled departments according to the function they perform, such as orthopedics, surgery, physical therapy, etc. (Ben-Tovim et al., 2008; Vera & Kuntz, 2007). As a result, the healthcare service delivery processes are fragmented across healthcare providers and departments and not according to the patient process (Gonçalves, Hagenbeek, & Vissers, 2013, p. 3). Consequently, this structure does not favor the organization of patients' care through healthcare. A patient is usually treated by various healthcare professionals from different levels of care. During this journey, the patient moves from unit to unit, receiving care from different healthcare providers and professionals (Ben-Tovim et al., 2008). The patient, according to Ben-Tovim et al. (2008), is the only person who sees the whole journey, also called the patient process. Healthcare professionals only see the component for which they are responsible, and no single staff member oversees all the steps in a patient's process through healthcare. This leads to a lack of control and coordination of the care activities within a patient care trajectory, which in turn affects the efficiency and quality of care delivery (Gonçalves et al., 2013; Shtub & Karni, 2010). Generally, in developing healthcare services, it has thus been shown that process orientation with supporting information systems is an important and valuable methodology (Hellström et al., 2011) as it can lead to more patient-centered care, cost reductions, and quality improvements (Gonçalves et al., 2013). In such efforts, the patient and the patient's process is considered one of the most important processes and therefore an important starting point (Elg et al., 2011; Åhlfeldt, 2008). The recent trends towards a more mobile patient and demands on integrated care have increased the need to effectively support interdisciplinary cooperation along the patient process. Information system support for healthcare processes therefore has the potential to significantly reduce the rate of adverse events, by selectively providing accurate and timely medical knowledge and patient information at the point of care (Lenz & Reichert, 2007). However, as shown in previous chapters, there are essential limitations on information system support for healthcare processes.

An important aspect of a process-oriented organizational design is that it thus focuses on the optimal organization of the process of care instead of functional departments. This means that healthcare professionals from different disciplines and organizational boundaries involved in the delivery of care to a patient must work together as a group in satisfying the patients' care needs. In contrast, in a function-based organizational setting, the functions are disconnected from each other and from the process of common goals (Tello-Leal, Chiotti, & Villarreal, 2012; Vos et al., 2011). Working in teams empowers staff, decentralizes decision-making and allows greater across organizational learning (Gonçalves et al., 2013), which is important in an evidence-based practice.

In spite of the benefits offered by the process-based view, there are also some challenges in applying the process perspective. Organizations pursuing the process approach appear to have achieved only partial or marginal success and, in some cases, failure. The problems have been traced to a number of sources. One is in the difficulty of identifying processes, and a second is in their way of managing and redesigning processes (Kiraka & Manning, 2005). Organizational processes represent a difficult challenge for identification and analysis, because they are often unknown quantities, have no names, are not represented in organizational charts, and examples are often disputed. Processes are also difficult to identify because their boundaries are poorly defined. Furthermore, processes are selected portions of larger streams of activity. According to Kiraka and Manning (2005), process boundaries must be set or established in this larger context, before they can be adequately identified. Since boundaries are arbitrary, managers are faced with the task of defining them, which often leads to them being contested, resulting in discrepancies and internal conflicts.

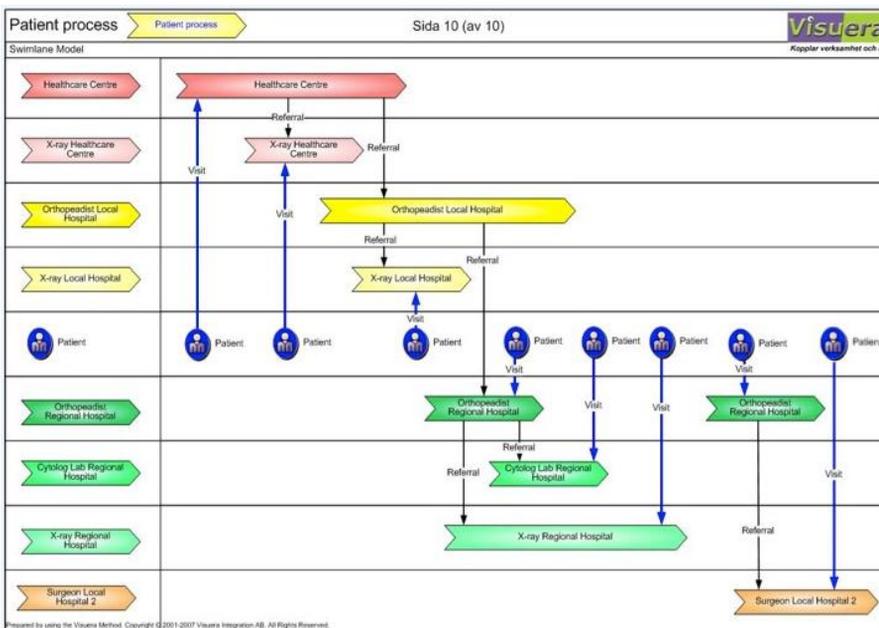
The process perspective has also been criticized for its apparent demands on the organization. According to Kiraka and Manning (2005), this has been traced to the need of new styles of management that include the ability to coach, collaborate, communicate, motivate, negotiate and work as a team player. Those maintaining traditional management styles of command, control, resource allocation and assignment of responsibilities may find themselves replaced, as these styles have no place in a process organization. Adopting the process view thus often constitutes a major change and demands full commitment from the management. Without this commitment, process orientation initiatives often fail to deliver the expected results. The severity and immense complexity of necessary transformational changes could be too much for some managers and organizations, leading them to failure. Shifting to the process perspective is time consuming, because it requires significant changes in corporate culture, work design, management and philosophy. Traditional managers may balk when they have to give up power and authority. Moreover, employees have to be trained to work effectively in a team environment (Sarlak, 2010). Despite these challenges, the process-based view is the proposed way of coping with the dynamism and complexity of organizations (Mathisen & Krogstie, 2012).

### 2.2.2 THE PATIENT PROCESS

The patient process in this thesis is defined in accordance with the definition by Winge, Johannesson, Perjons, and Wangler (2015, p. 3):

Patient care process is the sequence of activities carried out for the patient by health care or social care personnel from various organizations and in which the patient and often his relatives or friends participate.

The definition implies that the patient process is the process that follows the patient through an event of illness. During this process, different activities are performed by healthcare professionals in order to promote health. Patients whose conditions necessitate complex care require care from a wide range of healthcare providers, such as primary and secondary care doctors and nurses. Each of these actors generates information that is needed by the others. To ensure high quality and safe care, this information must be accessible to healthcare professionals in a uniform and transparent way, anywhere and anytime, as required by the patient process. For instance, healthcare providers need to exchange information, such as clinical notes, laboratory tests, treatments, allergies, x-rays, etc. However, due to interoperability issues, patient information is fragmented in the proprietary, heterogeneous information systems of healthcare organizations. Consequently, vital information stored in these systems cannot be easily accessed, in order to present a clear and complete picture of the patient. One example of a patient process and the healthcare providers involved in the context of this process is presented in figure 4.



**Figure 4:** Example of a patient process and the care providers involved (Åhlfeldt & Söderström, 2010).

Figure 4 represents an abstract view of a real patient process and illustrates the care providers involved in the context of this process. In this example, 42 different contacts between the healthcare providers and the patient were made. The number of contacts between the healthcare providers is not known. Twenty of the 42 contacts, of which 14 were made by the patient, were due to the poor management of information. Moreover, the whole process was extended by two and a half months, due to the ineffective exchange of information (Åhlfeldt, 2008; Åhlfeldt & Söderström, 2010). Organizational processes are frequently modeled internally in the organization. However, no one, to the best of our knowledge, has modeled the patient process, although some projects, as “VITA Nova Hemma”, have indicated the need for this kind of work (Perjons, Wangler, & Åhlfeldt, 2005).

### 2.3 KNOWLEDGE MANAGEMENT IN EVIDENCE-BASED HEALTHCARE

Healthcare professionals are confronted with a dramatic rise in medical knowledge. However, current research reveals that this growth of knowledge is not consistent with the users' ability to effectively disseminate, transfer and apply it at the point of care and point of need (Del Fiol et al., 2014; McGlynn et al., 2003). The large volume of medical knowledge is often dispersed across different mediums, which, according to Abidi (2008), makes it difficult for healthcare professionals to be aware of the relevant knowledge and make the best patient care decisions. In evidence-based practice, decisions about the care of a patient must be based on the best available medical knowledge applied in line with the patients' current medical condition, as well as their values and preferences (Abidi, 2008). Hence, medical knowledge is central to healthcare decisions that are made along the patient process. To arrive at correct diagnostic decisions that are based on the latest medical evidence and integrated with clinical expertise and the patient's unique values and circumstances, the evidence must be easily available for both healthcare professionals and patients. However, as described in chapter 1.1, the inability of healthcare professionals to access and apply current and relevant medical knowledge leads to medical errors, incorrect healthcare decisions and high healthcare delivery costs (do Rosário Cabrita, Cabrita, & Cruz-Machado, 2014). On the other hand, patients may find it difficult to participate in decisions because they cannot access both information about their healthcare and medical knowledge, such as diseases, treatments and side effects of medicine. Hence, the key to successful decisions is the timely availability of correct and relevant medical knowledge and patient information, with respect to the clinical context (Abidi, 2008).

Evidence-based medicine thus focuses on the need for healthcare professionals to keep up to date and improve not only their own skills in seeking evidence, but also their own medical knowledge base regarding what effective practice is (Abidi, 2008). In an evidence-based practice, healthcare professionals and patients must also participate jointly in shared decision-making along the patient process, where joint participation requires that patients have access to the same information streams as their physician(s) and/or nurse(s). Moreover, since patients receive care from multiple healthcare professionals, such as family physicians, specialists, nurses, radiologic technology technicians, lab technicians, etc., operating in many geographical areas, a huge amount of information is created. Any information created by one partner is of

utmost importance to all others, in order to deliver good quality care (El Morr & Subercaze, 2010). Hence, knowledge management in the context of evidence-based medicine and shared decision-making can provide an effective and efficient way to structure and provide timely medical knowledge to healthcare professionals and patients, when and where they need it, in order to help them make high quality healthcare decisions (do Rosário Cabrita et al., 2014). Providing medical knowledge to support evidence-based medicine and shared decision-making is, according to Fennessy and Burstein (2007), a complex component of knowledge management, where information is acquired, retrieved and appraised before it is sent to healthcare professionals and patients so that decisions can be informed. Therefore, knowledge management in the context of evidence-based healthcare creates a learning environment and ensures that “best practice” is captured and disseminated (Fennessy & Burstein, 2007). In accordance with do Rosário Cabrita et al. (2014), Fennessy and Burstein (2007) and Quinn, Huckel-Schneider, Campbell, Seale, and Milat (2014), knowledge management in this thesis is seen as central to evidence-based decision-making, as it involves organizations and individuals, both healthcare professionals and patients, creating, accessing and exchanging knowledge (both explicit and tacit). Managing knowledge in healthcare organizations is therefore crucial for the practice of evidence-based medicine and shared decision-making, as well as important for supporting the optimal achievement of good quality care (Desouza, 2005).

### 2.3.1 BASIC CONCEPTS OF KNOWLEDGE MANAGEMENT

Researchers in the information system community address the question of defining knowledge by distinguishing it from data and information. The assumption, according to Fahey and Prusak (1998), seems to be that if knowledge is not distinguished from data and information, then there is nothing new about knowledge management. A commonly held view is that data is raw numbers and facts, information is processed data and knowledge is authenticated information. Alavi and Leidner (2001) argue that knowledge is information that is possessed in the mind of individuals. It is thus personalized information related to facts, procedures, concepts, interpretations, ideas, observations, and judgments (Alavi & Leidner, 2001, p. 109). Consistent with this view, Davenport and Prusak (1998) describe information as a message, usually in the form of a document or an audible communication. As with any message, information has a sender and a receiver and aims to change the way the receiver perceives something. Knowledge is seen as broader, deeper and richer than data and information. They further suggest that knowledge originates and is applied in the minds of people. In organizations, knowledge becomes embedded in documents, repositories, routines, norms and processes. Alter (2006), in accordance with Davenport and Prusak (1998), views knowledge as an evolving mix of framed experience, values, contextual information, and expert insights that provide a framework for evaluating and incorporating new experiences and information. Knowledge is thus necessary for the effective use of information, regardless of how brilliantly the information is gathered and combined. Nonaka and Takeuchi (1995) expand this view by claiming that knowledge is context-specific. In order for knowledge to have a meaning for the users, they must understand and have experience of the context, or surrounding conditions and influences, in which the knowledge is generated and used. Alavi and Leidner (2001, p. 109) also provide a definition that can be compared with the other researchers above:

[...] we posit that information is converted to knowledge once it is processed in the mind of individuals and knowledge becomes information once it is articulated and presented in the form of text, graphics, words, or other symbolic forms (Alavi & Leidner, 2001, p. 109).

In accordance with Nonaka and Takeuchi (1995), Alavi and Leidner (2001) also emphasize the importance of a shared knowledge base. They argue:

[...] for individuals to arrive at the same understanding of data or information, they must share a certain knowledge base (Alavi & Leidner, 2001, p. 109).

According to Alavi and Leidner (2001), knowledge can also be viewed from several perspectives:

- a. A state of mind: Knowledge is the state of knowing and understanding.
- b. An object: Knowledge is an object to be stored and manipulated.
- c. A process: Knowledge is a process of applying expertise.
- d. A capability: Knowledge is the potential to influence action.
- e. Access to information: Knowledge is a condition of access to information.

These different views of knowledge lead to different information system support. For example, if knowledge is seen as (e) access to information, the role of information system support will be to provide healthcare professionals and patients with effective search functions and retrieval mechanisms for locating relevant medical evidence.

The definition by Tuomi (1999) differs from the hierarchical view of data, information, and knowledge, as described above. According to Tuomi (1999), knowledge must exist before information can be formulated and before data can be measured to information. This is therefore an inverse view. According to Alavi and Leidner (2001), critical to this argument is the fact that knowledge does not exist outside of a knower. Consistent with the view of Alavi and Leidner (2001), in this thesis we posit that information is converted to knowledge once it is processed in the mind of people. Knowledge becomes information once it is articulated and presented in the form of text, symbols, graphics, etc. Individuals must also, to a certain extent, share a particular knowledge base in order to arrive at the same understanding of the information presented. One significant implication of this view is that knowledge cannot be stored in an information system, since it exists in the human mind. However, through the use of information systems, we can process and store information that supports knowledge transformation (Scarborough, Swan, & Preston, 1999). Another important implication of this view, as argued by Alavi and Leidner (2001), is that it is not necessary for the design of information systems that support knowledge in organizations to have a different appearance from other forms of information systems. Instead, they will be expanded toward helping healthcare professionals and patients to access and share medical knowledge and patient information.

Additionally, knowledge in organizations has been classified as: (1) tacit knowledge and (2) explicit knowledge. According to do Rosário Cabrita et al. (2014), explicit knowledge can be embodied in a code or language and, as a consequence, it can be verbalized and communicated, processed, transmitted and stored (do Rosário Cabrita et al., 2014, p. 1124). The explicit dimension of knowledge is also supported by other researchers, such as Nonaka (1994) and Alavi and Leidner (2001). Explicit knowledge in the healthcare domain is available, e.g., in EHRs, in medical journals, research reports, memos, e-mails, books and manuals. In turn, explicit knowledge can arise from both internal and external sources. Internal is all knowledge that is relevant to the practice of medicine, e.g., medical journals, as well as the skills and expertise of healthcare professionals (e.g., nurses, physicians, managers). External is indirect knowledge; legal, government and other documents that do not directly affect patient treatment, but govern general medical practices (Wickramasinghe, Gupta & Sharma, 2005). However, the knowledge embodied in, e.g., journals does not necessarily and automatically convert into useful and usable knowledge, unless it is processed in the minds of individuals and used. In other words, knowledge can only reside in the minds of people (Acharyulu, 2011).

The term tacit knowledge was first introduced by Michael Polanyi (1966) and many researchers that write about tacit knowledge refer to Polanyi (1966). Polanyi stated (1966, p.4), “we can know more than we can tell”, meaning that we know more than what we can express in writing (Polanyi, 2009). Thus, unlike explicit knowledge, tacit knowledge is shared mainly through direct interaction between individuals. Tacit knowledge is therefore highly personal and hard to codify, as it is embodied in the expertise and experience of individuals. This type of knowledge is mainly stored in the minds of people and therefore more difficult to express in formalized ways (Kothari et al., 2012; Nonaka & Takeuchi, 1995). Thus, one of the characteristics of tacit knowledge is that it is difficult to write down and to formalize. Another characteristic of tacit knowledge is that it is personal knowledge. Tacit knowledge, according to Nonaka (1994), consists of mental models that individuals follow in certain situations. These are deeply embedded in individuals and tend to be taken for granted. This is why it cannot be expressed easily and why it is attached to the knower (Ambrosini & Bowman, 2001). Nonaka (1994) further argues that tacit knowledge is deeply rooted in action, commitment, and involvement in a specific context. In healthcare, the tacit knowledge of healthcare professionals is manifested in terms of their problem-solving skills, judgment and intuition. The tacit knowledge of patients can be manifested in terms of knowledge about their medical condition and the way they experience their conditions. This tacit knowledge is of great importance for the care of the patient care, as it allows the healthcare professional to gain insight into patients’ experience and hence understand their quality of life (El Morr & Subercaze, 2010), as well as their preferences and values. In accordance with current research, explicit knowledge, in this thesis, is viewed as information that can be expressed in words and numbers, as well as easily communicated and shared with individuals. This type of knowledge is easy to capture, structure, and share. On the other hand, tacit knowledge consists of experience and skills that an individual can acquire over time and apply to problems. Tacit knowledge is highly personal and hard to formalize. Subjective insights and intuitions fall into this category of knowledge (Chen, 2013). Alavi and Leidner (2001) see a danger in the classification of knowledge according to the dimensions of tacit and explicit, as there seems to be an assumption that tacit knowledge is more valuable than

explicit knowledge. Based on the previously stated definitions of evidence-based medicine and shared decision-making, we argue that explicit and tacit knowledge possessed by doctors and patients respectively is crucial, when making decisions about the care of a patient. However, to the best of our knowledge, little is known regarding how patients' tacit knowledge fits into the evidence-based practice.

### 2.3.2 KNOWLEDGE MANAGEMENT

Knowledge Management (KM), as a discipline, has not been clearly agreed upon. There is still no established definition of KM, just as there is no agreement on what constitutes knowledge in the first place. Instead, there are varying opinions on what it is and how it should be used, if used at all. A contributing factor to this may be that KM is drawn from a wide range of established disciplines, such as organizational learning, social construction and social interaction, which has resulted in a multiplicity of terms that are often used interchangeably. This lack of consensus and precision in terminology has resulted in conflicting definitions of KM (Beesley & Cooper, 2008). Hicks, Dattero, and Galup (2006) state the following:

There is a consensus that data are discrete facts, but after that, consensus is lacking. The lack of consistent definitions of data, information, and knowledge make rigorous discussions of KM difficult (Hicks et al., 2006, p. 19).

According to Jennex, Smolnik, and Croasdell (2016), knowledge management is the discipline that focuses on managing knowledge, knowledge initiatives, and the gathering, storing, and application of knowledge. Jennex et al. (2016) further argue that “the main goals for knowledge management are to identify critical organizational knowledge assets, acquire those assets in an accessible repository, establish mechanisms for sharing the assets among organizational workers, apply the appropriate knowledge to specific decision domains, determine the effectiveness of knowledge application, and adjust knowledge artifacts to improve their effectiveness” (Jennex et al., 2016, p. 4202). Unlike Jennex et al. (2016), Heisig (2009) emphasizes that the goal of KM is not only to improve the systematic handling of existing knowledge, but also potential knowledge within the organization. KM from this view is considered as the systematic process established to capture and use knowledge in an organization for the purpose of improving organizational performance. Alavi and Leidner (2001) have also a process view of KM. They argue that KM involves distinct but interdependent processes of knowledge creation, knowledge storage and retrieval, knowledge transfer, and knowledge application.

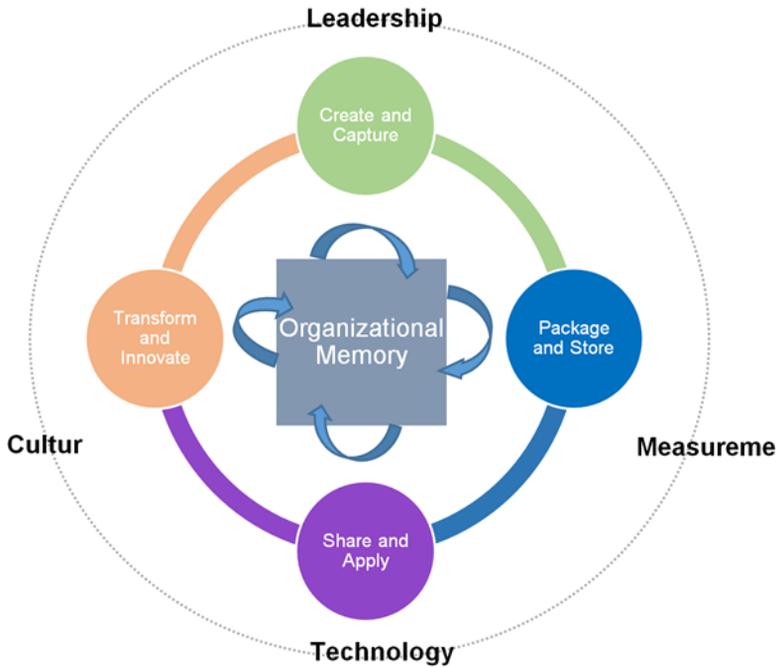
Persson and Stirna (2007) have a similar definition. They argue that KM consists of a number of processes that cover the whole life cycle of knowledge in an organization (see figure 5). The cycle is adopted from O'Dell, Grayson, and Essaides (1998) and is similar to the spiral of organizational knowledge creation presented by Nonaka and Takeuchi (1995). The model consists of four socially enacted “knowledge processes”: capture and create, package and store, share and apply, transform and innovate. A key strength of the KM process model proposed by Persson and Stirna (2007) is the emphasis on knowledge innovation (transform and innovate). This activity highlights the

importance of transforming shared information into knowledge which is in the human mind. People must thus learn from shared information and learn to apply it in practice (Desouza, 2005). A slightly different definition of KM, is given by Jones and Leonard (2009), whose definition focuses on the need for organizations to turn the tacit knowledge of employees into explicit information that they can use in order to transform it into their own knowledge. This knowledge can then be used, shared and developed to become additional knowledge. In this way, the organization prevents knowledge loss. They argue the following:

An organization needs to “know what it knows,” but this cannot be the full extent of KM. The organization also needs to be able to put this knowledge in some format where employees can utilize it. In other words, the organization must be able to turn tacit knowledge into explicit information.

In turn, employees need to be able to use the explicit information to turn it into their own knowledge and be able to create and share additional knowledge from it (Jones & Leonard, 2009, p. 28).

Moreover, Quintas, Lefere, and Jones (1997) conclude that KM is the process or practice of creating, acquiring, sharing and using knowledge, wherever it resides, to enhance learning and performance in organizations. KM, according to this definition, refers to the process in which organizations acquire information, store and share it, so that individuals in the organization can transform it into knowledge for the purpose of learning. The inclusion of “wherever it resides” refers not only to explicit knowledge, but also tacit knowledge that resides in people’s minds (Loermans, 2002). In order to transform individual knowledge into value which can benefit the organization, the individual knowledge must then be transformed back into information. The captured knowledge must be stored as information and will again provide a foundation for the creation of new individual knowledge (Jensen, 2005).



**Figure 5:** *The knowledge cycle in organizations (Persson & Stirna, 2007).*

Within the context of healthcare, KM, according to Abidi (2008), can be characterized as the “systematic creation, modeling, sharing, operationalization and translation of healthcare knowledge to improve the quality of patient care. The goal of healthcare knowledge management (HKM) is to promote and provide optimal, timely, effective and pragmatic healthcare knowledge to healthcare professionals (and even to patients and individuals) where and when they need it to help them make high quality, well-informed and cost-effective patient care decisions” (Abidi, 2008, p. 2). From this perspective, KM provides the methodological and technological framework to pro-actively capture both the experiential and empirical types of knowledge, which are of importance for an evidence-based practice and shared decision-making.

The systematic handling of knowledge is a core element of the above mentioned definitions of KM. In the literature, this knowledge handling is described in KM frameworks in the form of activities or processes. Slight discrepancies in the delineation of the processes appear in the literature, in terms of the number and labeling of processes. At a minimum, one considers the four basic processes of creating, storing/retrieving, transferring, and applying knowledge. Given that knowledge, both explicit and tacit, is critical for evidence-based medicine and shared decision-making, this thesis concludes, in accordance with, e.g., Persson and Stirna (2007), Abidi (2008) and Alavi and Leidner (2001), that the goal of KM is to provide current, relevant and timely medical knowledge to healthcare professionals and patients, where and when they need it. This knowledge is then used to help them make healthcare decisions based on the latest medical evidence and integrated with clinical expertise and patients’ unique values and circumstances. It involves the process of creating, capturing, packaging,

storing, sharing and using knowledge. Moreover, when knowledge is successfully and effectively shared and used, it can turn into improvements and the creation of new knowledge.

It is important to note that none of the above definitions of KM are purely technical in nature. KM involves information technology as an enabler, however, it should be emphasized that technology alone is insufficient. Instead, KM technology consists of numerous building blocks that support various KM activities, namely, people, process and technology (Barnes, 2011; Persson & Stirna, 2007). Many KM initiatives have failed because they focused on the technology alone. This is due to the fact that people, not technology, carry out KM. People must thus be willing to share their knowledge and expertise with one another in the workplace. KM initiatives that focus on the people and embedded knowledge management in processes, such as the patient process, as well as use technology as an enabler have succeeded more often than those that do not (Barnes, 2011). For example, one way to provide appropriate knowledge to healthcare professionals and patients, when it is needed, is to implement an IT-based knowledge repository that supports them through the patient process, giving them a place to access, share and collaborate (Information technology and KM embedded in the patient process as enabler). Deng and Tian (2008) argue that KM activities which are not combined with daily work tasks and integrated into organizational processes usually result in situations where employees involved in the execution of the process feel that “they are busy with the execution of more important tasks related to the process and that they do not have time to spend on knowledge management activities such as searching for relevant knowledge” (Deng & Tian, 2008). Therefore, integrating KM activities into daily work tasks and responsibilities is a challenge that needs to be solved in the healthcare organization. IT-based knowledge repositories, which are sometimes called Electronic Knowledge Repositories (EKR) or Digital Learning Repositories, are important solutions to the problems identified in this thesis. Such IT-based knowledge repositories can help the healthcare organization to connect patients and healthcare professionals with information and expertise, for instance, via online searchable libraries, discussion forums and other elements. Thus, they provide a central location for collecting, contributing and sharing both explicit and tacit knowledge. Moreover, for KM to be effective as a transformation tool, it must include an organizational culture that promotes learning and knowledge sharing. For knowledge sharing to take place, people must be willing to share their knowledge and expertise with one another in the workplace (People and culture as enabler). For example, in an evidence-based practice it is not enough that the knowledge is shared between healthcare professionals. Knowledge sharing must also take place between healthcare professionals and patients. Hence, information technology and KM have a symbolic relationship, but it is important that technology does not become “the be all and end all” of KM. Information technology can connect people, but it does not make KM happen. Developing and implementing, for example, an IT-based knowledge repository does not, in itself, guarantee the usage and sharing of best practice and know-how.

## 2.4 KNOWLEDGE MANAGEMENT AND ORGANIZATIONAL PROCESSES

KM is considered to be an important function for the creation of organizational value. However, for organizations to gain maximum benefits from KM, they must link KM

activities to organizational processes, such as the patient process (Barnes, 2011). Edwards and Kidd (2003, p. 133) assert that the best route for organizations to follow is to consider KM in terms of organizational processes. This means looking at knowledge needs in terms of their underlying business processes. El Sawy and Josefek (2004) argue that the application and generation of new domain knowledge take place in the context of the process. Therefore, the key activities of the process are the central objects for analysis and design, and KM has to demonstrate its benefits to the core processes (Heisig, 2009). Additionally, Mertins, Heisig, and Vorbeck (2003) and Deng and Tian (2008) argue that knowledge from a process-oriented approach can be viewed as a crucial resource to fulfill process tasks. It can also be regarded as a product generated by this task or process. The authors further emphasize that a process-oriented knowledge management approach requires an integrative perspective of the elements of information and knowledge, as the lack of one of the elements can constrain the performance goals. Implementing the KM infrastructure around the organizational process can thus create significant value for process execution, process recipients and the organization (El Sawy & Josefek, 2004).

Deng and Tian (2008) argue that KM activities which are not combined with daily work tasks and integrated into organizational processes usually result in situations where employees involved in the execution of the process feel that “they are busy with the execution of more important tasks related to the process and that they do not have time to spend on knowledge management activities such as searching for relevant knowledge” (Deng & Tian, 2008). Therefore, integrating KM activities into daily work tasks and responsibilities is a challenge that needs to be solved. In recent years, industries have increasingly paid attention to the potential benefits of linking KM to organizational processes. However, to date, linking KM to processes has had less focus in healthcare organizations. This is somewhat surprising, since the patient process is characterized as knowledge-intensive, consisting of many and critical decision activities that require personal judgment based on patient information and scientific evidence.

Consider the following hypothetical example in which the KM process is linked to organizational processes. The setting is a healthcare organization where the core organizational process is the patient process. A physician at secondary care receives a referral from a primary care unit regarding a patient with hip pain. As the referral is processed and the process for the patient encounter is planned and conducted, a considerable amount of information is collected, from, e.g., physical examinations, the patient’s electronic healthcare record, and current scientific medical knowledge. A great deal of information is also exchanged between the patient and the physician and between the physician in secondary care and the primary care unit. When the physician plans and conducts the patient encounter, the most appropriate examination and investigation for the patient must be selected on the basis of evidence and in conjunction with clinical expertise, the patient’s medical history, current clinical status, as well as preferences and values (Clancy & Cronin, 2005; Lenz & Reichert, 2007). The patient encounter also requires that the physician carries out some sort of decision-making, which involves an active interplay between various medical knowledge modalities, spanning from explicit to tacit knowledge. More specifically, it may involve the consideration of medical knowledge from outside and inside the organization, such as (a) national and/or regional medical guidelines, (b) medical literature, (c) the physician’s

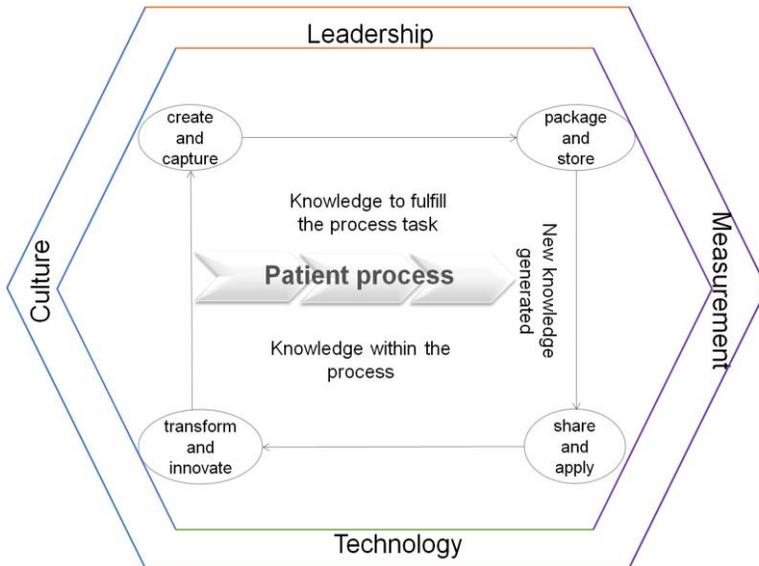
tacit knowledge in terms of judgment and intuition, (d) discussions and consultation with other practitioners. Enabling a healthcare professional to work according to the latest scientific medical knowledge will require an analysis of the type of knowledge needed in the different parts of the patient process. This knowledge, which may be in the form of medical guidelines, can then be integrated with an information system. However, beyond medical guidelines, a healthcare professional may also need to consult colleagues. In order to make decisions based on EBM and SDM, practitioners must be able to access and integrate multiple types of knowledge derived from various sources. The integration of these types of knowledge (both tacit and explicit knowledge) is particularly essential, as healthcare professionals often have to deal with clinical situations that lack strong evidence. For instance, the absence of explicit knowledge in a clinical case regarding the side effects of a particular medicine, reported by the patient, may require healthcare professionals to refer to tacit knowledge, such as the clinical expertise of their peers (Abidi, 2005).

Additionally, every time the process is executed, new knowledge can be generated, e.g., if a medical guideline recommends a new medication, patients' experiences of the medication become important knowledge that must be captured and shared. Capturing, storing, sharing and applying this knowledge can add value to the organization, but most importantly, it can improve quality of care.

Knowledge that has been identified and captured by a physician can thus be used to improve the patient process. However, for this to work, the KM process must be smoothly integrated into the daily work activities of the patient process (Persson, Stirna, & Aggestam, 2008). For example, if an organization wants to develop an IT-based knowledge repository that is integrated into a process support system, work must begin with 1) identifying the knowledge that can be relevant to the execution of the different activities in the patient process, 2) identifying where the knowledge can be found, also called "capture points", i.e., situations or events where knowledge is usually created, e.g., during a patient encounter, 3) identifying responsible people for the capture process. If, for example, a physician has identified knowledge that may be of interest to other colleagues, the physician would then report it to those responsible. In this process, one must also identify potential reviewers of the particular type of knowledge produced, 4) defining rules to govern the kind of knowledge that should be stored in the repository and in the process support system (Persson, Stirna & Aggestam, 2008).

The integration of the KM process alone is, however, not sufficient for successful knowledge management. The success of KM activities is also influenced by the enablers: leadership, measurement, information technology and culture (see figure 6). For example, sharing and applying knowledge cannot be done mechanically, by integrating medical guidelines into an information system, or by developing an IT-based repository that supports knowledge sharing, thus expecting the organization to suddenly start to use and share knowledge. Particular attention should be paid to building a knowledge sharing culture. A culture that encourages sharing and group learning helps KM initiatives. Technology can only play a supporting role in the application and sharing of knowledge – its role is to make the sharing and application of knowledge easier and more effective. To reinforce the application and sharing of knowledge, leadership is critical. Managers must participate in sharing and show healthcare professionals that they are personally committed to learning, because the sharing and usage

of best practice are the most important aspects that can be carried out by individuals within an organization (O'Dell et al., 1998; Persson et al., 2008). They must motivate employees to share and especially show them how to capture, share and use knowledge throughout the patient process, by giving staff self-service tools. The Chinese proverb fits well here; “Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime”. Thus, in order to encourage sharing, managers should not just hand out, e.g., web links to sources of knowledge - give the fish. Instead, they must teach by giving employees the right tools with which to capture and share knowledge – thus teaching them how to fish. Moreover, it is equally important to encourage practitioners to teach each other – learning how to fish from each other.



**Figure 6:** *The integration of KM into organizational process and its enablers (Adapted from Persson & Stirna, 2007).*

## 2.5 OTHER RELATED RESEARCH

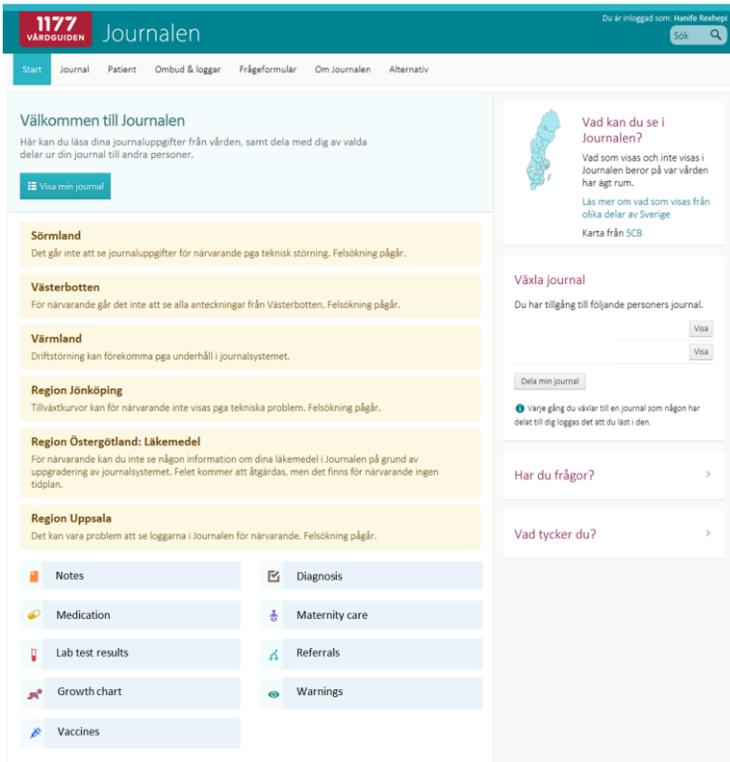
Given the importance of the exchange of information between healthcare professionals and patients in the practice of EBM and SDM, it is not surprising that various kinds of information system solutions have been and are being developed to help bridge the information and communication gap. For example, Winge et al. (2015) propose a solution in the form of a Coordination Hub. This is an integrated software service that offers a number of information services which can facilitate the communication between different healthcare providers in process conglomerations, thereby supporting patient-centered collaboration. In their research, Raghupathi and Kesh (2007) have explored the potential of service-oriented architecture (SOA) in the development of

interoperable EHRs, by developing a prototype SOA model. Russ et al. (2010) have identified a set of characteristics for workflow systems that support the patient processes. The research from, e.g., Winge et al. (2015) and Russ et al. (2010) focuses on the communication needs of healthcare professionals and how the patient process can be supported, by making individual patient information available at all points of care, which of course is of interest for this work. However, none of these have taken a holistic perspective that brings patients and healthcare professionals together where they jointly can collaborate by accessing and exchanging patient information and medical knowledge along the patient process.

Various solutions have also been presented to support patients in shared decision-making through information system support, such as decision-support tools resulting from the integration of patient information and virtual support/group networks. Research suggests that decision aids can be useful when weighing up the benefits and harms of various treatment options, and when considering symptom management and appropriate levels of care (de Silva, 2012). However, according to Schroy et al. (2011), the overall effectiveness of decision aids depends on the extent to which healthcare professionals are willing to discuss and include patients' views. Another initiative that aims to improve communication between healthcare professionals and patients, ultimately increasing patients' engagement in care and improving the shared decision-making process, is providing patients with online access to, and more control over, their EHRs (Safford, 2017; Silber, 2009). In the US, the OpenNotes initiative that gives patients access to their EHR began as a pilot and evaluation project that included 105 volunteer primary care physicians and 19,000 of their patients (Delbanco et al., 2012; Walker et al., 2015). The project started in 2010 and has since spread throughout the US (Bell et al., 2016). Similar schemes have been initiated in Australia (Pearce & Bainbridge, 2014), Finland (Kaipio et al., 2017), Canada (Wiljer et al., 2008), Denmark (Rahbek, 2013), Estonia (Tiik & Ross, 2010), the UK (Mold & de Lusignan, 2015), and Sweden (Erlingsdóttir & Lindholm, 2015). However, in several countries, the implementation progress has been slow, due to legal constraints (Tiik & Ross, 2010) and because healthcare professionals are concerned about security and privacy risks (Erlingsdóttir & Lindholm, 2015; Wiljer et al., 2008).

In Sweden, Region Uppsala started a project to give patients access to their medical information, already in 1997. The project, called SUSTAINS (Support Users To Access Information and Services), received financial support from the European Commission (Joustra-Enquist & Eklund, 2004). A follow-up EU-funded project with the same name later resulted in a pilot, in which all healthcare professionals in Uppsala were given online access to their own health records. In 2012, Region Uppsala gave all citizens over 18 years of age online access to their EHR through the eHealth service "Journalen". The service, Journalen, was eventually launched as the national system in Sweden, accessible through a national patient portal. The service allows access to EHR information through a national health information exchange platform. This means that patients have one access point to all their health record information, regardless of a) how many healthcare providers they have visited, and b) which EHR system their healthcare providers use (Hägglund & Scandurra, 2017). However, there are limitations and exceptions to patient access. Patients' access to their EHR depends on whether they receive care from a public or private healthcare provider. If a patient receives care from a public provider, access depends on whether Journalen has already

been implemented in that specific county council. Some private healthcare providers give their patients access to their EHR, even if that county has not yet implemented Journalen. However, it is also possible that the county council has implemented Journalen, but specific private healthcare providers do not give access to their medical notes. Currently, when patients access Journalen, they find various clinical content, such as medical notes from the EHRs (from all healthcare professions and all connected healthcare providers that have agreed to give access, both public and private), a list of prescribed medications, lab results, warnings, diagnosis, maternity care records, referrals and vaccinations (see figure 7).



**Figure 7:** Journalen after log-in, showing the functions and information available (partially translated).

Although the Journalen interface is identical for all users, there are significant differences in how much information each healthcare provider gives access to (see table 3). Such differences in information access mean that patients cannot participate in their own healthcare on equal terms. Consequently, the question arises whether such differences imply that the healthcare system does not meet the requirement in the first paragraph of the Swedish Health and Medical Services Act, which states that care should be provided under equal conditions to everyone (SFS, 2017:30).

**Table 3:** Information shown in Journalen depending on county council/healthcare provider [Inera 2017]

	Medical Notes	Diagnoses	Visits (time/date /provider)	Lab Results	Medications	Immunizations	Referrals	Medical alerts	Access Log Lists	Psychiatry	Health Declaration Forms	Blocking of record	TOTAL
Blekinge													6
Dalarna													3
Gotland													4
Gävleborg													4
Halland													5
Jämtland/Härjedalen													5
Jönköping													4
Kalmar													4
Kronoberg													4
Norrbottn													5
Skåne													4
Stockholm													4
Södermanland													4
Uppsala													10
Värmland													7
Västerbotten													4
Väster-norrland													4
Västmanland													3
VGR													4
Örebro													7
Ostergötland													7

Moreover, the implementation process of the service, Journalen, has been long and fraught with issues, necessitating legal changes and research to allay a series of concerns raised mostly by clinicians. They are troubled that online access to EHRs will increase their workload and cause concerns, confusion and anxiety, if patients misinterpret what has been written. This is considered particularly worrying if patients access their records during weekends and evenings, when no staff is available at the hospital unit to answer questions or deal with concerns (Erlingsdóttir & Lindholm, 2015; Grünloh et al., 2016). Some healthcare professionals also worry that patients might misuse the information – attempt to diagnose themselves or decline beneficial treatment because they misunderstand the content. These concerns are not unique to Swedish clinicians. Similar reactions have been reported from other countries, such the

US and the UK (Gerard, Fossa, Folcarelli, Walker, & Bell, 2017). However, there seems to be a disagreement in the literature, regarding the effects of making healthcare records available to patients. Some have reported increased anxiety among patients who have accessed their records, while others have concluded that having full access neither decreased nor increased anxiety (Gravis et al., 2011). Other researchers, such as Ross, Moore, Earnest, Wittevrongel, and Lin (2004), suggest that online access to EHRs can improve adherence to medical advice and increase patient satisfaction with doctor-patient communication. Recent studies on the OpenNotes initiative have also shown that doctors and patients experienced relational benefits when medical notes were shared (Bell et al., 2016). Wolff et al. (2017) and Vermeir et al. (2017) suggest that offering patients access to doctors' notes is acceptable and improves the adequacy and efficiency of communication between physician and patient, which in turn facilitates decision-making and self-management.

Although the aforementioned information system solutions are considered effective, they have limitations, since they focus on supporting one or some of the characteristics of SDM and not on the intended complete process (Davis, Roudsari, Raworth, Courtney, & MacKay, 2017). For example, patients' access to their EHRs supports a part of the first step "information exchange" in the Charles et al. (1997) model of shared decision-making. Thus, it only supports access to information not the exchange of information between patient and healthcare professional. The flow of information is thus one way.

Moreover, there is much research on different methods and tools for 1) translating medical guidelines into computer-based medical guidelines and 2) improving the design of computer-based medical guidelines (Shalom et al., 2008; Shiffman, Michel, Essaihi, & Thornquist, 2004). Other researchers have focused on studying how medical guidelines can be integrated into EHRs and organizational workflows (Peleg, Keren, & Denekamp, 2008; Shiffman et al., 2004). For example, Peleg et al. (2008), in their research, have studied how encodings of guidelines in a computer-interpretable format and their integration with EHRs can enable the delivery of medical knowledge, in the form of patient-specific recommendations, when and where needed. El-Gayar and Timsina (2014) have presented a research agenda for leveraging business intelligence and big data analytics in evidence-based medicine, and illustrate how analytics can be used to support EBM. Furthermore, Lenz and Reichert (2007) have demonstrated how pathway compliance can be improved, by developing a successful IT-application that brings pathway recommendations to the point of care. The application is closely integrated into the EHR and is based on workflow-enabled electronic forms in which coded data from a central database are reused to place reminders and alerts. As the main purpose of computer-based medical guidelines is to reduce errors and increase quality and safety, validation and verification techniques are other topics of interest to many researches (Peleg, 2013; Peleg et al., 2008). Although computer-based medical guidelines include medical knowledge, the management of knowledge from a KM perspective is seldom mentioned in these research examples. Moreover, Fennessy and Burstein (2007) argue that computer-based medical guidelines provide important summaries of good quality evidence, but they are usually limited in scope and topic coverage. High costs and the amount of time involved in developing them are seen as the main reasons. Therefore, and as a complement to computer-based

medical guidelines, IT-based knowledge repository solutions have been implemented within healthcare organizations, but the results have often been unimpressive.

In Sweden, several national projects have been initiated, with the aim of developing IT-based knowledge repositories. The solutions are built on web-based services that help healthcare professionals to access scientific medical knowledge. Some well-known project initiatives are “Kunskapsguiden” and “Vårdaktörsportalen”. These IT-based knowledge repositories aim to give healthcare professionals easy access to scientific medical knowledge, such as medical guidelines, without supporting the second element of evidence-based medicine, namely, the sharing of individual clinical expertise. Moreover, the medical knowledge within these knowledge repositories is made available in “document form”, containing a multitude of pages. Even though these knowledge repositories contain crucial scientific medical knowledge, none of them are integrated with existing information systems, such as an EHR. They are thus “stand-alone” systems that have been developed and are still being developed separately from existing information systems. Finding relevant and current medical knowledge that is related to the clinical situation, when it is needed, is therefore difficult. Various solutions have also been presented to support healthcare professionals in SDM. Most of these studies focus on different training approaches that aim to build skills and overcome resistance to SDM (Knops, Ubbink, Legemate, de Haes, & Goossens, 2010; Légaré et al., 2011; Légaré & Witteman, 2013). Other strategies to support healthcare professionals in SDM involve journal articles, guidelines and reminder systems. Research has, however, concluded that medical articles may not include evidence-based information necessary to foster SDM in clinical practice (Labrecque et al., 2010).

The current information system solutions targeting healthcare professionals thus focus on either the provision of patient information or medical knowledge, as a way of supporting EBM, or on decision aids to better support SDM. Furthermore, to our knowledge, how information systems can be used to elicit patient values and preferences is not extensively discussed in current research. Separating patient information from medical knowledge and patient preferences will not only result in the development of suboptimal information systems that can be viewed as isolated islands, but also result in the separation of EBM and SDM. Hence, the quality of healthcare may be negatively affected. Moreover, current information system solutions also seem to treat patients and healthcare professionals as separate user groups and not as partners that must collaborate throughout the patient process in order to achieve the best care.

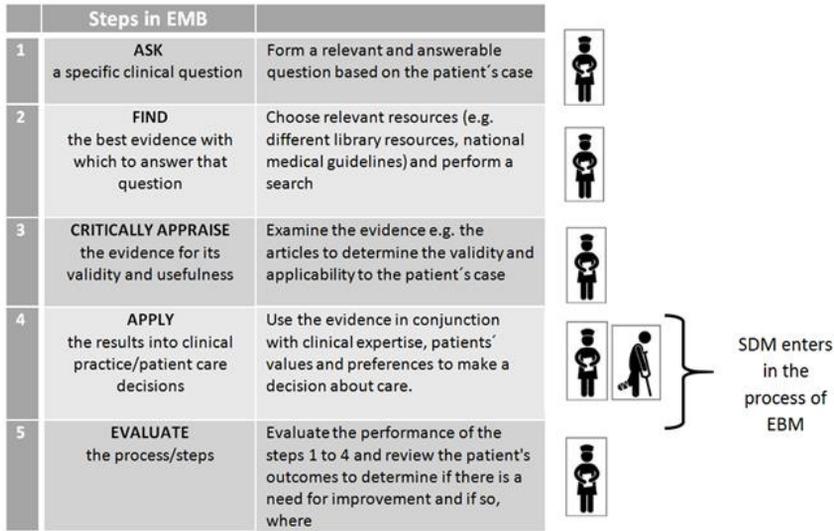
Based on the analysis of prior research and the scope of the problem that has been presented in this thesis, we conclude that the various elements of evidence-based medicine and shared decision-making are treated as distinct components. Consequently, the information system solutions that are presented in current research deal with supporting one or some other characteristics of EBM and SDM. A holistic perspective is thus missing. Information systems can contribute significantly to quality and safety improvements in healthcare only when 1) patient information and medical knowledge are regarded as interconnected, such that they continually impact on each other, and 2) when the patient is seen as a distinct and active collaborator. Therefore, an efficient synergy must be developed between future information systems, EBM and SDM. An additional limitation in existing research relates to the presented solutions regarding how medical knowledge can be made available to healthcare professionals. It seems that existing research either studies how guidelines can be integrated into EHRs or

how IT-based knowledge repository solutions can bridge the gap between evidence and practice. Considering that medical guidelines provide summaries of evidence, future research should also examine how an IT-based knowledge repository can be used as a complement to computer-based medical guidelines.

## 2.6 AN ANALYSIS OF THE RELATIONSHIP BETWEEN EBM, SDM, PROCESS ORIENTATION AND KNOWLEDGE MANAGEMENT

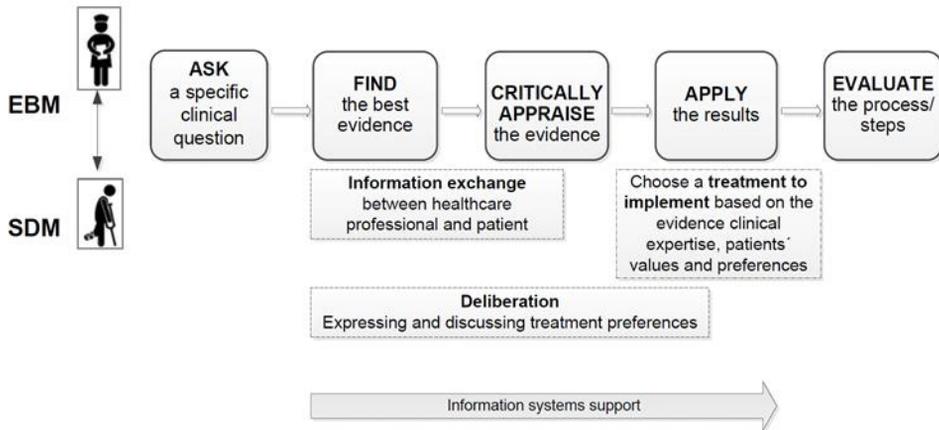
The definitions of the concepts and theories in the previous sections demonstrate a clear relationship between evidence-based medicine, shared decision-making, business process orientation, and knowledge management. Firstly, EBM is an approach to decision-making, in which the healthcare professional, in consultation with the patient, uses clinical expertise and the best evidence available to decide upon the treatment option that best suits the patient. Secondly, SDM is the process wherein a healthcare professional and patient jointly participate in making a healthcare decision, after incorporating the body of evidence (the options, benefits and harms) and considering the patient's values, preferences, and circumstances. Without SDM, authentic EBM cannot occur, as EBM requires that the healthcare professional includes evidence in the consultation and discusses it with the patient. Likewise, without attention to the principles of EBM, SDM becomes limited, because a number of its steps are inextricably linked to the evidence. For example, a patient's values, preferences, and circumstances must be discussed in relation to the benefits and harms of each possible treatment option before a joint decision is made. Hence, the connection between evidence-based medicine and shared decision-making is essential to quality healthcare.

When studying the five essential steps of EBM one can see that these steps are mainly performed by the healthcare professional. For example, the second and third step in EBM; finding the best evidence with which to answer the questions and critically appraising the evidence for its validity and usefulness, are usually only performed by the healthcare professional. Step number four on the other hand; applying the results to clinical practice and making a decision, involve both the healthcare professional and the patient. It is in this step (step four) where SDM enters the process of EBM (see figure 8). In these original models of EBM and SDM, the healthcare professional is seen as the primary source of medical knowledge (see figure 8). However, the relevance of this view can be questioned.



**Figure 8:** The original model of EBM and SDM. The model shows the steps in EBM and what steps are performed by the healthcare professionals alone and those performed together with the patient namely, step four. Thus SDM enters EBM in step four.

In recent years, it has been reported that patients seek information outside of the clinical setting and use a number of additional information sources such as websites, friends, relatives and patient support groups to meet their information needs (Protière, Moumjid, Bouhnik, Le Corroller Soriano, & Moatti, 2012). Seeing the healthcare professional as the main source of medical information is thus no longer true. Hence, the performance of the second step in the EBM process can also include the patient. For example, the patient may already have found information about different treatment options that he/she brings to the patient encounter. Therefore, the focus in this step will be on evaluating the information found by the patient. Once there is an agreement on the information that will form the basis for a decision, the healthcare professional and the patient can continue with the deliberation process and finally implement the decision. The healthcare professional can also encourage the patient to seek out medical information online and bring their questions for discussion at the next patient encounter. Taking into consideration patients' changing information behavior, the original model of EBM and SDM (see figure 9) requires tailoring according to this change (see figure 9).

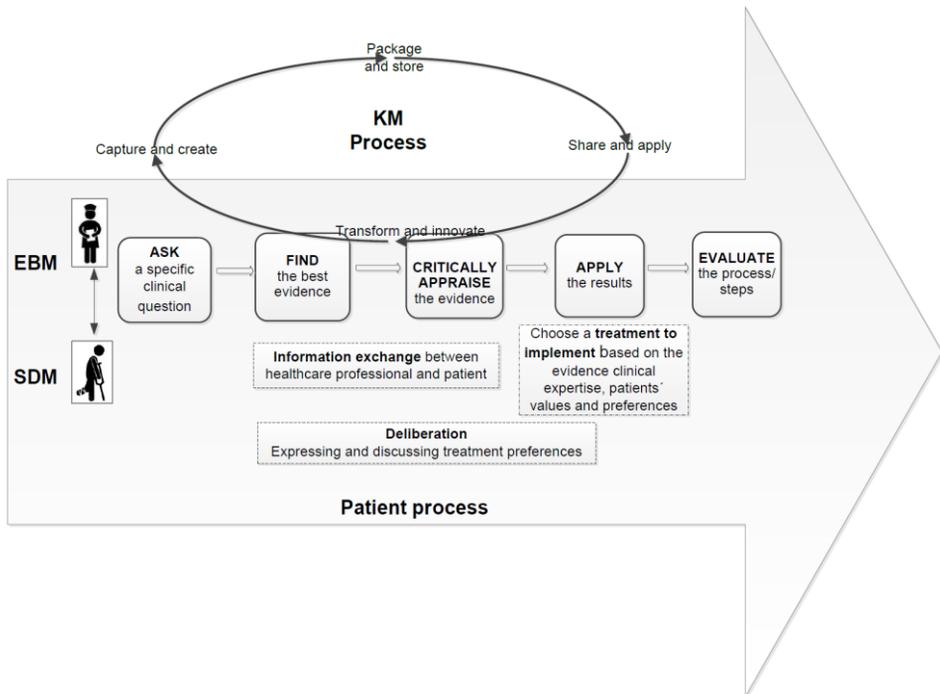


**Figure 9:** Patients' changing information behavior requires that the process of SDM enters EBM in step two.

In order to develop information systems that support healthcare professionals in their efforts to work according to evidence-based medicine where they together with the patient participate in a healthcare decision, it is necessary to consider whether other theories can be used in the development of such systems and, if so, how. The foundation of EBM and SDM is the availability of patient information and medical knowledge. After studying these theories, it seems obvious that the theories of knowledge management and process-orientation need to be employed. Knowledge management, in the context of evidence-based medicine and shared decision-making, can provide an effective and efficient way to structure, promote and provide timely medical knowledge to healthcare professionals and patients, when and where they need it, in order to help them make high quality healthcare decisions (do Rosário Cabrita et al., 2014).

As mentioned in section 2.1, the implementation of EBM involves five sequential steps. These steps are about asking/creating a well-built clinical question, finding the best evidence to answer the clinical question, critically appraise the evidence to determine its validity and applicability to the clinical question, apply the evidence in conjunction with the patient's values and expectations and evaluate the outcomes. These concepts of EBM are part of the KM cycle that offers a structured process for capturing, creating, storing, sharing and applying/using the medical evidence. This includes both tacit knowledge (clinical expertise in EBM) and explicit knowledge (medical evidence in EBM). The abundance of the medical evidence together with limited information systems support makes it difficult for healthcare professionals to perform the various steps of EBM especially those steps aimed at finding the medical evidence and evaluating it. Hence there is a need to deliver current and relevant evidence, at the right time and in the right format. Failing to do so will have significant negative effects on the quality of care and patient safety. In this context, KM can play an important role by organizing information and making it accessible to healthcare professionals and patients at the right time and in the right format as required by the patient process. Therefore, knowledge management in the context of evidence-based healthcare creates a learning environment and ensures that "best practice" is captured, stored and shared (Fennessy & Burstein, 2007) (see figure 10). In accordance with do Rosário

Cabrita et al. (2014), Fennessy and Burstein (2007) and Quinn et al. (2014), knowledge management in this thesis is seen as central to evidence-based decision-making, as it involves organizations and individuals, both healthcare professionals and patients, creating, accessing and exchanging knowledge (both explicit and tacit). Managing knowledge in healthcare organizations is therefore crucial for the practice of evidence-based medicine and shared decision-making, and thereby also important for supporting the optimal achievement of good quality care (Desouza, 2005).



**Figure 10:** The synergy between EBM, SDM, process orientation and KM.

To ensure that relevant medical knowledge is made available to healthcare professionals and patients, healthcare organizations must thus adopt the KM perspective in the development of future information system support. Therefore, the theory of KM has been described and discussed in this chapter. However, successful knowledge management efforts require that KM activities are embedded into organizational processes. These can be any organizational process, for example, the patient process. Once the process has been selected, information regarding the kind of knowledge that will flow through the process and the knowledge that is needed during the different activities within the process must be identified and documented (Barnes, 2011). Since EBM and SDM comprise explicit and tacit knowledge, the theory of KM can be used to show how it can be linked in the execution of organizational processes, and ensure that only relevant medical knowledge is made available in the context of this process. Thus, by grounding KM activities around the process, it can help the organization understand

the knowledge needs of health professionals and patients during the different parts of the process. Hence, it will be possible to ensure that only relevant knowledge for the specific process is made available to those who need it, when they need it (El Sawy & Josefek, 2004). Moreover, EBM and SDM comprise patient information, preferences and values. In order to improve the quality and safety of care, this information needs to be available when decisions about the care of individual patients must be made. Therefore, the concept of process orientation has been adopted in this thesis. Process orientation places emphasis on organizational processes based on the patient perspective, instead of an emphasis on functional and hierarchical structures (Kohlbacher, 2010). A process-oriented approach with a supporting information system is crucial, as it can streamline the flow of both patient information and medical knowledge. It can thereby ensure that healthcare professionals and patients always have access to the right information when healthcare decisions must be made. Moreover, in order to contribute to improvements in healthcare, one must view patient information and medical knowledge as interconnected, continually impacting on each other. Therefore, when future healthcare information systems are developed, the synergy between EBM, SDM, process orientation and KM must be considered (see figure 10).

# METHODOLOGY



## CHAPTER 3

# METHODOLOGY

This chapter first describes the research paradigm and approach applied to the research presented in this thesis. A description of the research process then follows, while a discussion regarding trustworthiness of the research concludes the chapter.

### 3.1 RESEARCH PARADIGM AND RESEARCH APPROACH

A paradigm is a set of shared assumptions or ways of thinking about some aspect of the world (Oates, 2005). A research paradigm is an underlying set of common beliefs and agreements, shared between scientists, about how problems of research should be understood and addressed and how elements of research fit together (Kuhn & Hawkins, 1963; Wisker, 2007). These basic beliefs guide the action to be taken in research (Denzin & Lincoln, 2011). According to Oates (2005), different philosophical paradigms have different views about the nature of our world/reality (ontology) and the ways we can acquire knowledge about it (epistemology). Crotty (1998) further argues that ontology is the study of being. It is concerned with the “what is”, with the nature of existence, the structure of reality as such. Epistemology deals with the “nature of knowledge”. It involves knowledge and embodies a certain understanding of what is entailed in knowing, that is, how we know what we know (Crotty, 1998). The two major philosophical paradigms are positivist and interpretivist (sometimes written as interpretive). Positivists see the world as a collection of observable events and facts which can be measured. Hence, the emphasis is on quantitative data (Williamson, 2002). The deductive approach, linked with the hypothesis testing, is mainly associated with this paradigm. The interpretivist paradigm emphasizes the meanings made by people as they interpret their world (Williamson, 2002, Oates, 2005). Researchers who are interpretivists favor naturalistic inquiry (where field work usually takes place in the “natural setting”) and are concerned with “meaning” (Williamson, 2002). They believe that the social world is interpreted or constructed by people and is therefore different from the world of nature. Therefore, they look at how people perceive their world (individually or in groups) and try to understand phenomena through the meanings and values that people assign to them. Hence, this paradigm is associated with inductive reasoning (Oates, 2005).

Moreover, researchers believe that the interpretivist paradigm predominantly uses qualitative methods. Several researchers have argued that the research questions and the phenomenon under investigation should determine what methodology to use (Pope & Mays, 1995; Silverman, 2013). According to Mays and Pope (1995), the crucial question is therefore not “what is the best research method?” but “what is the best research method for answering this question most effectively and efficiently?” The nature of the research problem and the questions addressed in this thesis requires a rich understanding of the healthcare organization and how healthcare professionals and patients make sense of their perceived worlds. Hence, the interpretivist paradigm and the qualitative approach were considered the most appropriate methods to address the research. As explained by Willis and Jost (2007) and Williamson (2002), the qualitative approach provides rich reports that interpretivists require to fully understand people, as well as the social and cultural circumstances in which they live, by enabling them to verbalize thoughts about the context under study. The qualitative and interpretive research approach can help us understand the challenges faced by healthcare professionals and patients, with regard to information access and communication issues, by putting emphasis on the meanings, experiences and views of the participants (Mays & Pope, 1995). Qualitative researchers are thus interested in the beliefs, feelings and interpretation of people. Therefore, they tend to use qualitative research methods, such as action research, case study research and ethnography. Qualitative techniques for data collection include observations, interviews, questionnaires and text analysis (Myers, 1997). In qualitative research, the research participants are viewed as “helping to construct the reality with the researchers” (Robson & McCartan, 2016). Bridget Byrne (2004) in Silverman (2006) suggests that qualitative interviewing is “particularly useful for accessing individual’s attitude and values – things that cannot necessarily be observed or accommodated in a formal questionnaire”. The author further argues that “open-ended and flexible questions are likely to get a more considered response than closed questions and therefore provide better access to the interviewees’, interpretation of events, understandings, experiences and options... [qualitative interviewing] when done well is able to achieve a level of depth and complexity that is not available to other, particularity survey-based, approaches” (Silverman, 2006). Kaplan and Maxwell (2005) also argue that the goal of understanding a phenomenon from the point of view of the participants and its particular social and institutional context is largely lost when textual data are quantified.

A qualitative research methodology is viewed as significant in information system research, due to the value of capturing and explaining what is going on in real organizations (Jabar, Sidi, Selamat, Ghani, & Ibrahim, 2009). Additionally, as information systems research shifts from technological to managerial and organizational issues, qualitative research methods become increasingly useful (Myers, 1997). Our field of study involves a complex social context in which the care of a patient evolves from an isolated process towards a continuous one that incorporates multiple independent healthcare providers and different healthcare professionals, each with their own requirements and expectations of healthcare information systems. The social context makes it difficult to use controlled experiments and/or survey methods. There may be some aspects of the area that could be investigated by survey methods, but considering the research questions of the thesis, we have strong doubts about the relevance and effectiveness of such an approach.

In conclusion, we argue that answering the research questions requires a research approach that focuses on understanding people as well as the social and cultural contexts

in which they communicate and act. Taking the aim of this thesis and the discussion about the research methods into consideration, we concluded that the case study approach in combination with data collection techniques, such as interviews and observations, were the most appropriate methods to use, in order to gain empirical data. A detailed description of the research process and the data collection techniques that were used for each case study are described in the next section.

### 3.1.1 CASE STUDY RESEARCH

Case study research is the most common qualitative method used in information systems (Myers, 1997). Clearly, the case study research is particularly well suited to information system research, since the object of the discipline is the study of information systems in organizations, where the research interest has shifted to organizational rather than technical issues (Benbasat, Goldstein, & Mead, 1987). A case study is, according to Yin (2013), an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, 2013). In a case study, the case may be a group of people, an organization, process, or an information system. Since there is no standard definition of a case study, this thesis draws the definition from Benbasat et al. (1987, p. 370):

A case study examines a phenomenon in its natural setting, employing multiple methods of data collection to gather information from one or a few entities (people, groups, or organizations). The boundaries of the phenomenon are not clearly evident at the outset of the research and no experimental control or manipulation is used (Benbasat et al., 1987, p. 370).

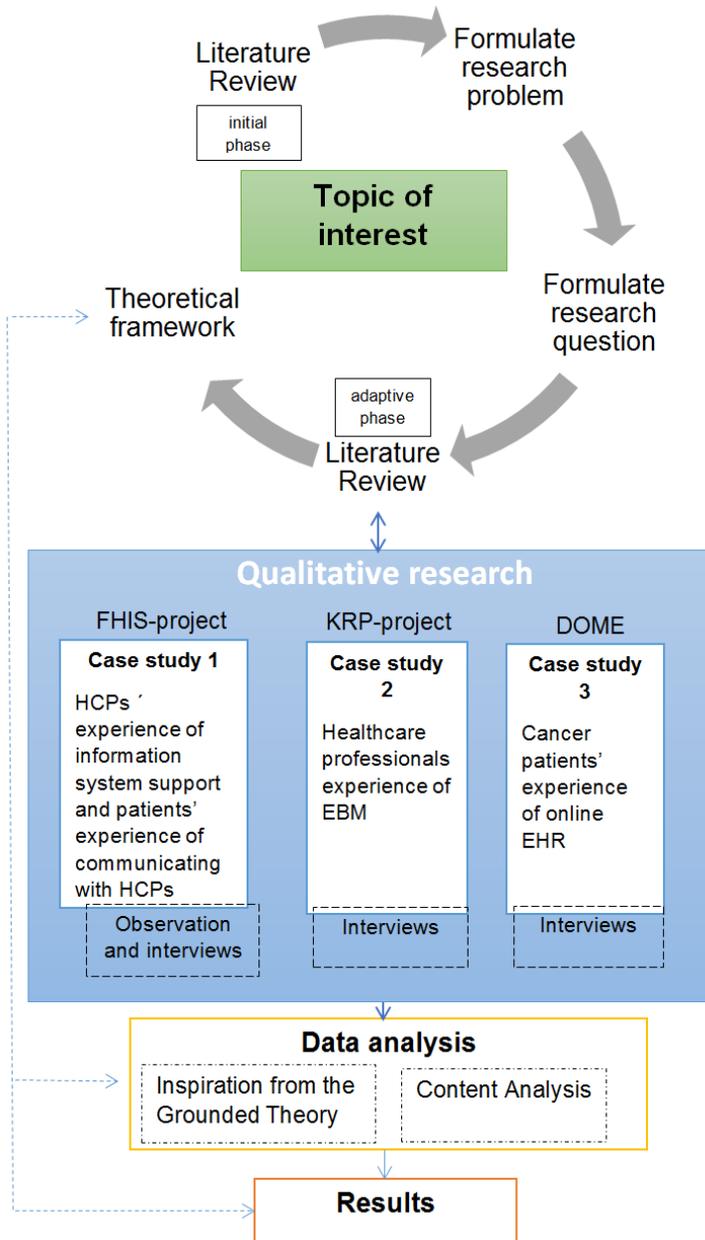
Case study research is particularly appropriate for situations in which the examination and understanding of the context is important, such as areas where there is little understanding of how and why phenomena occur, and where the experience of individuals and the contexts of action are critical (Williamson, 2002). Since patients' experiences and the requirements of communicating with healthcare providers, as well as healthcare professionals' experiences regarding the availability of patient information and medical knowledge are not well understood, case study research is appropriate for this thesis. Case study research uses multiple data collection techniques, such as interviews, observations, questionnaires, as well as document and text analysis. Three case studies are included in this research. These case studies are compatible because they deal with the availability of patient information and medical knowledge, when and where it is needed by healthcare professionals and patients.

## 3.2 RESEARCH PROCESS

The research is based on three case studies (see figure 11). In 2009, a research project, Future Healthcare Information Systems (FHIS), was initiated. Within this project, one case study was conducted regarding "healthcare professionals' experience of information system support and patients' experience of communicating with healthcare professionals". This case study started before the author of this thesis formally began her doctoral education. Consequently, observations and interviews with healthcare practitioners and patients within the case study had already been carried out as part of the first research activity, "A current state analysis". The author entered the project

at the later phase of this research activity, where the plan was to carry out “As-Is” process models based on the collected data from the case study. Therefore, the author’s work as a participant researcher in the FHIS project started with analyzing the collected data from the interviews and observations and carrying out process modeling. In addition, the author has had a central role in the development and evaluation of the process support system (PSS) that is a central part of this thesis. Shortly after the FHIS project, the author entered the “Knowledge repository project” (KRP), which was a collaborative venture between Vårdsamverkan Skaraborg and the University of Skövde, Sweden. Within this project, one case study was conducted, “healthcare professionals experience of EBM”. The author had a leading role in this case study, planning and executing the research. The main data collection technique used to collect the empirical data was interviews and the author had the sole responsibility of conducting the interviews and analyzing the data. The third case study, “cancer patients’ experience of online EHR”, was carried out as part of the consortium “Deployment of Online Medical Records and eHealth services” (DOME). The author entered the DOME consortium after the case study had been planned, with interviews as the main data collection technique. These interviews were conducted by three researchers, one of which is the author. The data analysis took place in cooperation with three other researchers, all part of DOME.

Moreover, within each case study, a literature review was carried out in two distinct phases; an initial phase that aimed to gain knowledge about the studied object and an adaptive phase where the literature was used to understand the empirical results in relation to existing research (see figure 11).



**Figure 11:** *The research process.*

### 3.2.1 LITERATURE REVIEW

According to Webster and Watson (2002), a literature review of prior research is an essential feature of any academic project, since it creates a firm foundation for advancing knowledge. Moreover, “it facilitates theory development, closes areas where a plethora of research exists, and uncovers areas where research is needed” (Webster &

Watson, 2002, p. xiii). A literature review comprising two phases was carried out. In the initial phase, the aim was to establish an overview of past and contemporary work on information system research, in relation to EBM and SDM. This phase helped in gaining knowledge about the studied object, which included (Robson & McCartan, 2016):

- Gaining knowledge about what is already known regarding, e.g., information system solutions in healthcare, how evidence-based medicine and shared decision-making are supported through information technology, as well as limitations and possibilities of these.
- Identifying general patterns to findings from multiple examples of research in the field of EBM, SDM, business process orientation and KM.
- Identifying variations of definitions used by researchers with regard to, e.g., KM, EBM and SDM.
- Exposing gaps in knowledge and identifying principal areas of dispute and uncertainty.

Through this phase, it was also possible to identify relevant key theories and previous research (both empirical and theoretical) as well as form a greater understanding of the gap in previous research that needed to be filled. For example, at the beginning of the literature study, the focus was on how EBM can be supported through information systems. However, the literature study showed that much of the existing research describes the support of EBM from a healthcare perspective. Thus, the patient was omitted, even though evidence-based medicine emphasizes patient involvement. At this point, it became clear that shared decision-making and its relation to evidence-based medicine required more exploration. Therefore, the literature review in this phase served as the driving force and the jumping off point for the research investigation presented in this thesis. When an understanding of the research problem was gained, a new literature study was conducted to obtain deeper knowledge of the theories that are the basis of this study, the relationship between them and the degree to which the existing theories have been investigated. Moreover, the literature review helped in identifying appropriate research methodologies and data collection techniques (Robson & McCartan, 2016). It also played an important role in the formulation of the interview questions for the case studies. In the adaptive phase, the aim of the literature review was to understand the empirical results in relation to existing research.

In order to identify relevant papers, the literature review started with the identification of keywords. These were found by analyzing the concepts that are used in the research problem and research questions. Some of the keywords used include: “information system and healthcare processes”, “knowledge management and knowledge management processes”, “evidence-based medicine and knowledge management”, “patient engagement”, “evidence-based medicine and information systems”, “shared decision-making and healthcare decisions”. When these keywords had been identified, the literature review started with a general search of scientific papers through the use of various databases, such as Worldcat Local, ScienceDirect, Google Scholar and MEDLINE (PubMed). Papers were also found by searching in leading journals, such as Information Systems Research, MIS Quarterly, BMJ, Patient Education and Counseling, Health Informatics Journal, and Journal of Knowledge Management. As the search continued, alternative useful words that occurred during the searches were added to a keyword list.

Research papers were selected by reading the title and abstract. The reading of papers was iterative, which means they were read several times, in order to ensure a correct understanding of the content. Relevant phrases and concepts were underlined and summarized. While reading the papers, attention was also paid to the reference list of each paper. The purpose was to use Bates' technique of "linking" (Bates, 2002), which aims to find new references from the reference lists of others. The paper by Lenz and Reichert (2007) made an early impression, because it has contributed to the identification of other relevant literature, such as Musen and van Bommel (1997) who emphasize the importance of having access to patient information and medical knowledge in healthcare decision-making.

### 3.2.2 CASE STUDIES

#### **CS1: Healthcare professionals' experience of information system support and patients' experience of communicating with healthcare professionals**

The aim of the project "Future Healthcare Information Systems" was to develop a prototype visualization of a process support system (PSS) that demonstrates the requirements for future process-oriented information system support in healthcare. The vision for the process support system is that healthcare professionals, from all levels of healthcare, and patients should have access to efficient collaborative information systems that support process-oriented care in which the patient is a distinct and active collaborator.

The process support system was developed in close collaboration between researchers at the University of Skövde, a local hospital in the Västra Götaland region of Sweden, and healthcare organizations in the southern region. The overall healthcare process is extremely complex, and endeavors to tackle it all within one project would clearly not be feasible. Therefore, one of the first tasks of the case study was to select a suitable sub-process as the focus of the work. However, the chosen sub-process had to meet certain requirements, such as:

- Enable the patient to play an active role in their own healthcare.
- Be relevant for more than one level of care (primary care, hospital care and municipality care) in order to demonstrate general applicability.
- Be relevant for more than one healthcare profession.
- Exhibit enough complexity, particularly in terms of information flow, to demonstrate a substantial difference between the existing way of working and the proposed future way of working, and
- Occur often enough for the changed way of working to have a substantial impact on both healthcare professionals and patients.

Based on these requirements, the process of initiating, planning, carrying out and following up a patient's visit/patient encounter at a healthcare provider was selected. This process was termed "Patient Visit" and was limited to involving only ambulatory care. Moreover, the selected process occurs frequently and exists both in primary and hospital care. Instances of the process in primary and hospital care also communicate with each other. Hence, it involves the desired element of complexity. Several professional groups are involved in the process and the patient needs to play an active role.

Also, the chosen process was suitable to demonstrate the intricacies of the communication between a patient and healthcare providers. In order to be able to make the demonstrator concrete and illustrative, two scenarios of the “Patient Visit” process were chosen for implementation; a patient with hip osteoarthritis and a patient diagnosed with angina.

The first step in the prototype development was to collect data within the case study regarding 1) how current information systems support healthcare professionals in their daily work practice with regard to availability of patient information, and to a certain extent availability of medical knowledge, 2) how patients experience the exchange of information with healthcare providers, and 3) identifying user requirements for future process-oriented information system support. For this purpose, three main activities were carried out:

### **1. A current state analysis**

This activity was carried out in close collaboration with healthcare professionals as well as patients from an orthopedic clinic. Additional information was gathered from a cardiology clinic, eye clinic, emergency department and primary care centers. The objective of this activity was to (1) explore and create a comprehensive picture of how current information systems support healthcare professionals and patients’ information needs and (2) identify requirements for future information system support. For this purpose, interviews and direct observations were regarded as adequate techniques for data collection (Berg, 2004). Eighteen semi-structured interviews (see appendix A) and direct observations of healthcare professionals were conducted. The observations of the healthcare professionals lasted from a half to a full working day and involved visual inspection of their everyday work activities, observing what and how tasks were being carried out.

Moreover, the consultations and conversations that took place between the patient and the physician during the patient meeting were observed. In total, seven direct observations that lasted between 10 - 20 minutes were conducted. Each observation was complemented with a semi-structured interview (see appendix A), which made it possible to gain a deeper understanding of the data collected through the observations. The aim of the interviews was to study how patients perceive their patient process.

All interviews with healthcare professionals and patients were taped, transcribed and analyzed (see section 3.2.3 for the qualitative data analysis), and lasted approximately two hours each. During the interviews, the interviewer took notes of the responses, which allowed the interviewer to highlight key points that needed further reviewing. All transcripts followed a standard format and included the following information:

- Date, time and place (city and healthcare provider, e.g., primary care) of the interview.
- The profession of the interviewee.
- To assure the anonymity of the interviewee, each interview was marked according to a coding system, e.g., VN550, whose code key was kept at a different location to the interviews, so that only the interviewer could identify the participants (Thomsson, 2010)
- List of acronyms (e.g., I = interviewee, and R = researcher, thus the interviewer).

An observation protocol was used to record information obtained during the observations of the healthcare professionals and the patient encounter. A descriptive notes section for the description of activities was also included in the protocol (Creswell, Hanson, Clark Plano, & Morales, 2007). In addition, the results of the observations and the interviews were discussed with the healthcare professionals and the project team members.

The possibility of complementing direct observations with other techniques, such as interviews or questionnaires, is, according to Robson and McCartan (2016), one of the main advantages of observation. Interviewing is a conversation for the purpose of gathering information about the context under study (Berg, 2004). Conducting semi-structured interviews enabled the in advance predetermination of the ground to be covered and the main questions, related to the patient visit process, to be asked. Although a list of predetermined questions was prepared, the interviewer was allowed the freedom to change the order of the questions or the way they were worded, in order to adapt to the flow of the interview and to explore issues deemed important (Berg, 2004).

Data obtained from the interviews and observations resulted in “As-Is” process models that described the patient meeting. These models helped to gain an overall picture of the business practice in the organization, and to describe how tasks are carried out during the patient visit and what kind of information is needed to perform various work activities. The models also helped to identify user requirements for the process support system. The process models have played an important role in the communication between the healthcare professionals and the researchers within the project. Modeling business processes, or workflows, often plays a central part in the development of information systems, as well as the re-engineering of work practices (Krogstie, Sindre, & Jørgensen, 2006).

The method used for modeling the chosen process and for the prototype development was the “Visuera method”. It was chosen for the following reasons:

- The Visuera method is a process modeling method that enables the modeling of activities and related actors in an organizational process. One particular feature of the method is that it integrates the flow of information with the activities in the process and also allows for the definition of concepts used in the process. Since the general focus of our research is to enhance the support that information can provide to healthcare processes, this was considered an important feature.
- The models produced with the method are fairly easy for non-experts to understand. Since an important part of the work required that healthcare professionals evaluate the feasibility of the proposed future process before it was implemented in the demonstrator, the aspect of usability for non-experts was considered to be essential.
- The method comes with a supporting tool that can take a graphical model describing a process and the related information flows and “translate” it into a simulation/demonstrator of how a system will work and how it will look, without actually implementing the system. Since the objective of the FHIS project was to develop a demonstrator, it was a reasonable choice.

Moreover, the method consists of five steps:

1. Analyzing the As-Is processes. In this step, current activities are documented in a graphical As-Is process model.
2. Specifying the requirements (To-Be). Here, components in the As-Is process models, which have the potential to be made more efficient, are identified. A To-Be process model is developed. Efficiency can be achieved by:
  - i. Automating work currently being performed manually.
  - ii. Removing manual or automated tasks that have no significance for activities later in the process.
  - iii. Improving the quality of activities in the process.
  - iv. Making sure that the end results of all activities have the highest quality.
  - v. Improving throughput time by adding, deleting or reassigning tasks in the process.
  - vi. Improving information quality in the processes.
3. Developing a supporting information system if technological change is necessary, based on To-Be process models.
4. Deploying the new process and information system. In this step, employees affected by the information system are educated.
5. The production and monitoring of improved processes and their support systems.

The Visuera method follows strict rules and has its own tool; the Visuera Business Process Modeler, which aims to ensure that process models have the same look and feel, regardless of organizational domain. The process models contain only a few symbols that intend to be intuitive. In addition, it is possible to abstract or detail the process models into an unlimited number of levels. The prototype, presented in this thesis, acquired all its sample data and flow logic directly from the process model. Moreover, to increase the models' accuracy, they were discussed with healthcare professionals. It was also important to make the models as generalizable as possible, in order for them to be valid for several different healthcare units.

## **2. Modeling of the intended future state**

Based on the assessment of the current clinical situation and the “As-Is” process models, work began on specifying the requirements of the proposed future state (To-Be models). The identification of the requirements began with an “idea seminar” that included the project’s reference group. During this seminar, a number of “objectives” for the future state were identified. These objectives and the current state description of the first project activity formed the basis of a number of idea seminars/workshops with healthcare professionals. During these seminars/workshops, healthcare professionals were asked to discuss objectives and ideas regarding how an ideal process for the patient visit should work in the future and what type of information system support would be needed to accomplish the goals. A total of four seminars were held with approximately 15 to 20 people per session. The purpose of these seminars/workshops was thus to identify user requirements for the future state. Based on these requirements, the future patient meeting process was elaborated, in order to identify the sub-

processes and information flows. Process models of the different sub-processes, comprising activities, roles, and information flows, were then created. An important part of this work was to identify the detailed contents of the information needed for the various activities in the future patient meeting process. The information content was sketched in forms with the Visuera Business Process Modelling 2007 tool. Subsequently, the process models and the information content were validated by healthcare professionals during workshop sessions, brainstorming meetings, seminars and lectures. In addition, a representative from a patient organization provided feedback on the models.

### 3. Prototype development:

Based on the identified user requirements and after a number of iterations to ensure the quality of the process models and the information content, key design principles for a future process-oriented information system were identified. To visualize the key principles, a prototype of a process support system was developed with several user interface screens. The resulting prototype was evaluated in relation to the user requirements identified through observations, workshops and interviews. In addition, identified user needs were also evaluated in relation to the Swedish national strategy for eHealth and in seminars involving healthcare professionals, patients, and information system providers. Based on this evaluation, the prototype was refined.

The findings of this case study have resulted in five published research papers:

Rexhepi, H., Åhlfeldt, R. M., & Persson, A. (2015). Towards effective and efficient information system support for healthcare processes: A healthcare practitioner perspective. *IADIS International Journal on Computer Science and Information System*, 10(1), 80-96.

Krasniqi, H., Åhlfeldt, R. M., & Persson, A. (2011). Patients' experiences of communicating with healthcare- an information exchange perspective. *In 15th International Symposium on Health Information Management Research (ISHIMR 2011)* (pp. 241-251). University of Zurich.

Åhlfeldt, R. M., Persson, A., Rexhepi, H., & Wåhlander, K. (2016). Supporting active patient and health care collaboration: A prototype for future health care information systems. *Health informatics journal*, 22(4), 839-853.

Rexhepi, H. (2015). Process oriented information systems: A key to evidence based medicine. *IADIS International Journal on Computer Science and Information System*, 10(1), 64-79.

Rexhepi, H. (2016). Information Systems for the Practice of Evidence-Based Medicine and Shared Decision Making. *In 10th European Conference on Information Systems Management: ECISM 2016* (p. 258). (pp. 258-270).

## **CS2: Healthcare professionals' experience of EBM**

The “Knowledge repository project” was a collaborative endeavor between all the healthcare providers in Skaraborg, a sub-region of Västra Götaland, and the University of Skövde, Sweden. The aim of the project was to:

“Explore the possibility of creating a structured, resource-efficient and sustainable model for developing and managing a coherent IT-based knowledge repository for different areas of knowledge bases in healthcare. Coherent, means that there is one entrance to the knowledge the portal includes. Healthcare practitioners can use the IT-based knowledge repository to search for relevant and current medical knowledge”

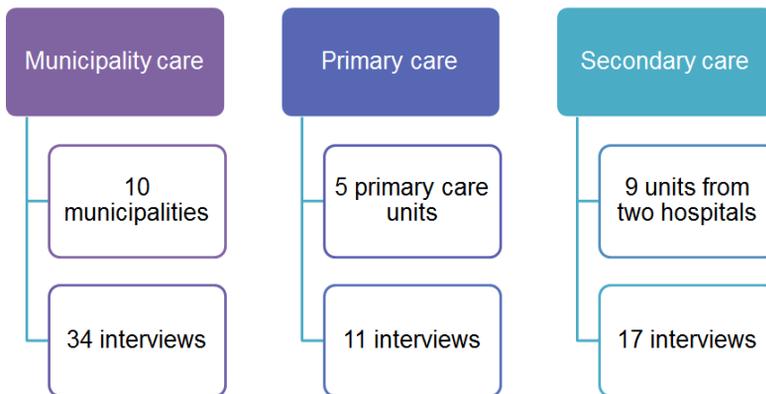
One case study was conducted within the frame of the project. The case study was conducted in two parts. The aim of the first part of the case study was to gain insights and an understanding of existing IT-based knowledge repositories in Sweden. For this purpose, the characteristics and challenges of Swedish IT-based knowledge repositories containing medical knowledge were analyzed. This analysis not only identified challenges that current Swedish knowledge repositories are facing, but also the need for a comprehensive IT-based knowledge repository. Based on these results, the case study continued by exploring:

- How healthcare professionals experience the availability of medical knowledge when and where they need it.
- What kind of medical knowledge is missing and/or difficult to obtain at the point of care, and what are the requirements for the development of a future IT-based knowledge repository.
- The conditions for developing a coherent IT-based knowledge repository for different areas of knowledge bases in healthcare.

Within the first part of the case study, 15 IT-based knowledge repositories were included in the analysis. In order to collect empirical data, two data collection techniques were used. The first was a review of the IT-based knowledge repositories according to predefined questions. The aim of this review was to collect a variety of IT-based knowledge repositories at national, local and regional levels, which would demonstrate the multitude of approaches to creating knowledge repositories. The second method employed telephone interviews with managers of the IT-based knowledge repository (see appendix B). Since telephone interviews lack face-to-face, non-verbal cues that researchers use to pace their interviews and determine the direction in which to move, they are not regarded as a major way of collecting qualitative data (Berg, 2004). However, in accordance with Berg (2004), telephone interviews were an effective means of gathering data, owing to the geographic locations of the interviewees.

Within the second part of the case study, 62 semi-structured interviews were conducted with managers, nurses and nursing assistants from primary, specialist, and municipality care (see appendix B). A letter requesting participation in the research project was sent to managers within each municipality in the Skaraborg region of Sweden. A request was also sent to managers in primary care and to different specialist care units in Skaraborg, Sweden. The letter requested interviews with one manager,

two nurses and two nursing assistants with varying experiences of working in the healthcare sector. Since the results of the first study showed that the majority of IT-based knowledge repositories had physicians as the main target group, they were excluded from this stage of the research study. The inclusion criteria also comprised factors such as different age range and gender. The managers then suggested one or two individuals who were willing to participate in the study. When the researcher started to gather information from the respondents, she was then put into contact with others. However, there is always a risk with this type sampling. For example, there is a risk that managers only suggest practitioners who are familiar with KM and who will talk well about the organization. However, based on the analyzed data, managers have been successful in recommending healthcare professionals who were willing to share the KM difficulties that the organization is experiencing. Moreover, an equitable distribution of the professional roles that participated in the study has been sought. Unfortunately, it was not possible to achieve an even distribution of healthcare professionals and managers at all three levels of healthcare, which could weaken the results (see figure 12). However, in the qualitative interviews, there is a condition known as theoretical saturation, which occurs when the researcher, through a series of interviews, can see a clear pattern and no new data are obtained. For the purpose of this work, we therefore believe that theoretical saturation was achieved at all three levels of healthcare.



**Figure 12:** Overview of the conducted interviews within municipality, primary and secondary care.

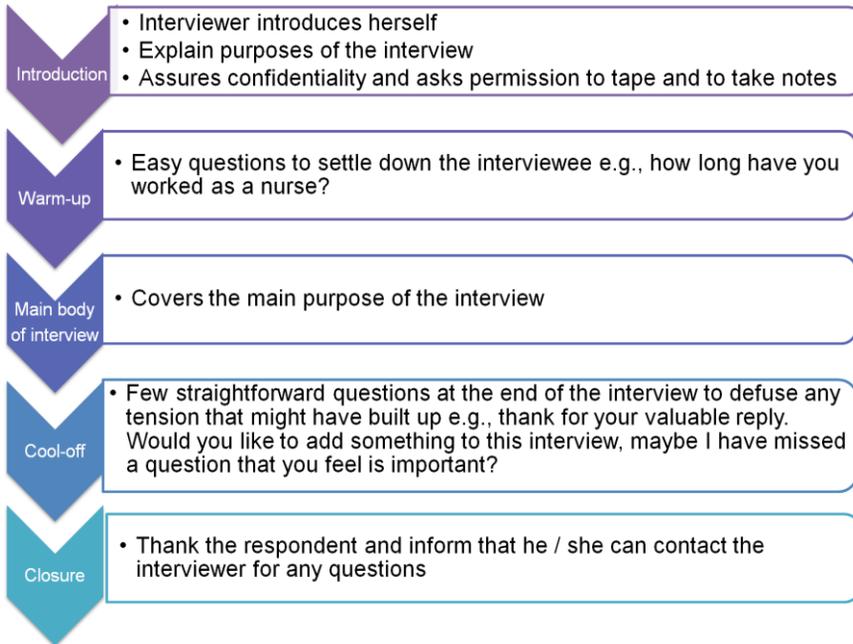
Two interview guides were developed for the second part of the case study; one for managers and one for healthcare professionals, with associated questions based on the KM cycle/process, which means that the following aspects were addressed (see Appendix B):

- Processes for capturing and creating knowledge.
- Processes for packaging, storing, sharing, applying and measuring whether knowledge has contributed to changes in the organization.

The healthcare professionals' interview guide also includes questions with regard to lack of medical knowledge in a clinical situation, for example, "What kind of knowledge do you most often lack access to? Why is this knowledge important for you?"

Interviews as the main data collection technique were thus used during both parts of the case study. There are different forms of interviewing. A commonly used typology distinguishes between structured, semi-structured and unstructured interviews. According to Robson and McCartan (2016), this can be linked, to some extent, to the depth of the response being sought. Using semi-structured interviews as the main data collection technique was appropriate, since the aim was to focus the interview around specific topics related to the availability of medical knowledge. According to Williamson (2002), the semi-structured interview is closer to the unstructured, in-depth interview than to the structured, standardized form. This interview form is best suited when the researcher wants to capture and understand the respondent's perspective on a situation or event under study (Williamson, 2002).

A set of questions was thus prepared in advance for both parts of the case study. However, as the interviews were intended to be conversational, the interviewer changed the order of the questions or the way they were worded, to adapt to the flow of the interview. The technique of "probing" recommended by Robson and McCartan (2016) was also used. This helped the interviewer to encourage the respondent to provide more details to a response, i.e., to say more about a particular topic. Tactics, such as "Can you give me an example?", "Tell me more about that", "Why was that important to you?", were used. Additional unplanned questions were put to follow up the answers (Robson & McCartan, 2016). Moreover, the interview questions were organized according to a commonly used sequence, described by Robson and McCartan (2016) in the figure below (figure 13).



**Figure 13:** *Sequence of interview questions*

The interviews from the first and second part of the case study were taped, transcribed (with pauses and all of the words spoken) and analyzed (see section 3.2.3 for qualitative analysis). The audio taping of a research interview is a considerable advantage, as it provides a permanent record. The taping also allows the interviewer to concentrate on conducting the interview (Robson & McCartan, 2016). During the interview, the interviewer took notes of the responses, which allowed the interviewer to highlight key points that needed further reviewing. The transcription processes started by first listening to each interview and thereafter starting the transcription. In this way, it was possible to obtain a comprehensive understanding of the content of the interview. This approach also facilitated the transcription. When possible, the interview was transcribed on the same day as it was conducted. All transcripts followed a standard format and included the following information:

- Date, time and place (city and healthcare provider, e.g., specialist care, primary care) of the interview.
- The profession of the interviewee.
- To assure the anonymity of the interviewee, each interview was marked according to a coding system, e.g., VN550, whose code key was kept at a different location to the interviews, so that only the interviewer could identify the participants (Thomsson, 2010).
- List of acronyms (e.g. I = interviewee, and R = researcher, thus the interviewer).

The findings of this case study have resulted in two published research papers:

Krasniqi, H., & Persson, A. (2012, September). Web-based Knowledge Portals in Swedish Healthcare-Overview and Challenges. *In Scandinavian Conference on Health Informatics 2012*; October 2-3; Linköping; Sverige (No. 070, pp. 9-12). Linköping University Electronic Press.

Rexhepi, H., & Persson, A. (2017). Challenges to Implementing IT Support for Evidence Based Practice Among Nurses and Assistant Nurses: A Qualitative Study. *Journal of Electronic Commerce in Organizations (JECO)*, 15(2), 61-76.

### **CS3: Cancer patients' experience of online EHR**

The purpose of the DOME consortium is to build knowledge about the implementation and use of eHealth services, such as patients' online access to their electronic healthcare records. For this purpose, research is conducted within three different areas. The first area is part of this case study:

- *Patients and Relatives*: Focus on the patients' and their relatives' perceived benefit of healthcare and eHealth services, such as online access to EHRs.
- *Professions and Management*: Focus on the professionals and management in relation to eHealth services.
- *Development and Implementation*: Focus on information systems development and implementation of eHealth services.

The County Council of Uppsala (LUL) in Sweden was the first county to introduce online access to EHRs, by giving all patients over 18 years of age access to their personal records through the national patient portal '1177.se'. The idea that patients can access their EHR online without the mediation of physicians is, however, controversial. Since the evidence and the qualitative understanding of the impact regarding patients' access to their records (especially severely ill patients such as cancer patients) have remained inconclusive in current research, a case study of cancer patients was conducted in the County of Uppsala between 2013 and 2014. The aim of the case study was to (1) explore severely ill patients' attitudes and experiences of reading their EHRs online, and (2) to increase the understanding of the complexities of developing and launching eHealth services based on direct access to patients' EHRs.

So far, a large number of studies on patients reading their EHRs are based on surveys. In contrast to the earlier efforts, we could, in the literature review, identify a lack of comprehensive qualitative understanding of how specific patients interact with the EHRs in a specific context. Therefore, data were gathered using a semi-structured interview approach. Unlike quantitative surveys, the qualitative research method allowed us to capture and explain (Jabar et al., 2009) patients' experience of reading their records and whether the access affected their role in decision-making.

The Regional Ethical Review Board in Uppsala approved the empirical study. Participants were recruited using an information leaflet that was placed in the waiting area at the Department of Oncology, Uppsala University Hospital, during the summer and autumn of 2013. The sampling of participants was conducted in two groups. Patients in the first group (A) had consulted their EHR online, while patients in the second group (B) had no experience of accessing their EHR online. Thirty (30) patients (15 in

each group) who had volunteered to participate in the study were contacted and subsequently interviewed by four researchers from the DOME consortium (see appendix C). Depending on the patient's wishes, the interviews were conducted either at the patient's home or at the department of Oncology. The cancer patients were under treatment during the period the interviews were conducted. They were also in different stages of their cancer; some had been diagnosed with a recurrence of cancer and had been ill for a longer time. Others were newly diagnosed. Several patients suffered from advanced cancer and were given palliative treatment. The patients were between 30 and 92 years old and nine of them were men.

The interviews were divided among four researchers, of which I was one. The interview guide dealt with six different topic areas:

1. Personal health-related questions
2. Demographic
3. General questions related to the eHealth service, Journalen
4. Questions targeting the content of Journalen and patients' response to it
5. Information security
6. General questions about handling of information, behavior and information-seeking styles

The interviews which lasted between 45 - 60 minutes were all taped, transcribed (with pauses and all of the words spoken) and analyzed (see section 3.2.3 for qualitative analysis). As in previous case studies, the interviewer took notes of the responses during the interview, which enabled the interviewer to highlight certain issues that needed further reviewing. The transcripts also followed the same standard format as in previous studies. However, unlike the other studies, the interviews in this case study were transcribed by a professional and then analyzed by the four researchers involved in the case study.

The research approach used in this case study has some limitations. The qualitative interview approach with a focus on understanding means that the results are transferable to other settings through the readers' own interpretations. Another limitation is that the study is based on a convenience sample of patients with some apparent interest in the EHRs, since they were engaged enough to volunteer as participants in the study. In spite of these limitations, we argue that the chosen method is appropriate in the context of the study, as it provided relevant in-depth insights into the cancer patients' experiences and views of reading their EHRs.

The findings of this case study have resulted in one published research paper:

Rexhepi, H., Åhlfeldt, R. M., Cajander, Å., & Huvila, I. (2016). Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health informatics journal*, 1-10. 1460458216658778.

### 3.2.3 QUALITATIVE ANALYSIS IN THE CASE STUDIES

- **CS1:** Healthcare professionals' experience of information system support and patients' experience of communicating with healthcare professionals & **CS2:** Healthcare professionals' experience of EBM

Grounded theory is both a strategy for conducting research and a particular style of analyzing the data arising from that research (Robson & McCartan, 2016). Each of these aspects has a particular set of procedures and techniques. Ideally, grounded theory is applied throughout the research process, that is, from the initial research question to sampling and data analysis. However, according to Foley and Timonen (2015), grounded theory also allows for the use of grounded theory coding procedures after most or all of the data have been collected. Hence, the analysis of the empirical data from the case studies within FHIS and the Knowledge repository project has been conducted with inspiration from grounded theory. Grounded theory analyses are especially suitable when the research attempts to understand the nature of the studied object (Merriam, 1988). Since this work seeks to describe how healthcare professionals experience the availability of patient information and medical knowledge, as well as how patients experience the exchange of information with healthcare providers, grounded theory analysis was considered suitable, due to its ability to produce a rich, deep description of people's experiences. The aim of the analysis was to find central core categories which, according to Robson and McCartan (2016), are both at a high level of abstraction and grounded in the collected and analyzed data. This was achieved by carrying out two kinds of coding: open coding and axial coding.

Open coding is the first step of the analysis that pertains to the initial discovery of categories and their properties. This first step of open coding began with reading the transcribed interviews several times, in order to achieve a deeper understanding of the respondents' statements. Thereafter, the actual coding started. The open coding of the transcribed data has involved the line-by-line coding of words and phrases through the use of highlighting (Strauss & Corbin, 1990). Each word or phrase was assigned a concept noted in the margin. An example of an identified concept is "support in decision-making". At this stage, the coding was conducted directly in the word document program, by using the "insert comment" function. When all the concepts had been identified, they were grouped into border categories. An example of a category that relates to the above concept is "information explosion". Furthermore, to obtain a better overview of the data, phrases and/or words already marked with the associated concept were transferred to an excel sheet. In order to identify the categories, the concepts, as well as the phrases and/or words related to the specific concepts, were closely examined and compared for similarities and differences, while constantly questioning the data with the neutral inquiry; "what does this indicate and how does it relate to other concepts?" The open coding together with the questions asked constitute the basic grounded approaches to the data and will, according to Glaser (1992), lead to emergent discoveries.

Axial coding involved further exploration of the categories and concepts that were developed in the process of open coding (Oktay, 2012; Strauss & Corbin, 1990). It constituted the process of identifying the relationship between and within the categories. Furthermore, axial coding provided depth to the description of the identified concepts, which evolved into a deep understanding of, e.g., how practitioners experience access to information in the patient process and how patients experience the exchange of information with healthcare providers. It also gave a deeper understanding of the difficulties practitioners experience with regard to the availability of information, as well as how they want future information systems to support their work practice and thereby improve the quality of the delivery of care.

Consider the following example of categories that are related to each other. In the analysis of the transcribed interviews that were conducted as part of the second case study, two major categories which are critical to knowledge management work in an organization were identified, namely, “people’s interest in knowledge searching” and “a dedicated manager”. The comprehensive analysis of these two categories clarified the relationship, i.e., if managers are not personally committed to learning or do not regard sharing and using best practice as critical parts of the quality of care, their attitudes affect people’s interest in KM activities.

Throughout the analysis, “memo-writing” was used to record the researcher’s thoughts about the meaning of codes, as well as how and why they occurred. Memos were also used to clarify the relationship between categories, and to systematically question ideas in relation to what had been said in the interviews (Glaser, 1992; Sbaraini, Carter, Evans, & Blinkhorn, 2011). As this thesis is concerned with exploring and describing the phenomena under study, the open and axial coding of grounded theory completed the interview analysis. This conclusion is supported by Robson and McCartan (2016) who argues that open coding and axial coding complete the analysis, if the aim of the research is not to develop a theory. Otherwise, one must proceed with the third step of the coding, namely, selective coding.

- **CS3:** Cancer patients’ experience of online EHR

At the time of the “Cancer patients’ experience of online EHR” case study, there was little knowledge about cancer patients’ experience of reading their online EHRs. Hence, the use of content analysis was appropriate, as it seeks to provide knowledge, new insights, a representation of facts and a practical guide to action (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Similar to grounded theory, the analysis process started with open coding. The transcribed interviews were read several times, in order to achieve a deeper understanding of the respondents’ statements. While reading, notes were made in the margin when interesting or relevant information was found. When no new information was found, the notes in the margins were carefully analyzed and categorized. The purpose of creating categories was to provide a means of describing the phenomenon and to increase understanding and generate knowledge (Elo & Kyngäs, 2008). Each category was then given a description of what it concerns. During the analysis of the categories, it was also possible to identify major themes with associated categories. To ensure that all the necessary information had been categorized, and categorized correctly, the researchers returned to the original transcripts.

### 3.3 TRUSTWORTHINESS OF THE RESEARCH

Due to the differences between qualitative and quantitative methods, the traditional quality criteria for validity and reliability used within quantitative methods cannot be addressed in the same way in qualitative research (Pitney, 2004). Nevertheless, qualitative researchers tend to use different terminology to distance themselves from the positivist paradigm. Guba (1981), for example, proposes four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

The **credibility** criterion concerns whether the results are credible or believable, from the perspective of the participant in the research, and corresponds to internal

validity in quantitative research (Lincoln & Guba, 1985). To increase credibility in the first case study “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals”, different techniques for data collection, such as observations, interviews and process modeling, were used. The use of these various techniques made it possible to capture different dimensions of the same phenomenon. To test our interpretation, participants provided feedback on the collected data. For example, the business models were continuously discussed and corrected, after feedback from participants such as healthcare professionals.

Credibility can also be discussed within the frame of the second case study, “Healthcare professionals’ experience of EBM”, and the third, “Cancer patients’ experience of online EHR”, where interviews were the main data collection techniques.

The second case study, “Healthcare professionals’ experience of EBM”, was conducted in two parts. The first aimed at analyzing a number of Swedish IT-based knowledge repositories. For this purpose, telephone interviews were conducted with managers of the repositories. To increase credibility, respondents that participated in the telephone interviews were given the opportunity to provide written feedback on the conclusions drawn from the interviews. Unfortunately, only a few took the opportunity to do so. However, before the conclusion of each interview, the interviewer orally summarized the interview, in order to test interpretations and conclusions. In this manner, the respondent was given the opportunity to correct any misunderstandings. During the second part of the study, healthcare professionals and managers were interviewed. Unfortunately, the data collected from this study were not validated with the respondents, which may be a limitation. However, the conclusions from the study were discussed with the project participants that have insight into the different levels of healthcare. Moreover, the respondents did not review the transcribed interviews and the interpretation of the interview data from the third case study, “Cancer patients’ experience of online EHR”, which can be seen as a weakness. However, preliminary results were presented to a focus group where patients could shed more light on the results.

**Transferability** in qualitative research refers to the degree to which the study findings can be generalized or transferred to other contexts or settings. Transferability is synonymous with generalizability, or external validity, in quantitative research. Since the results of qualitative research are specific to a small number of particular environments and individuals, it is impossible to demonstrate that the findings and conclusions are applicable to other situations and populations (Shenton, 2004, p. 69). The responsibility of the researcher is therefore to provide sufficient descriptions of the phenomenon under investigation, so that the readers can understand it properly. This enables them to compare the instances of the phenomenon described in the research report with those they have seen emerge in their situations (Lincoln & Guba, 1985; Shenton, 2004). We have sought a detailed description of the three case studies, so that the readers can decide for themselves whether the results are transferable to their own contexts. For example, information on the following issues has been given:

- The number of organizations taking part in the research studies and where they are based,
- The number of participants involved in the fieldwork,
- The data collection methods that were employed,

- The number and length of the data collection sessions.

**Dependability** is a criterion considered to be equivalent to reliability in quantitative research. It is concerned with the stability of the results over time (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), dependability can be enhanced by using overlapping methods, such as the focus group and individual interviews and an inquiry audit. Overlapping methods were used in the first case study, “Healthcare professionals experience of information system support and patients experience of communicating with healthcare professionals”, which has strengthened dependability. In order to address the dependability issue more directly, project participants, who were not involved in the performance of the studies within the second and third case studies, have examined the processes of data collection, data analysis, and the results of the research study. Moreover, the processes within the three case studies have been reported in detail, thereby enabling the reader to assess the extent to which proper research practices have been followed (Shenton, 2004). In addition, by submitting the research results to peer reviewed conferences and scientific journals, the research process and the research results have been verified by an outside expert “auditor”.

**Confirmability** is “concerned with establishing that data and interpretations of the findings are not figments of the inquirer’s imagination, but are clearly derived from the data” (Tobin & Begley, 2004, p. 392). Strategies, such as recorded interviews and field notes, can enhance conformability, since recorded data can be reviewed and examined (Williamson, 2002). These two strategies have been used in all three case studies. Through record keeping, the researcher has been able to recheck the data throughout the study. Furthermore, the transcribed interviews with associated memos facilitated the review of the identified categories. Moreover, a detailed methodological description of each case study has been given, which enables the reader to determine the extent to which the data and its constructs can be accepted. By using these strategies, conformability has been enhanced.

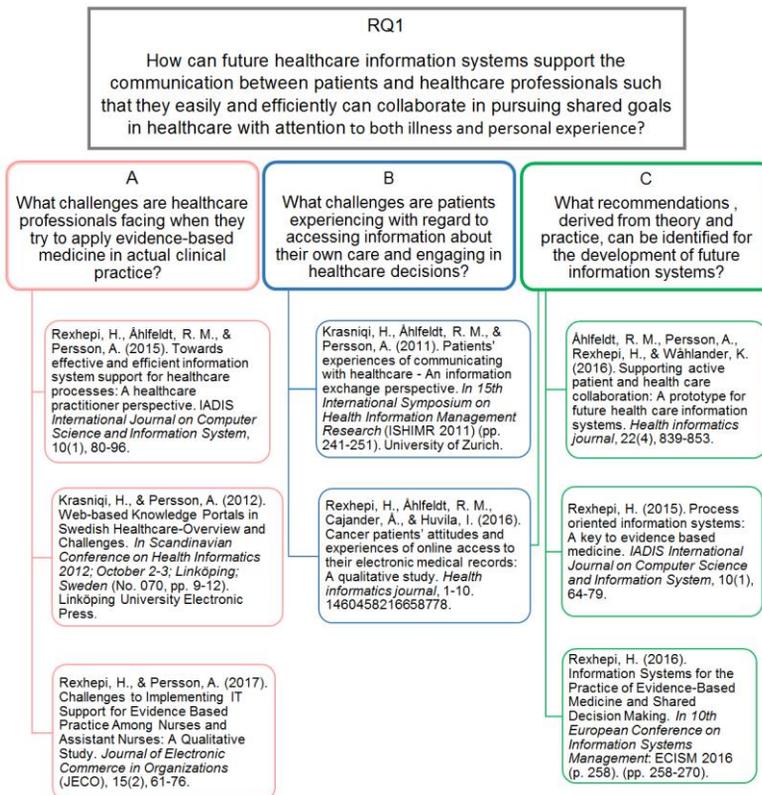






# CHAPTER 4 RESULTS

This chapter provides a brief summary of each research paper, focusing on aims and conclusions drawn. In total, eight research papers serve as the foundation of this thesis. The papers relate to different research questions and they all respond to the aim of the thesis. Figure 14 presents an overview of how each of the research papers contributes to the research questions.



**Figure 14:** An overview of the research questions and related paper.

## 4.1 RQ 1A: WHAT CHALLENGES ARE HEALTHCARE PROFESSIONALS FACING?

Based on the first case study, “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals”, and the second case study, “Healthcare professionals’ experience of EBM”, it was possible to identify the challenges that healthcare professionals experience with regard to accessing both patient information and medical knowledge at the point of need. These challenges have been reported in three research papers and are described below. Hence, they answer research question 1a.

### 4.1.1 PAPER 1: TOWARDS EFFECTIVE AND EFFICIENT INFORMATION SYSTEM SUPPORT FOR HEALTHCARE PROCESSES: A HEALTHCARE PRACTITIONER PERSPECTIVE

This paper is based on the first case study, “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals”. Its aim was to (1) explore how healthcare professionals in Sweden experience information system support in their daily work practice, and (2) present and illustrate how key design principles of a process support system in the form of a prototype can support healthcare professionals in performing their work activities and increase patient engagement.

To understand current, information system support, a current state analysis was first conducted, involving both healthcare professionals and patients. The main research activities included observations and interviews with healthcare professionals and administrators, patients and patient organizations, as well as process modeling and workshops involving professionals from a broad range of disciplines.

The study findings show that healthcare professionals lack access to patient information when preparing and conducting patient visits, as well as when making decisions about the care of the patient. Lack of patient information resulted in inefficiency problems, unnecessary waiting times for patients, and inefficient workflows. For example, during the observation studies, it was apparent that before a patient encounter, a physician had to access several information systems, in order to obtain an overview of the patient’s medical history. Although a number of different systems were used, the physician could never be sure that he/she had a clear and complete picture of the patient. In the absence of this information, a complex set of patient flows emerged, during which healthcare professionals had to spend valuable time locating and collecting relevant patient information. These overall issues affected the degree to which healthcare professionals could apply evidence-based medicine in clinical practice.

In accordance with current research, the study findings also confirmed that the design of EHRs, in particular, the user interface, is related to interruptions in workflow, delays and increased incidence of different types of error. For example, unstructured information in the EHR is a challenge for healthcare professionals. Since the information in the EHR is recorded as free text, without limitations to the format or structure, reviewing them manually was regarded as time-consuming and unsafe because important information was overlooked in the large amount of text. The unstructured format also made it difficult for healthcare professionals to extract important information. Another issue relates to terminology. One doctor may have a particular background and training, whereas another doctor has a different background. Hence, they

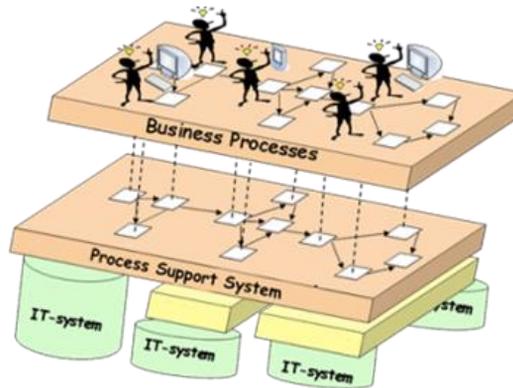
document differently and use different terminologies. Consequently, there is a need to “rationalize” the data, render the terminology into standard sets of terms. Lack of coordination of patient care was also identified as a major problem affecting the care of patients. Interoperability issues were considered to be one of the reasons. Another was the functional organizational structure of task specialization, resulting in the lack of care coordination. Lack of interoperable information systems and the absence of the electronic booking of treatments and examinations complicated the situation even more. Moreover, a recurring problem experienced by the healthcare professionals was related to the care request/referral process. The problem is based on the following:

- (1) It is not possible for healthcare professionals or patients to electronically fill in and send a care request.
- (2) Incoming care requests from primary care usually lack important information. Referrals that did not include the required information were always sent back. This is, according to the healthcare professionals, one of the reasons why patients do not receive care within a reasonable period of time.

To address the above challenges, a prototype for a process support system was developed. The vision for the process support system is that healthcare professionals, involved in the care of a patient, and patients should have access to efficient collaborative information systems that support process-oriented care in which the patient is a distinct and active collaborator, this means that:

- Appropriate parts of the process support system are available to both patients and healthcare professionals, and take into account usability for different user groups.
- The involved roles/users interact through the process support system. The underlying approach is process-oriented.
- Various relevant, individual information systems interact with patients and healthcare professionals through the process support system.

The demonstrated process support system is not a new information system that aims to replace an existing one. It is a process support system that can be viewed as a layer of abstraction or user interface above the various individual information systems. The process support system, enables the enactment of the process and interaction between patients and healthcare professionals through computers and mobile devices, without accessing each individual information system (see figure 15). Moreover, the process support system drives the process forward, ensuring that it is carried out properly and, hence, supports users in performing work activities.



**Figure 15:** The principle of the PSS. The PSS enables interaction between patients and healthcare professionals through computers and mobile devices, without accessing each individual information system.

The architecture of the process support system makes it possible, at least in theory, to replace individual information systems without a significant effect on the user. The process support system connects the following aspects:

- Access to relevant patient information, both medical and administrative.
- Process control providing integrated support for the user.
- Access to relevant medical knowledge through the integration of medical guidelines and an IT-based knowledge repository.

As reported in this paper, patients receive healthcare from several healthcare providers, such as doctors' practices, hospitals, emergency care centers, etc. Since patients' medical and administrative information is fragmented among various proprietary information systems throughout the healthcare organizations, it is difficult for a healthcare professional to access information originally documented by another healthcare provider, causing numerous difficulties for both healthcare professionals and patients. A process support solution, such as the one described in this paper, creates new opportunities to organize and coordinate healthcare. The process support system focuses on the patient process and the information flows within this process. For healthcare professionals, the process support system solution improves the availability of patient information in a uniform and transparent way, anywhere and anytime, as required by the patient process. The process support system reduces double documentation and the manual handling of information, which in turn reduces the risk of making errors. Since healthcare professionals no longer need to spend time on locating patient information, more time can be spent on meeting patients. However, much work remains before a process support system, such as the one presented in this paper, can be fully implemented. For example, there is a need to render the terminology into standard sets of terms and to determine the ownership and responsibility of a process support system that crosses organizational boundaries and supports patient-centered care. Another challenge regards determining who would be responsible for the ownership and quality of the process data.

#### 4.1.2 **PAPER 2: WEB-BASED KNOWLEDGE PORTALS IN SWEDISH-HEALTHCARE – OVERVIEW AND CHALLENGES**

This paper is based on the second case study, “Healthcare professionals’ experience of EBM”. The aim of the study was to explore the possibility of creating a structured, resource-efficient and sustainable model for developing and managing a coherent IT-based knowledge repository for different areas of knowledge bases in healthcare. The purpose of the paper was to report on an analysis of a representative number of Swedish IT-based knowledge repositories. The analysis resulted in the identification of several challenges:

- IT-based knowledge repositories are usually designed to support specific functions and a specific user group, in this case physicians.
- Medical knowledge from IT-based knowledge repositories is usually infrequently available in a form that can be acted upon at the time decisions must be made. The knowledge is often structured in a hierarchical and linear manner comparable to that of a book or report. When a large amount of information is presented to a user all at once, it can lead to confusion and complicate the filtering of unnecessary information. In turn, it can lead to difficulties in managing situations that require choices to be made. Also, this type of structure focuses on gathering information rather than on learning. The problem emphasizes that future IT-based knowledge repositories need to be developed using a governing method that structures knowledge in a suitable way.
- Current IT-based knowledge repositories do not support the exchange of clinical expertise.
- There is a lack of processes and resources in place for maintaining IT-based knowledge repositories.

The conclusions of this study confirm that IT-based knowledge repositories are becoming more and more common in modern healthcare, not only in Sweden but throughout the world. They have the potential to contribute to both the prevention and treatment of health problems, by providing both healthcare professionals and citizens with medical knowledge, when and where they need it. However, in order for IT-based knowledge repositories to live up to expectations, a number of challenges need to be addressed, of which some have been discussed in this paper. The issues addressed in this paper have an impact on the development and the survival of IT-based knowledge repositories over time.

#### 4.1.3 **PAPER 3: CHALLENGES TO IMPLEMENTING IT SUPPORT FOR EVIDENCE BASED PRACTICE AMONG NURSES AND ASSISTANT NURSES: A QUALITATIVE STUDY**

This research paper is also based on the second case study (“Healthcare professionals’ experience of EBM”). Its aim was to (1) explore how primary, secondary, and municipality care in Sweden works with the process of managing medical knowledge, (2) explore how healthcare professionals experience the availability of medical knowledge when and where they need it, and (3) study conditions for developing a coherent IT-based knowledge repository for different areas of knowledge bases in healthcare. Sixty two semi-structured interviews were conducted with managers, nurses and nursing

assistants from primary, specialist, and municipality care. The target groups of the IT-based knowledge repository were nurses and nursing assistants. Physicians were excluded due to the results from a previous study (see Krasniqi & Persson, 2012), showing that the majority of the IT-based knowledge repositories in Sweden had physicians as the main target group, while nurses and assistant nurses were to a large extent neglected.

The following main issues were identified within this study:

- A crucial role in the practice of evidence-based medicine is the possibility of healthcare professionals to access evidence-based medical knowledge when they need it. This study has confirmed that healthcare professionals lack access to evidence-based medical knowledge when they prepare and conduct patient visits, as well as when they make decisions about the care of a patient. One of the main reasons is that the participating organizations have failed to embed the KM process in everyday processes. It is evident that the processes and information flows are not understood and documented.
- The main barrier hindering the adoption of KM is related to people and organizational culture. For example, it was evident that the effort, interest and skills needed to search for medical knowledge among the massive volumes of research being produced were generally lacking. The organization has also failed to establish a tacit knowledge-sharing culture and to build a working environment that encourages the sharing of knowledge.
- Healthcare professionals lack access to adequate information system support for accessing and sharing medical knowledge when and where it is needed.
- To simplify access and ensure the application of knowledge that guides practitioners in the delivery of good quality care, healthcare professionals expressed an urgent need to integrate medical guidelines and other relevant medical knowledge sources with EHRs. Furthermore, information systems that support the sharing of tacit knowledge between healthcare professionals within and outside the organization are also urgently needed.
- As the main KM problems were related to people and organizational culture, it was decided that a coherent IT-based knowledge repository would not be developed at this stage. Instead, it was considered more appropriate for the participating organizations to focus on the systematization of their KM processes.

#### 4.2 **RQ 1B: WHAT CHALLENGES ARE PATIENTS EXPERIENCING WITH REGARD TO ACCESSING INFORMATION ABOUT THEIR OWN CARE AND ENGAGING IN DECISIONS?**

Based on the first case study, “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals” and the third case study, “Cancer patients’ experience of online EHR”, it was possible to identify the difficulties the patients experience when (1) they try to communicate and collaborate with healthcare professionals, (2) try to become more involved in their own healthcare and (3) access information regarding their own care. As with the previous research question, these challenges have been reported in two research papers and are described below. Hence, they answer research question 1b.

#### 4.2.1 PAPER 4: PATIENTS' EXPERIENCES OF COMMUNICATING WITH HEALTHCARE – AN INFORMATION EXCHANGE PERSPECTIVE

This paper is part of the first case study, “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals”. Its aim was to explore how patients experience the exchange of information with healthcare professionals and how this relates to the six areas that constitute good quality care. The main results are the following:

- When seeking care for medical problems, patients reported that they experienced information gaps between themselves, their health information, and their healthcare providers. Patients reported that they had difficulties with receiving information about their own diagnoses, medications, allergies, lab test results, visit summaries, and other findings over time.
- Patients experienced problems with receiving individualized information about diagnoses, interventions and treatment options and, in some cases, with understanding the information that was provided.
- Patients often felt that physicians did not listen to their perception of their own illness, their values and expectations.
- Patients commonly left their appointments feeling confused, unable to recall what had been discussed, or simply that they were missing information about their health conditions and treatment options.
- Such lack of information and communication difficulties left gaps in patients’ knowledge about their own health condition and prognosis.
- Gaps in the exchange of information forced patients to take greater responsibility for the communication of their health information between different healthcare providers. Therefore, much of the patients’ time and energy was spent on locating and communicating information between healthcare practitioners, despite being ill or injured.
- Patients felt that they were not given the opportunity to influence their own healthcare.
- Deficiencies in the exchange of information between healthcare professionals and patients seem to prevent the fulfillment, to the extent that is possible, of the six areas that constitute good quality care, namely; effective, safe, efficient, equitable, timely and patient-centered healthcare

Although information systems have enormous potential to improve the quality of healthcare, the results conclude that deficiencies in the exchange of information between healthcare professionals and between healthcare professionals and patients prevent the fulfillment, to the extent that is possible, of the six areas that constitute good quality care. Moreover, this study demonstrates that patients are not given the opportunity to communicate values and expectations, and participate in their own care. When the exchange of information does not function properly and when patients are not involved in decisions regarding their own care, it will have a negative effect on the quality of the care provided.

#### 4.2.2 PAPER 5: CANCER PATIENTS' ATTITUDES AND EXPERIENCES OF ONLINE ACCESS TO THEIR ELECTRONIC MEDICAL RECORDS: A QUALITATIVE STUDY

The research presented in this paper is part of the third case study “Cancer patients’ experience of online EHR”. This paper aims to provide an understanding of cancer patients’ attitudes and experiences of online EHR, as well as an increased understanding of the complexities of developing and launching eHealth services. The following can be concluded from the study:

- Patients read their online EHRs because they want to gain knowledge about their medical condition, treatments and lab test results. Obtaining such knowledge seems to be important for the patient's sense of control and well-being.
- Online access to EHRs helped patients to prepare for doctor visits.
- For some patients, the preparation for doctor visits brought a number of other benefits, including improved physician-patient communication and an increased appreciation of the physician’s skill. According to these patients, being prepared for a doctor’s visit contributed to more efficient communication and dialogue between patient and doctor, which in turn seems to positively affect the physician-patient relationship.
- The majority of the patients regard the online access to their EHRs as a way to increase engagement in their own healthcare.
- The ability to easily and quickly access lab test results is one of the main reasons patients wanted to read their online EHRs.
- The study participants had not experienced the negative aspects of online access anticipated by physicians. For example, in contrast to the fears expressed by many physicians, online access to EHRs did not generate substantial anxiety, concerns, or an increase of phone calls from patients seeking explanations. It seems that patients are more respectful of wasting doctors’ time spent addressing questions that may arise from patients reading their EHRs than many doctors have assumed. Moreover, although patients did find some parts of the medical record difficult to understand, they did not perceive it as problematic.
- When patients did not understand the contents of the healthcare record, they used the search engine Google to find additional information.
- It is crucial to include the patients’ perspective in the development of eHealth services, since they have experiences and opinions unknown to healthcare professionals.
- Online access to EHRs is appropriate and probably benefits some patients, but not for all. Therefore, there is a need to consider and respect the differences between individuals, and develop eHealth services according to the needs of individuals. It could therefore be relevant to identify the characteristics of those patients who experience anxiety and determine which ones should and which ones should not have access to comprehensive information through eHealth services.

### 4.3 RQ 1C: WHAT RECOMMENDATIONS CAN BE IDENTIFIED FOR THE DEVELOPMENT OF FUTURE INFORMATION SYSTEMS

Based on the three case studies, challenges with current information system support and future requirements have been identified. To expand the understanding of the collected empirical data, it has also been evaluated against existing research and the theories of process orientation and knowledge management. Consequently, a number of recommendations have been identified.

#### 4.3.1 PAPER 6: SUPPORTING ACTIVE PATIENT AND HEALTHCARE COLLABORATION: A PROTOTYPE FOR FUTURE HEALTHCARE INFORMATION SYSTEMS

This paper is based on data from the first case study, “Healthcare professionals’ experience of information system support and patients’ experience of communicating with healthcare professionals”. The paper’s aim was to present and illustrate the main features of a proposed process-oriented approach for the distribution of patient information in future healthcare information systems, by using a prototype of a process support system. The vision for the process support system is that healthcare professionals and patients should have access to effective, collaborative information systems that support process-oriented care in which the patient is a distinct and active collaborator. To achieve the vision, a healthcare process that is repeated throughout the healthcare system and can demonstrate patient/healthcare communication, i.e., initiate, plan, carry out and follow up a patient’s visit to a healthcare provider, was selected. This process was termed “Patient meeting”. In order to demonstrate how a process-oriented information system can support an active patient and improve healthcare collaboration, seven key design principles for the process support system were identified; thus helping to answer this research question. Some of the key design principles include the following:

- **The patient process is in focus:** The process support system focuses on the patient process through healthcare and on the information that is needed during this process, making sure that practitioners always have easy access to patient information; both medical (e.g., medical records, lab results, medical list) and administrative information (e.g., appointments) in a timely manner. The process support system also supports the patient's information needs and supports his/her engagement in their own healthcare. For example, the patient can send an electronic care request to primary and secondary care, as well as book appointments with doctors online.
- **Shared goals for the patient visit:** In order to ensure that healthcare professionals take into account a patient's expectations of the patient visit, the process support system provides an opportunity for patients to share their expectations in advance.
- **The process support system is based on standardized information:** To improve the availability of information, it is essential that the information is standardized and structured. To achieve this requirement in the process support system, the information content of the national quality registers for selected diagnoses has been used. The different types of information stored in quality registers have been transformed into checklists for each diagnosis.

- **Efficient information flows:** By adopting a process-oriented approach, the information flows can be more efficient. The process support system can ensure that patients and practitioners always perform the correct activities during the different parts of the patient process. A major advantage of a process-oriented approach and tools to support the process is that the process support system drives the process forward. When a task is completed, it will initiate and show the upcoming activities. For example, when a healthcare professional in specialist care has written and signed the final documentation for the patient's healthcare record, the process support system automatically "picks up" the form "response to care request" that will be sent back to the physician in primary care.
- **Digital booking and coordination of patient treatments and examinations:** The process support system enables electronic booking and coordination of treatments and examinations. It is also possible to follow the status of these activities. If some activities, such as, e.g., laboratory tests, are not completed before the scheduled patient visit, then the visit can be cancelled in advance; thus preventing unnecessary visits.

The main conclusions of the paper are the following:

- A visualized prototype is a suitable tool for illustrating both the opportunities and constraints of future ideas and solutions in eHealth.
- A process support system, such as the one described in this paper, can provide many advantages for healthcare professionals and patients. However, technical and organizational/management challenges need to be dealt with before a fully functional, process support system can be developed and implemented.

Examples of challenges that have been identified are:

- The interfaces between the process support system and the underlying IT-systems need to be developed. This is especially important, as concepts are frequently defined and written in different formats. However, it is not just a question of making this technically possible; it is also a question of information quality.
- One of the main challenges relates to the ownership and management of a process support system that crosses organizational boundaries and supports patient-centered care. An example of such a challenge involves solving the following questions: who owns all the process data generated in the process support system, who takes responsibility for the quality of the process data, and who will be the process owner of the entire patient process? If the technical challenges can be solved, then this will be the biggest challenge for the implementation of the process support system.

#### 4.3.2 PAPER 7: PROCESS-ORIENTED INFORMATION SYSTEMS – A KEY TO EVIDENCE BASED MEDICINE

The aim of this paper was to present and illustrate how a prototype visualization of a process support system can support the availability of relevant and current medical knowledge in a way that is seamlessly integrated with healthcare professionals' work practices, thereby enabling them to work in accordance with EBM. Based on the data

(both identified challenges and requirements) from the first and the third case studies, the PSS system was further developed in order to fulfill the purpose of this study.

The study results in this paper confirm that a process support system can reshape the practice of EBM, by providing timely access to up-to-date patient information that is matched to relevant and current medical knowledge and an IT-based knowledge repository. In order to ensure that the physician works with the latest scientific medical knowledge, the PSS is based on national evidence-based medical guidelines and standardized checklists designed using national quality registers. Medical guidelines deliver patient-specific advice at the time and place of a consultation and can therefore reduce variability in the practice and improve patient outcomes. To ensure that only relevant medical knowledge is made available to healthcare professionals within the patient process, the knowledge-sharing solution is carried out in two stages.

1. Unique patient information is matched to relevant and current medical knowledge (in this case medical guidelines) within the PSS.
2. A comprehensive IT-based knowledge repository that is linked to the PSS provides a more holistic view of knowledge related to the entered patient information. Additionally, to support healthcare professionals in the practice of EBM, IT-based knowledge repositories should not only be (1) integrated within the PSS or within an EHR, in order to provide a single integrated point of access, and (2) provide access to more structured information, but also (3) include the communication perspective. This perspective implies that the current, traditional view of IT-based knowledge repositories must evolve from simply being a one-way retrieval of information to a two-way system that provides collaboration and information exchange features which support the capture, transfer, and exchange of knowledge.

An important key solution to the problems identified in papers 1, 2 and 3 is thus to view patient information and medical knowledge as interconnected, such that they continually impact on each other. This solution is based on the assumption that relevant medical knowledge, such as medical guidelines, can be derived from previously entered patient data. In this manner, we can ensure that healthcare professionals always have access to relevant and the best explicit scientific medical knowledge, when they need it. Subsequently, since EBM also includes clinical expertise, an IT-based knowledge repository is integrated into the process support system. An IT-based knowledge repository can thus facilitate the sharing of experiences.

Before we try to support EBM by means of a process-oriented information system, we must be aware of the challenge related to organization specific consensus. Since the guidelines for good medical practice exist at national, regional, and local levels, contradictions between the guidelines exist. Hence, a crucial challenge will be reaching an agreement on the medical guidelines that should be implemented within the process support system. Another challenge relates to identifying who will be responsible for the ownership and quality of the medical knowledge within the process support system and the IT-based knowledge repository.

#### 4.3.3 **PAPER 8: INFORMATION SYSTEMS FOR THE PRACTICE OF EVIDENCE BASED MEDICINE AND SHARED DECISION MAKING**

The provision of high quality healthcare is affected by the amount of information shared among and between healthcare professionals and patients, and how well that information is integrated into the system and processes of each clinical setting. Therefore, for EBM and SDM to serve their purpose, patients and healthcare professionals need information systems that give them quick and trouble-free access to all-round patient information and medical knowledge. They also need information systems that can influence the patient and doctor relationships, thus facilitating their collaboration in the pursuance of shared goals in healthcare, with attention to both illness and personal experience.

This paper is based on the data collected from case study one. However, the results from study two and three have also served as inspiration for the solutions presented in this paper. The aim of the paper was to present and illustrate how a prototype visualization of a process support system can enhance the communication and collaboration among healthcare professionals and patients, by improving the access to patient information and medical knowledge, and, in so doing, support the practice EBM and SDM. A number of functions have been further developed in the process support system to visualize how future healthcare information systems can support the practice of EBM and SDM as well as enable patients to play an active role in their own healthcare. Examples of such features include the following:

- **Shared goals for the patient visit:** SDM requires that patients are given the opportunity to not only access information regarding their own care, but also to express their values, preferences and expectations before a patient visit. Since this is a precondition for EBM and SDM, the PSS helps patients capture and share information about their expectations of a patient visit, in addition to their values, preferences and other expressed needs. In this matter, we can, to a certain extent, ensure that patient values guide all clinical decisions.
- **Digital booking, electronic care request/referral and online EHRs:** Overall, the role of the patient has changed from that of a passive recipient of care to a more active participant in care delivery. The PSS presented enables patients to participate in their own care by providing easy access to information. Such information, which can include laboratory test results and medical notes from consultations, is available to patients through online access to EHRs. The patient can also book an appointment directly with their physician or nurse and electronically submit care requests to primary and secondary care.

Many healthcare decisions are not clear cut. Patients and healthcare professionals need to discuss the options using the best available medical evidence and make informed joint decisions based on the patients clinical condition, values, and preferences. However, implementing EBM and SDM is not easy. In addition to skills, healthcare professionals need access to patient information and the best medical evidence. Patients need information and support. This study also confirms that one of the most common sources of patient dissatisfaction is not feeling properly informed about and, involved in their care process. Therefore, patients want more information than they are routinely given by healthcare professionals, and many would like a greater share in the process of making decisions about their own care. Shared decision-mak-

ing, with supporting information systems where patients are involved as active partners with their healthcare professionals in decisions can be recommended as an effective and important initiative to significantly improve the current situation. However, this will require a change in how current information systems are developed.



# SYNTHESIZED RESULTS



## CHAPTER 5

# SYNTHESIZED RESULTS

This chapter presents the synthesized result and suggests recommendations for the development of future healthcare information systems. These recommendations are derived from: (1) the theory of EBM, SDM, as well as process-orientation and knowledge management, (2) the empirical data that has been presented in the various research papers. Hence, these recommendations constitute the final step towards answering the main research question, namely:

*How can future healthcare information systems support the communication between patients and healthcare professionals such that they easily and efficiently can collaborate in pursuing shared goals in healthcare with attention to both illness and personal experience?*

The recommendations presented consist of one primary and five supporting recommendations. These are:

- **Primary recommendation**
  - Supporting the core characteristics of EBM and SDM in an integrated manner.
- **Supporting recommendations**
  - A process-oriented approach.
  - From repositories of health information to interactive tools.
  - Preparing patients – “It takes two to tango”.
  - Current and relevant information integrated into the current context.
  - Enable a combination of access, communication, creation and capture of medical knowledge.

The primary recommendation forms the basis of the others in a way that it emphasizes the fact that future information systems must focus on supporting the characteristics of evidence-based medicine and the process of shared decision-making, as described by e.g., Charles et al. (1999). The purpose of the supporting recommendations is to demonstrate how the primary recommendation can be achieved. The process support system (PSS) developed through this work is used to demonstrate the recommendations.

## 5.1 SUPPORTING THE CORE CHARACTERISTICS OF EBM AND SDM IN AN INTEGRATED MANNER

As shown in the previous chapter, EBM and SDM are essential to patient safety and healthcare quality. EBM is about using individual clinical expertise, together with the best available medical evidence as well as patients' values and preferences, in making decisions about the care of individual patients. Shared decision-making provides a process that brings the medical evidence and clinical expertise into the consultation, incorporating them, together with the patient's values and preferences, into the discussions with the patient (Charles et al., 1999; Hoffmann, Montori, et al., 2014). In other words, SDM is an important complement to EBM. Although EBM and SDM have been promoted as the optimal approaches in making healthcare decisions, associated with evidence of patient benefits and touted as the pinnacles of patient-centered care, they have been difficult to implement in routine practice, partly due to inadequate information systems support. Hence, future healthcare information systems must support the core characteristics of EBM and SDM, in an *integrated manner*, and using the one without the other is not enough. This means the following:

1. Future healthcare information systems must support healthcare professionals to easily access and share patient information (both medical and administrative information, e.g., appointments with other healthcare providers). They must also support them to easily access current and relevant medical knowledge at the point of care. All of this must be supported in a way that seamlessly integrates with the healthcare professionals' work practice. Hence, future healthcare information systems should:
  - Support the access to (1) patient information and, (2) current and relevant medical knowledge in a way that seamlessly integrates with the healthcare professionals' work practice.
  - Provide timely access to patient information - matched with relevant medical knowledge and an IT-based knowledge repository.
2. In an evidence-based practice where shared decision-making is a component of EBM, the healthcare professional and the patient collaborate in making healthcare decisions: "it takes two to tango". Hence, future healthcare information systems must support the patient in accessing the same information streams—in "patient-accessible" form—as those available to their physician(s) and care team, throughout their journey (process) in healthcare.
3. Future healthcare information systems must support healthcare professionals and patients, by facilitating their collaboration in pursuing shared goals in healthcare, with attention to both illness and personal experience. Hence, future healthcare information systems should support:
  - Healthcare professionals in initiating SDM.
  - Healthcare professionals in sending and referring patients to sources of additional medical knowledge related to options, risks and benefits. This should be done before, during and after a patient encounter.
  - Patients' preparations for the patient encounter, by providing them with online access to their EHRs.
  - Patients' access to detailed information about options, benefits and risks, through an integrated IT-based knowledge repository.

- Patients in sharing their expectations, values and preferences before and during a consultation.
- Patients in contributing information about their health e.g., chronic disease management, interval history, medication updates, weight, allergies and other information before a patient encounter.

### 5.1.1 A PROCESS-ORIENTED APPROACH

In recent years, the move towards integrated care, the emergence of evidence-based medicine and shared decision-making have led to an increased interest in process-oriented information systems. Although the importance of this orientation is widely shared, it cannot be said that it has already led to successful systems. Before we even start discussing process-oriented information system support, we have to agree on the core processes in healthcare. The patient process is considered one of the most important processes by many healthcare organizations. By modeling the patient process, we can capture information flows, and the responsibilities between actors, as well as identify constraints and bottlenecks that make this journey less effective, etc. Once the ‘environment’ within which the information system is to operate has been modeled in detail, the development of the process-oriented information system can begin. The basis of evidence-based practice, where the patient has an active role in decisions, is the timely access to relevant, high-quality evidence and patient information in the context of patient care decision-making. Hence, a process-oriented approach with supporting information systems is vital for the support of an evidence-based practice where the patient is an important and active collaborator. Adopting a process-oriented approach is an important foundation as it:

- Places focus on the patient process from the patient's perspective,
- Places focus on the patient information and medical knowledge needed during the patient process,
- Streamlines the flow of information and medical knowledge and thereby places the patients and their journey through healthcare at the center.

Through such process support, healthcare professionals and patients can access relevant and current medical knowledge and patient information at the point of care, as required by the patient process. The key design principles of the PSS, presented in papers six and seven, provide ideas regarding how future process-oriented healthcare information systems can support the communication and collaboration between patients and healthcare professionals.

### 5.1.2 FROM REPOSITORIES OF HEALTH INFORMATION TO INTERACTIVE TOOLS

Shared decision-making is considered a hallmark of good clinical practice, respecting patients’ right to know that their informed preferences should be the basis of all medical actions (Gartlehner & Matyas, 2016) and a way of enhancing patient engagement (Hoffmann, Légaré, et al., 2014; Hoffmann, Montori, et al., 2014). According to Carman et al. (2013, p. 224) patient engagement is characterized by the amount of information shared between patient and healthcare professionals and how active a role the patient has in healthcare decisions. Without the efficient exchange of information, patients are not able to participate and be engaged in their own healthcare, particularly

in decisions regarding e.g., medical tests and treatment options. However, patient engagement not only concerns giving patients access to health information, it also concerns engaging the patient in making decisions, by enabling them to ask informed questions and express personal values and opinions about their conditions and treatment options.

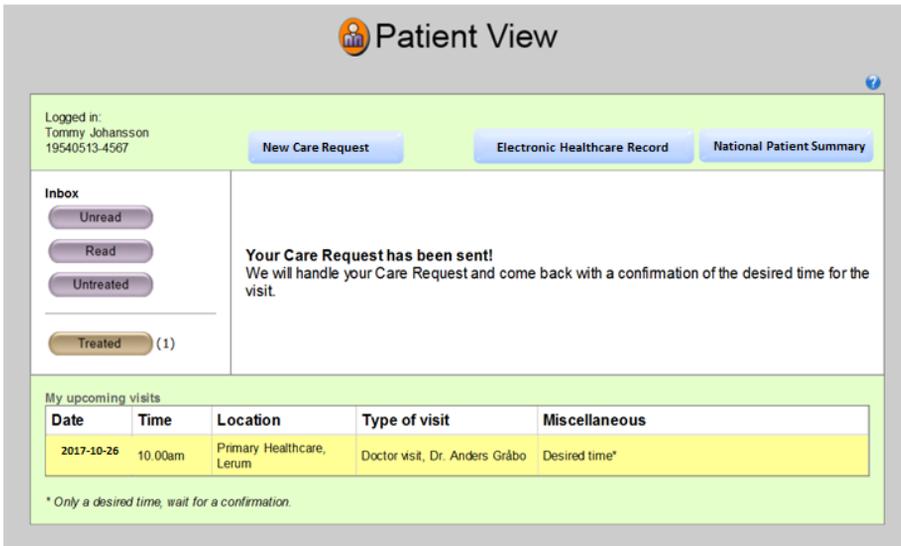
Two important key steps in shared decision-making are (1) communication and collaboration between the healthcare professional and the patient, and (2) making sure that the patient is fully informed about their medical condition and options. Despite the fact that patients want to participate in making decisions, studies on the barriers to and facilitators of SDM indicate that they cannot participate, revealing that the inadequate provision of information is the most significant barrier (Joseph-Williams, Elwyn, & Edwards, 2014). Hence, future healthcare information systems need to evolve from being passive archives of recorded health information to becoming active tools that support collaboration by enabling the access and sharing of information between patients and healthcare professionals, throughout the patient process. These recommendations are further specified below.

#### 5.1.2.1 PREPARING PATIENTS - "IT TAKES TWO TO TANGO"

It is difficult, if not impossible, for patients to be involved in making decisions when they do not have information about their health condition, the treatment options, what they entail, and any possible outcomes (Charles et al., 1999; Joseph-Williams et al., 2014; Nordgren & Fridlund, 2001; Wilson et al., 2010). Consequently, for a patient to become an active and involved partner with healthcare professionals in making healthcare decisions, they must be given the opportunity to prepare for a patient encounter. The preparation should focus on information provision and encouragement. We propose that at a minimum before the patient encounter the patient should:

1. Receive information about their medical condition and if necessary, treatment options available, their benefits and harms.
2. Receive information about SDM; what is it, what to expect, and why it is appropriate.
3. Be encouraged to consider questions that they want to discuss, values and preferences.

From an information system perspective, this can be achieved (as demonstrated in the PSS, see figure 16), by providing the patient with online access to their EHRs and the National patient summary that provides patients with a synopsis of the most important information obtained from a consultation. Such online access can help patients learn and understand more about their medical condition, which, in turn, can help them express and share their concerns, goals, and questions with healthcare professionals. Similar to previous studies, our research (see, e.g., Rexhepi et al. 2016) has shown that those patients who prepare themselves and ask questions become more engaged in their healthcare and are more satisfied with the patient encounter. It has also been found that online access to EHRs empowers patients, enabling them to take more control over their health and manage their care more effectively (Lott, Piepkorn, & Elmore, 2015; Delbanco et al., 2012; Ball, Carla Smith, & Bakalar, 2007; Silber, 2009).



**Figure 16:** The patient view in the PSS showing that the patient has direct access to their EHR and the National patient summary. It also shows nearby activities such as when to provide information. The patient can also see past and future patient visits.

Another important step in shared decision-making is for the healthcare professional to involve the patient in making decisions about their own care. Although SDM is considered fundamental to safe and effective healthcare, when legitimate options are available to patients, it has been difficult to implement in practice (Davis et al., 2017). Therefore, healthcare professionals and patients need tools that:

1. Provide healthcare professionals with the relevant and current medical knowledge they need to answer patients' evidence-based questions at the right time (see section 5.1.3).
2. Provide patients with current and relevant medical knowledge at the right time, enabling them to learn more about their medical condition, the pros and cons of treatment options, etc.
3. Provide patients with a free-text box to set a pre-visit agenda and express e.g., their goals, expectations, preferences and values prior to a patient encounter.
4. Help healthcare professionals elicit and integrate patient preferences and values into the decision.

The process support system, presented in paper 8, provides such support by “reminding” healthcare professionals to initiate SDM and allowing patients to share their expectations, values and preferences before an encounter (see figure 17). This is an example of how technology can be designed to encourage patients to consider questions, values and preferences before the patient encounter. Enabling patients to specify expectations, values and preferences before a patient encounter can better prepare them for the SDM process. It also enables healthcare professionals to prepare for the thought and wishes of patient in advance. Furthermore, to involve patients more in their own healthcare and help reduce the information gap between patients and healthcare professionals, they should also be able to contribute with valid information

about their own health electronically prior to an encounter. The patient can provide updates on chronic disease management (e.g., a blood pressure logs), interval history, medication updates, and other data. In the PSS, this recommendation has been exemplified by offering patients the opportunity to provide information prior to an encounter, e.g., by filling in a health declaration containing questions about weight, length, allergies, medication etc. This information can then be part of the EHR.

The screenshot shows a web-based form for patient information. At the top, there are three input fields: 'Weight (kg)', 'Height (cm)', and 'Allergies', each with a corresponding empty text box. Below these is a 'CONSENT' section with the text 'I agree that my health care provider use my patient information that another health care provider have made available.' and radio buttons for 'Yes' and 'No'. The next section is 'HEALTH CARE GUARANTEE' with the question 'Do you want to use the Health Care Guarantee which means you are eligible for a visit within 7 days?' and radio buttons for 'Yes' and 'No'. The 'NEED OF SOCIAL SERVICES' section includes 'Need an interpreter?' with radio buttons for 'Yes' and 'No', followed by 'If Yes, what language?' with a text box. Below that is 'Do you have disabilities?' with radio buttons for 'Yes' and 'No', and 'If Yes, describe what help you need' with a text box. A large text area is titled 'Please enter your expectations, values and preferences' with a placeholder 'Maximum five hundred (500) characters'. At the bottom are two buttons: 'Send the Care Request' and 'Cancel'.

**Figure 17:** Before a consultation the patient has the opportunity to share expectations of the patient encounter, values and preferences. They can also provide information such as, weight, length, allergies and current medications.

Another key step in SDM is making sure that patients are fully informed, not only about their health condition but also about their options. As shown in the paper by Krasniqi et al (2011), patients do not always remember what was discussed during an encounter, the decisions that were made and the grounds on which they are based. How the patient has perceived the information will also affect their participation in making decisions and thereby influence the outcome of care. This indicates that there is a need to support patients so that they can more easily cope with what has been discussed. As shown in the paper by Rexhepi et al (2016), giving patients access to their online EHR, is an important solution. However, this solution alone is not optimal, as patients often turn to the Internet to find more information about things they do not understand or want to learn more about. Hence, future healthcare information systems need to be developed beyond this type of access to ensure a shared decision

making practice. For this purpose, we recommend that an “information button” functionality should be implemented within the online EHR, directly referring patients to reliable sources of further medical information. An IT-based knowledge repository should also be linked to the future process-oriented information system, giving patients access to additional, quality assured texts and videos that provide information about diseases, the pros and cons of treatment and test options, etc. Ideally, patients should also have access to the same national, regional and local medical guidelines as their healthcare team. Implementing such tools is especially important, since patient behavior, regarding the search for information, is changing, as new technology for patients enters healthcare. In recent years, as the paper by Rexhepi et al (2016) also shows, a significant proportion of patients seek information outside the clinical setting and use a number of additional sources of information, such as Google, question and answer online services, support groups, etc. (Oh, Zhang, & Park, 2016; Protière et al., 2012). Therefore, it is also desirable to offer tools/functions directly within the IT-based knowledge repository that would enable patients to connect to different support groups. Patients would then be able to share experiences and receive support.

Future process-oriented information systems should also provide tools that enable healthcare professionals and patients to send educational materials (such as videos and handouts) to each other before, during and after a consultation. For example, patients may want to send materials to their physician in order to discuss the content during the consultation. Moreover, an important barrier, identified in the paper by Krasniqi, Åhlfeldt and Persson (2011), is that patients usually experience that they have no insight into their own care process or are unable to influence it, which causes unnecessary concerns. To help patients become more involved in their own healthcare and gain an overview of their care process, future healthcare information systems should also display nearby activities in the process (see figure 16) and enable patients to schedule their own appointments.

### 5.1.3 CURRENT AND RELEVANT INFORMATION INTEGRATED INTO THE CURRENT CONTEXT

The ability to access information about a patient at the right time is an important element of EBM and SDM. To ensure an evidence-based practice, clinical questions must be addressed at the moment they arise. Therefore, future healthcare information systems should not only present patient information to healthcare professionals, but also offer relevant information, according to the current context. Consequently, it is important to determine what relevant information is. This can be achieved by focusing on the type of information required within an episode of care and for a specific illness or diagnosis (see paper by Åhlfeldt et al., 2016).

In addition, the practice of EBM and SDM can be supported by bringing medical knowledge to the point of care. Having access to relevant medical knowledge at the right time can mean the difference between an accurate or erroneous diagnosis and treatment. Although medical knowledge guides decisions about the care of an individual patient, this information is today separated from patient information. This implies that the standard KM approaches for knowledge dissemination in healthcare organizations are the access approaches for stored information, e.g., access to information that is stored on the intranet and/or in IT-based knowledge repositories. Although

such approaches are necessary, they are not always sufficient. For example, if a physician is documenting in an EHR and has questions regarding a specific diagnosis, the physician must use a different information system to find the relevant medical knowledge. Therefore, a potential solution to this problem is to extend the KM approach in healthcare beyond the traditional form of disseminating knowledge through documents and unstructured information stored in distinct information systems. Ideally, future healthcare information systems should provide timely access to patient information, matched with relevant and current medical knowledge, such as medical guidelines, and an IT-based knowledge repository. In addition, recommendations derived from medical guidelines should also be reflected in reminders. Consequently, practitioners would not have to explicitly look for guidelines, thereby possibly avoiding the risk of missing important medical knowledge (Lenz & Reichert, 2007). These examples of recommendations are demonstrated in the paper by Rexhepi (2015) and clarified below.

To ensure that healthcare professionals work according to the latest scientific medical knowledge, future process-oriented information systems should be based on national evidence-based medical guidelines and standardized checklists designed on the basis of national quality registers. Medical guidelines deliver patient-specific advice at the time and place of a consultation and can therefore reduce variability in practice and improve patient outcomes. To ensure that only relevant knowledge is made available to the healthcare professional within the patient process, the knowledge-sharing solution within the process support system should be carried out in two stages (see figure 18):

- **Stage 1:** As demonstrated in the PSS (see papers 7 and 8), we recommend that unique patient information is matched with relevant medical knowledge (in this case medical guidelines) within the process support system. Medical guidelines can thus be derived from previously entered patient data. For example, as demonstrated in the PSS, when the healthcare professional prepares for a care request and decide on a diagnosis or a health issue, only medical guidelines and recommendations concerning the particular health issue will be shown, which means that only relevant information is displayed. In this case, the knowledge is more focused and case-specific. Deviation from a medical guideline is possible, but needs to be documented. If a specific guideline cannot be followed because of a patient's condition, the process support system should generate a warning. For example, if the guidelines suggest that the patient should be prescribed drug X, but the patient is allergic to it, a warning will be generated.
- **Stage 2:** Moreover, to improve the safety and quality of care, it is not enough that the information required by a healthcare professional is available someplace in the system application. Therefore, stage two should provide a more holistic knowledge view related to the entered patient information via a comprehensive IT-based knowledge repository that is linked to the process support system. When the IT-based knowledge repository is accessed, the medical information presented should be automatically linked to the diagnosis and/or problem, for which the patient sought care, and to the specific part of the process that the healthcare professional is in. This means that it is not necessary for the healthcare professional to explicitly search for the medical

knowledge, as this information is easily accessible through the process support system. Moreover, within the knowledge repository, one should be able to find different functionalities: (1) a search engine where healthcare professionals easily can search for publications, such as articles, books, medical guidelines, videos and audios, and (2) learn more about EBM and SDM in practice. This recommended solution means that patient information and medical knowledge should not be regarded as two separate aspects. Instead, they must be viewed as interconnected, such that they continually impact on each other. Only then can an evidence-based practice be fully supported.

The screenshot displays the 'Care Planner View' interface for a 'Priorities Care Request'. At the top, there are three tabs: 'National Patient Summary', 'Electronic Healthcare Record', and 'Knowledge Repository'. A bracket on the right side of these tabs is labeled 'Direct access to the IT-based knowledge repository'. Below the tabs is an 'Open Care Request' button. The 'PRIORITY' section has a dropdown menu set to 'Scheduled (within 7 days)'. The 'CARE REQUEST RECIPIENT' section contains a table with columns: Location, Requests for doctor, Desired time, and Reserved time. The table shows: Primary Healthcare, Lerum; Dr. Anders Gråbo; 2010-04-20, 10.00am; and 2010-04-20, 10.00am. A 'Reschedule' button is below this table. The 'CHECKLIST' section is titled 'RECOMMENDED TASKS' and has columns: Type, Status, Last performed, and To be carried out. It lists three tasks: X-ray (Status: Yes, Last performed: No, To be carried out: Yes), Blood pressure (Status: No, Last performed: Yes, To be carried out: No), and HB (Status: Yes, Last performed: No, To be carried out: Yes). A bracket on the left side of this section is labeled 'Embedded medical guidelines'. Below the checklist is a table for 'Recommended tasks not carried out' with columns: Recommended tasks not carried out and Explanation for deviate. It shows 'Blood pressure' with the explanation 'Determines that new values are not necessary'. A bracket on the left side of this table is labeled 'Deviation from a medical guideline is possible, but needs to be documented'. The 'OTHER ACTIONS' section includes buttons for 'Order medical service', 'Order treatment', and 'New Care Request'. At the bottom, there are buttons for 'Continue', 'Save to later', and 'Cancel'.

**Figure 18:** Snapshot of the patient's digital "care request", showing how medical knowledge is integrated with the PSS.

#### 5.1.4 ENABLE A COMBINATION OF ACCESS, COMMUNICATION, CREATION AND CAPTURE OF MEDICAL KNOWLEDGE

The traditional view of KM in healthcare, regarding the dissemination of medical knowledge, is thus the access approach. This view emphasizes knowledge access, but

not the exchange of experiences and the creation of new knowledge, which are important parts of EBM and SDM. Therefore, to support healthcare professionals and patients, an IT-based knowledge repository should be integrated into the future process-oriented information system. Applying such a recommendation means that healthcare professionals and patients can find the knowledge they need without having to take additional steps or use other separate information systems to find the knowledge required. IT-based knowledge repositories should not only (1) be integrated within an existing system (as demonstrated in the PSS), in order to provide a single integrated point of access and (2) provide access to more structured, explicit medical knowledge, but should also (3) include the communication perspective. This has been found to be important, since explicit medical knowledge on its own is not sufficient for making decisions. Even clinical expertise is considered to have a strong influence on healthcare decision-making. Therefore, the current, traditional view of IT-based knowledge repositories must evolve from simply being the one-way retrieval of information to becoming a two-way system that provides features to aid collaboration and information exchange. Informal online discussion forums, knowledge cafés, and communities of practice (CoPs) are examples of collaboration and information exchange features that are important to both healthcare professionals and patients. These features can be made available via an IT-based knowledge repository that is integrated into an information system, either a process support system as the one described in this thesis or an EHR. By including features that support collaboration, healthcare practitioners can share their clinical expertise. For example, during a consultation, the patient informs the physician that the drug Venlafaxin 20 mg has caused some particular side effects. The doctor prescribed the drug for the patient 8 months previously, after consulting the medical guidelines. The physician, who has prescribed the same drug to patients for more than 20 years, has never heard of these particular side effects. Therefore, the physician accesses the discussion forum in the IT-based knowledge repository that is integrated into the process support system. In the discussion forum, the physician seeks the advice of colleagues who may have experience of the problem, by presenting a question. Healthcare professionals, at local, regional and national levels, with experience of the topic, respond by offering their knowledge of the problem. A debate ensues between healthcare professionals who share and discuss their clinical experiences, scientific papers and theories (Abidi, 2007). Based on the discussion, important conclusions are drawn that help the physician in the decision-making. Although the knowledge shared in the discussion forum is not based on evidence, it can, according to Abidi (2007), still have a high trust value, as it originates from colleagues. The knowledge created in the online discussion forum can be captured (if relevant) to explicit knowledge, which can then be packaged, stored and shared through the knowledge repository, or be integrated as a guideline in the process support system. However, to ensure the creation, identification and use of new knowledge, the KM process must be integrated into organizational processes. There must also be well-defined rules governing the type of knowledge that should be captured and stored, who should be responsible for capturing and reviewing the quality of new knowledge, as well as how it should be packed and stored (Persson, Stirna & Aggestam, 2008). Furthermore, the enablers of the KM process must also be considered. Additionally, if an IT-based knowledge repository is to be integrated into an information system, either a process support system as the one described in this thesis

or an EHR, it is essential to decide on what level the repository should be available; national, regional or local, and who should be responsible for keeping it up to date.



# CONTRIBUTIONS AND FUTURE WORK



## CHAPTER 6

# CONTRIBUTIONS AND FUTURE WORK

The research presented in this thesis brings together knowledge from EBM, SDM, process orientation and knowledge management. Through the use of qualitative research methods, this thesis broadens our understanding of how information systems can be used to support the communication between patients and healthcare professionals, enabling them to easily and efficiently collaborate in pursuing shared goals in healthcare, with attention to both illness and personal experiences. Hence, the main knowledge contribution of this thesis is within the field of healthcare informatics.

### 6.1 CONTRIBUTIONS TO RESEARCH AND PRACTICE

The research presented in this thesis provides new and more detailed knowledge of how information systems, if developed from a process-oriented and knowledge management perspective, can support the characteristics of EBM and SDM in an integrated manner throughout the patient process. Viewed separately, these research areas are well documented, but combining them is an unexplored research field. By adding new research that addresses both theoretical as well as empirical aspects of process orientation and knowledge management in an evidence-based practice, this thesis expands our understanding of how tools, in the form of process-oriented information systems, can (i) provide healthcare professionals with not only best current but also *relevant* medical knowledge and patient information in a way that seamlessly integrates with their work practice, and thereby enables them to work in accordance with EBM e.g., (ii) provide patients with relevant medical knowledge and information about their own healthcare, (iii) provide healthcare professionals and patients with tools that enable them to collaborate throughout the patient process, e.g., by sending medical knowledge to each other, and (iv) help patients elicit and integrate their values and preferences prior to a consultation.

As discussed in Chapter 2.5 “other related research” the analysis of prior research has shown that the various elements of evidence-based medicine and shared decision-making are treated as distinct, when different information systems solutions are presented. This perspective has contributed to the existence of information systems that, among others, (1) only support healthcare professionals in the performance of one or some of the characteristics of EBM, and (2) only support patients in SDM by offering

tools for the consideration of different treatment options. Hence, these solutions not only separate SDM from EBM, they also prevent healthcare professionals and patients from jointly engaging in healthcare decisions. A holistic perspective is thus missing. Furthermore, since evidence-based practice, where the healthcare professional and patient jointly participate in a healthcare decision, is dependent on the availability of patient information and medical knowledge, this thesis has shown that one needs to consider theories that can help structure, provide and promote timely access to both current information and relevant medical knowledge. Therefore, the theories of process orientation and knowledge management have been included, and considering them in the development of future systems that intend to support EBM and SDM is thus regarded as important. For example, knowledge management in the context of evidence-based medicine and shared decision-making can provide an effective and efficient way to structure, promote and provide timely medical knowledge to healthcare professionals and patients, when and where they need it, in order to help them make high quality healthcare decisions. On the other hand, a process-oriented approach is crucial, as it can streamline the flow of both patient information and medical knowledge, thereby ensuring that healthcare professionals and patients always have access to the right information when healthcare decisions are made. To the best of our knowledge, existing research has not integrated all these four theories, when information system support for EBM and SDM is presented. Hence, we believe this is an important contribution to theory (see section 2.6). Another important contribution to theory is the tailoring of the integration between EMB and SDM. The existing model of EBM and SDM, regards healthcare professionals as the primary source of medical knowledge. However, with new information systems support as the one presented in this thesis, patients' access to medical knowledge and information about their own healthcare has resulted in a shift in the traditional information balance where patients are increasingly equipped with health information related to their condition, eroding the prior exclusivity of health information among healthcare professionals. In reality, a patient can bring up online information about treatment options during consultations. Hence, these changes require that the SDM process enter the evidence-based consultations earlier (see figure 9).

Moreover, the recommendations, identified and presented in this thesis, are derived from theory and practice. They contribute to both research and practice, as they provide ideas for solutions that must be considered before work can begin with the development of future healthcare information systems. This thesis has shown that information systems have the potential to reshape the practice of evidence-based medicine, by providing both patients and healthcare professionals with quick access to patient information and high quality research evidence at the point of need. However, to enable this, system developers must have an understanding of the characteristics of EBM and SDM, or the solutions provided will remain ineffective. Furthermore, an important knowledge contribution to the field of research and the field of practice is the importance of applying a process view on information system development based on the patient process. This thesis has shown that work towards a more evidence-based practice where patients are actively involved in their own healthcare requires information systems that support healthcare professionals and patients throughout the patient process. Such support will require that the patient process is seen as the core process. However, as shown in case study one, there seems to be another process view in the healthcare organization, where it is usually spoken of the surgery process, cancer

process etc. Focus on these processes and the optimization of them means that no one is actually responsible for the patient's entire process. Therefore, it may be more reasonable for e.g., the surgery and cancer process to be sub-processes in the patient process, where several different health conditions are diagnosed and maybe even treated in parallel.

Another important contribution to both theory and practice is the development, of the prototype, namely, the visualized PSS. On the basis of this research, we have shown that a visualized prototype, developed in close collaboration with end-users, is a suitable tool that can be used to illustrate both the opportunities and constraints with regard to the ideas and solutions for future healthcare information systems. The development of the prototype also contributes to the field of research, as it demonstrates solutions for the way in which a process support system can facilitate the practice of evidence-based medicine and shared decision-making.

As shown in research paper one, issues with information system interoperability and inadequate design of EHRs (e.g., an inadequate user-interface and poor performances) causes major challenges for healthcare professionals. However, as shown in all three case studies, the challenges identified with regard to information system support are not purely technical. For example, the practice of SDM will not occur, unless healthcare professionals accept patients' autonomy and support individual self-determination. SDM rests on accepting that individual self-determination is a desirable goal and that healthcare professionals need to support patients to achieve this goal. To oppose patients' right to access their EHRs online is an example of how healthcare professionals are not allowing patients' to make autonomous decisions about their healthcare. It should also be emphasized that information systems that supports patients to access their EHRs and sharing of values and preferences can help them reflect on their health status and care before a patient encounter, which is an important part of SDM. However, for SDM to take place it will require multiple approaches, including strategies such as training of healthcare professionals in shared decision-making, engagement of clinical champions and support from other organizational leaders. Patients will also need help from their physician and/or nurse to understand the presented information, the pros and cons of different treatment options and support in discussing their values and preferences. They will also need support to envision how their life might change based on their decision. However, information alone is not sufficient for patient involvement in decision-making. Many patients underestimate their expertise they bring to the patient encounter. Therefore, patients need to believe that they can and should be involved in making decisions, and healthcare professionals need to have the necessary skills and tools to support them. These are issues that technology alone cannot solve. Hence, information systems can partially support SDM. Shared decision-making occurs only when patients and healthcare professionals work together to reach a decision which means that attitudes and beliefs are necessary for effective SDM. Healthcare professionals and patients must see value in SDM and expect that it will work. Trust and an equal power dynamic are also necessary. Furthermore, information system support is not a magic bullet. No matter the brilliance of technology solutions, EBM and SDM will not be implemented in practice if healthcare professionals are not willing to involve the patient. Hence, it will require substantial change to the practice of healthcare to achieve the widespread implementation of EBM and SDM.

Furthermore, the identified and presented recommendations, together with the individual papers included in this thesis, provide important insights into the challenges that patients and healthcare professionals experience, with regard to information system support and solutions that can improve the quality and safety of care. We argue that information system developers, politicians and healthcare managers should find these insights interesting.

## 6.2 FUTURE WORK

Before a process-oriented information system, such as the one described in this thesis, can be implemented in practice, a number of challenges must be managed. For example, further research is needed regarding the ownership and responsibility of a process support system that crosses organizational boundaries and that supports patient-centered healthcare. Research into how the quality of the process data generated in a process support system can be assured and who bears the main responsibility for ownership of the process data are issues that future research must respond to. Other issues that need to be solved are who will pay for the coordination of the patient's process, and what care related activities should healthcare providers be responsible for, and can one make demands on each other? For example, in the PSS a primary care physician can schedule an appointment for the patient at specialist care while the patient is in the doctor's office. These activities will require transparency between the different levels of healthcare, which unfortunately does not exist today. Subsequently, if a process support, such as the one described in this thesis, handles medical knowledge, additional challenges will arise. A crucial challenge, among others, will be to agree on the level at which the IT-based knowledge repository integrated into the process support system should be; national, regional or local, the kind of medical knowledge that should be available in the repository, how this knowledge should be presented, and who will be accountable for the quality of the medical knowledge. Clearly, there are major obstacles to overcome if the developed PSS would be implemented within the frame of the current organizational structure of healthcare. The question then is; do the current organization of healthcare need to be reorganized if the patient's process is to be the process that information systems are to be built upon and, who will be responsible for initiating such organizational changes. These are issues that future research should study more closely.

Moreover, one important step in increasing patients' involvement in SDM has been to provide them with access to their online EHR. It is critical that we are innovative and try to find new ways to further develop current information systems so that they go beyond the storage of information and become interactive tools. Simply providing patients with information from their EHR will not automatically contribute to their involvement in decisions. Rather, such involvement will require finding a multitude of solutions that take into account the diverse patients and healthcare professionals who operate in a range of contexts and health services. As a next step, inviting patients and their families to contribute to their EHR (e.g., by commenting on the content and provide updates on blood pressure, weight, medication etc.) may improve patient involvement and the quality of the care provided. However, further research is needed to study how such functionality might work in practice and what effects it may have on SDM and the quality of care.





## CHAPTER 7

# APPENDIX

### A INTERVIEW GUIDE – CASE STUDY ONE

<b>Frågor till vårdpersonalen</b>	<b>Questions for healthcare practitioners</b>
<b>Frågor relaterade till ”handläggning av vårdbegäran”</b>	<b>Questions regarding the “processing of the referral”</b>
Vilka ingångar är möjliga för en vårdbegäran?	In what ways can a referral be requested?
Hur går du tillväga när du registrerar vårdbegäran?	How do you register the referral?
Vilka kriterier existerar vid prioritering av vårdbegäran? Var kommer dessa kriterier ifrån?	What criteria exist for prioritizing the referral? Where do these criteria come from?
Vad innebär kompletterande remiss? Vilken typ av kompletteringar är det som behövs?	What does supplemental referral mean? What types of supplements are needed?
Hur prioriteras vårdbegäran?	How is the referral prioritized?
<b>Frågor relaterade till ”planering av besök”</b>	<b>Questions regarding the “planning of patient visits”</b>
Vad betyder ”gå igenom patientinformation”? Vad är syftet? Vilka system används? Vem gör det?	What does it mean to go through “patient information”? What is the purpose? What systems are used? Who does that?
Vad gör du när du planerar ett mottagningsbesök?	What do you do when you plan a patient visit?

Hur vet du vilka prover som behöver tas till mottagningsbesöket? Vilka svar krävs innan besöket bokas och planeras?	How do you know which samples that must be taken for the patient visit? What responses are required before the visit is booked and planned?
Vad är "ELVIS" för typ av informationssystem? Är systemet integrerat med andra informationssystem som till exempel "Melior"	What type of information system is "ELVIS"? Is the system integrated with other information systems such as "Melior"?
Vilken typ av information innehåller kallelsen som sänds till patienten inför ett besök?	What type of information is included in the notification that is sent to the patient prior to a visit?
Hur går ombokningsprocessen till?	How does the cancellation process work?
<b>Frågor relaterade till "genomförande av besök"</b>	<b>Questions regarding "carrying out the patient visit"</b>
Vem ansvarar för ankomstförfarandet? Hur går man tillväga?	Who is responsible for the arrival process? How is this process carried out?
Hur sker provtagningen vid ankomstförfarandet?	How is the sampling at the arrival carried out?
Vad händer när vårdteamet möter patienten?	What happens when the care team meets the patient?
Hur går patientmötet till? Vilken information behövs? Vilken tillgång på information har du vid detta tillfälle?	How is the patient meeting carried out? What information is needed? What kind of information do you have access to during the patient meeting?
Hur dokumenterar du patientbesöket? Hur skulle du vilja dokumentera i framtiden?	How do you document the patient meeting? How would you like to document the patient meeting in the future?
Vilken information behöver du för att göra din bedömning? Har du tillgång till något beslutsstödssystem? Finns det behov för beslutsstödssystem? Vilka är dessa behov?	What information do you need in order to make your decision? Do you have access to any decision support system? Is there a need for decision support systems? What are these needs?
Hur sker dialogen med patienten idag?	How is the dialogue with the patient carried out today?
Hur sker den fortsatta planeringen? Hur skulle du önska att planeringen sker i framtiden?	How is continuing care plan carried out? How would you wish to conduct the planning in the future?
Hur används standardvårdplaner i det fortsatta planeringsarbetet?	How are standard care plans used in the continued planning?
Hur sker receptskrivningen? Vad finns det för fördelar respektive nackdelar med receptförskrivning?	How is the prescribing of medication carried out? What are the advantages and disadvantages?
<b>Frågor relaterade till "planera fortsättning"</b>	<b>Questions regarding the "continued planning"</b>

Hur planerar du för fortsatt behandling/fortsatt utredning? Hur skulle du vilja att det fungerade i framtiden?	How do you plan for the continued treatment / continued investigation and how would you prefer it to work in the future?
Vad innebär standardvårdplan? Vad innefattar en standardvårdplan?	What is a standard care plan? What type of information does a standard care plan include?
Hur sker uppföljning/återbesök?	How is the following up of a patient's visit carried out?
Hur skrivs den slutliga dokumentationen? Vilken information anges i dokumentationen?	How is the final documentation written? What type of information is included in the documentation?
Hur hanteras svar till inremitterande instans? Finns det några integrationsproblem?	How are the answers from the referring unit handled? Are there any integration problems?
Vilka kontaktytor finns med andra vårdgivare?	What kind of collaborations do you have with other healthcare providers? Which communication channels do you use?
Hur involveras patienten i planeringen av den fortsatta vården?	How is the patient involved in the planning of the continued care?
Hur skulle du vilja att patienten involveras i den fortsatta planeringen av vården i framtiden?	How would you like to involve the patient in the continued planning of care in the future?
<b>Frågor till patienter</b>	<b>Questions to patients</b>
<b>Frågor relaterade till ”planering av besök”</b>	<b>Questions regarding the “planning of patient visits”</b>
Hur upplever du kommunikationen med vården och vårdpersonalen som är involverad i din vård?	How do you experience communication with the healthcare and healthcare professionals involved in your care?
Hur upplever du tillgången till information inför ett besök?	How do you experience availability to information prior to a patient encounter?
Vilka informationsbehov har du?	What information needs do you have?
Vilka förväntningar har du inför ett läkarbesök?	What expectations do you have for a patient encounter?
Tillgodoses dina behov, förväntningar och önskemål av din läkare eller sjuksköterska under besöket?	Are your values, preferences and expectations taken into account by your physician or nurse during the patient encounter?
Hur ser du på att fylla i en hälsodeklaration innan ett vårdbesök?	What is your opinion about filling in a health declaration before a patient encounter?
<b>Frågor relaterade till ”genomförande av besök”</b>	<b>Questions regarding “carrying out the patient visit”</b>

Hur upplevde du patientmötet?	How did you experience the patient encounter?
Upplevde du att läkarna lyssnade på dig?	Did the physicians listen to you?
Förstod du den information som läkaren gav till dig?	Did you understand the information that the physician gave to you?
<b>Frågor relaterade till ”planera fortsättning”</b>	<b>Questions regarding the “continued planning”</b>
Hur planerar du för den fortsatta behandlingen och hur skulle du vilja att det fungerade i framtiden?	How do you plan for the continued treatment and how would you like it to work in the future?
Hur sker den slutliga dokumentationen av patientmötet ut? Hur går den till? Ser du några fördelar eller nackdelar?	How does the final documentation of the patient encounter take place? How does it work? Do you see any advantages or disadvantages?
Vilka kontaktytor finns med andra vårdgivare?	What contact areas are there with other healthcare providers?
Finns det ett intresse av att komma åt din journal?	Do you have any interest in reading your EHR?
Hur kan kommunikationen med vården bli tydligare och enklare för dig?	How can the communication with healthcare become clearer and easier for you?

## B INTERVIEW GUIDE – CASE STUDY TWO

### Interview guide for the first part of the study

<b>Frågor till ansvariga för kunskapsportalen</b>	<b>Questions for managers responsible for the IT-based knowledge repository</b>
Vilka är kunskapsportalens målgrupper? Varför har denna målgrupp prioriterats?	Which are the user groups of the IT-based knowledge repository? Why has these user groups been prioritized?
Vilken struktur och teknisk lösning har valts för kunskapsportalen. Varför har dessa val genomförts?	What type of structure and technical solution has been selected for the IT-based knowledge repository? Why have these choices been selected?
Vad har du för organisatorisk modell för kontinuerlig förvaltning, inkl. ansvarsförhållanden för kunskapsportalen?	What type of organizational model do you use for continuous management of the IT-based knowledge repository?

Hur utvärderas kunskapsportalen? Har kunskapsportalen fått genomslag i den aktuella målgruppen/erna?	How is the IT-based knowledge repository evaluated? Has the IT-based knowledge repository had an impact on the target group / s?
Vilka möjligheter och utmaningar ser du med kunskapsportalen?	What opportunities and challenges do you see with the IT-based knowledge repository?

***Interview guide for the second part of the study***

<b>Frågor till chefer med ansvar för kompetensförsörjning och kompetensutveckling</b>	<b>Questions for managers responsible for competence maintenance and skills development</b>
<b>Inledande frågor</b>	<b>Opening questions</b>
Vad ser du för utmaningar i att hålla verksamheten "högkompetent"?	What challenges do you see in keeping the organization "highly skilled"?
När anser du att verksamheten är högkompetent? Vilka kriterier arbetar du mot?	When do you think the organization is highly competent? What criteria are you working towards?
<b>Frågor relaterade till identifiering av kunskapsbehov</b>	<b>Questions related to the identification of knowledge needs</b>
Hur tar du reda på om verksamheten har den kunskap som behövs?	How do you work with finding out whether the organization has the necessary knowledge that is needed?
<b>Frågor relaterade till identifiering av kunskapskällor</b>	<b>Questions related to the identification of knowledge sources</b>
Hur arbetar du med att fånga in ny kunskap som behövs i verksamheten. Varifrån hämtar du ny kunskap?	How do you work with the capture of new knowledge that may be needed in the organization? Where do you capture new knowledge?
<b>Frågor relaterad till processer för att sprida och implementer ny kunskap</b>	<b>Questions related to the processes for dissemination and implementation of knowledge</b>

Hur arbetar du med att sprida och implementera ny kunskap i verksamheten?	How do you work with the dissemination and implementation of new knowledge in the organization?
Hur ser du på ett scenario där en datorbaserade hjälpmedlen spelar en roll för att sprida samt inhämta kunskap. Vilka är möjligheterna och utmaningar med ett datorbaserat hjälpmedel?	How do you view a scenario where computer-based aids play a role in acquiring and disseminating knowledge? What are the opportunities and challenges with a computer-based aid?
Om verksamheten erfar "best practice" vilket ansvar tar du för att sprida denna kunskap till övriga i verksamheten (både inom och utanför den egna verksamheten)?	If new "best practice" occurs in your organization, what responsibility do you take in disseminating that knowledge to other people (both within and outside the organization)?
<b>Typ av kunskap – Behov</b>	<b>Type of knowledge – Needs</b>
Vilken typ av kunskap behöver oftast "uppdateras" i verksamheten?	What knowledge in the organization does usually need "updating"?
Vilken typ av kunskap är svårast att fånga och implementera?	What kind of knowledge is most difficult to capture and implement?
Vilka områden anser du att personalen behöver mer kunskap om? Varför är den kunskapen viktig?	What areas of knowledge do you feel that the employees need to know more about? Why is this knowledge important?
Hur skulle du vilja att den kunskapen görs tillgänglig och presenteras? Varför just på ett sådant vis?	How would you like that knowledge to be made available and presented? Why in such a way?
Vilken kunskap är viktigast att prioritera utifrån din arbetsroll och varför?	What knowledge is most important to prioritize based on your professional role and why?
<b>Frågor till vårdpersonalen</b>	<b>Questions for the healthcare professionals</b>
<b>Frågor relaterade till identifiering av kunskap</b>	<b>Questions related to the identification of knowledge</b>

Vad gör du om ett behov av att inhämta ny kunskap uppstår?	What do you do when you feel the need to acquire new knowledge?
Hur brukar du ta del av kunskaper och erfarenheert som redan finns inom organisationen?	How do you take advantage of the knowledge and experiences that already exists within the organization?
Hur brukar du ta del av den senaste forskningen och de senaste rönen inom ditt arbete?	How do you take advantage of the latest research and the latest findings within your field?
<b>Frågor relaterad till processer för att sprida och implementer av ny kunskap</b>	<b>Questions related to the processes for dissemination and implementation of knowledge</b>
Hur arbetar man i verksamheten med att implementera ny kunskap?	How is new knowledge implemented in the organization?
Hur ser du på ett scenario där datorbaserade hjälpmedlen spelar roll för att inhämta och sprida kunskap? Vilka möjligheter och utmaningar uppfattar du?	How do you view a scenario where computer-based aids play a major role in acquiring and disseminating knowledge? What opportunities and challenges do you see?
I den bästa av världar, hur skulle du vilja få tillgång till kunskap via din dator?	How would you like to have access to knowledge through your computer?
<b>Frågor relaterade till identifiering av kunskapsbehov</b>	<b>Questions related to the identification of knowledge needs</b>
Vilken typ av kunskap saknar du oftast? Varför är den kunskapen viktig anser du?	What kind of knowledge do you miss most often? Why is this knowledge important for you?
Hur skulle du vilja att den kunskapen görs tillgänglig och presenteras? Varför just så? Kan det finnas andra alternativ?	How would you like that knowledge to be made available and presented? Why so? Could there be other alternatives?

## C INTERVIEW GUIDE – CASE STUDY THREE

### *Interview guide for patients who have read their EHR*

<b>Frågor till patienter i grupp A</b>	<b>Questions to patients in group A</b>
<b>Inledande frågor</b>	<b>Opening questions</b>
Ålder	Age

Hur länge har du haft en vårdrelation med Onkologen?	How long have you been a patient at the Oncology?
Har Du loggat in på tjänsten "Min journal på nätet"?  a) Om ja - varför gjorde du det? b) Om nej - varför gjorde Du inte det?	Have you logged in to the eHealth service "Journalen"  a) If yes- Why? b) If no- Why?
<b>Generella frågor relaterat till tjänsten Journalen</b>	<b>General questions related to the eHealth service Journalen</b>
Hur fick Du reda på att Du kunde läsa din journal på nätet?	How did you find out about the opportunity to read your EHR "Journalen" online?
Vilken betydelse (för- och nackdelar) har det för dig att kunna läsa din egen journal via nätet?	What advantages and disadvantages are there for you to read your own EHRs online?
Hur lång tid anser Du att det är acceptabelt att vänta efter ett vårdbesök innan Du får dina journaluppgifter tillgängliga via nätet?	How long do you think it is acceptable to wait after a healthcare visit before your medical information is made available online through Journalen?
Hur har tillgången till "Min journal på nätet" påverkat din relation med hälso- och sjukvården?	How has the access to the Journal affected your relationship with healthcare?
På vilket sätt anser Du att vårdpersonalen stöttar dej i att använda tjänster som "Min journal på nätet" och/eller andra Internetjänster.	In what way do you consider that healthcare professionals support you in using Journalen and other eHealth services?
I den mån Du kan bedöma, vilka tekniska brister anser Du att tjänsten har?	What technical flaws do you think the eHealth service Journalen has?
Vad anser Du om tjänstens användbarhet? Förstår Du hur den fungerar och hur Du ska använda den? Är den ett stöd för dig i din kontakt med vården?	What do you think about the usefulness of the eHealth service Journalen? Do you understand how it works and how to use it? Is it a support for you in your contact with care?
<b>Frågor relaterad till innehållet</b>	<b>Questions related to the content</b>
Vad skulle Du göra om det står något i journalen som Du inte förstår? Vilka kanaler tar Du till hjälp?	What would you do if there is something in the Journalen that you do not understand?

<p>Har Du läst något i journalen som gjort dig upprörd?</p> <p>a) Om ja, hur upplevde Du det?</p> <p>b) Om ja, var det information som Du tagit del av på annat sätt tidigare?</p>	<p>Have you read anything in Journalen that made you upset?</p> <p>a) If yes, how did you experience it?</p> <p>b) If yes, is it information that you have received earlier but in a different way?</p>
<p>Have you read something in the wrong journal?</p> <p>a) Om ja, vad gjorde Du då?</p>	<p>Have you found any errors in Journalen?</p> <p>a) If yes, what did you do about it?</p>
<p>Hur bedömer du innehållet i journalen? Anser du att information där speglar den information du tror att vården har om dig? Saknar du någon information i journalen som du anser borde finnas om din hälsa?</p>	<p>How do you perceive the content in Journalen? Do you think that the content reflects the information that the healthcare organization has about you? Is there any information missing in Journalen that you think should be stated there?</p>
<p>Hur har informationen i journalen påverkat dina möjligheter att följa ordinationer om behandling och vidta egna åtgärder för att förbättra välbefinnandet?</p>	<p>How has the information in Journal influenced your ability to follow through treatments and to take own actions in improving well-being?</p>
<p>Vad är din uppfattning om att kunna ta del av medicinska uppgifter som kan vara oroande, misstanke om någon allvarlig sjukdom etc? Finns det några fördelar och nackdelar?</p>	<p>What is your opinion about taking part of the medical information that may be worrying. Are there any advantages and disadvantages?</p>
<p>Vilken information eller ytterligare tjänster skulle Du vilja ha tillgång till?</p>	<p>What additional information or eHealth services would you like to have access to?</p>
<p>Vilken information eller tjänst vill Du inte ha tillgång till?</p>	<p>Is there any type of information or eHealth services that you don't want to have access to?</p>
<p><b>Informationssäkerhet</b></p>	<p><b>Information security</b></p>
<p>Hur upplever Du säkerheten generellt med tjänsten?</p>	<p>How do you experience the safety of the eHealth service Journalen?</p>
<p>Vad anser Du om det tekniska säkerhetsskyddet? Har Du haft problem med att logga in etc?</p>	<p>How do you experience the technical security? For example have you had trouble logging in?</p>
<p>Har Du sett varningstexten när Du loggade in? Vad är din reaktion på den?</p>	<p>Have you seen the text warning when you log in? What is your reaction to it?</p>

Vad anser Du om möjligheten att även närstående kan ta del av din information? Vad anser Du om att ha möjlighet att dölja viss information för närstående? Om du delar din information med närstående vad vet du om deras upplevelser/förväntningar av tjänsten? Positivt/negativt?	What do you think about the opportunity to share your information with relatives? What do you think about opportunity to hide certain information from relatives? If you share your information with relatives, do you know anything about their experiences / expectations of the service? Positive / negative?
Finns det några orosmoment med att nå din patientinformation via Internet	Do you have any concerns about accessing your patient information through the Internet?
<b>Hantering av din hälsoinformation generellt</b>	<b>Handling of health information in general</b>
Hur hanterar Du din hälsoinformation? Tex information om dina vårdbesök, information om din sjukdom och hälsa?	How do you handle your health information? For example, information about your healthcare visits, information about your illness and health?
Använder Du Internet för övrigt för att hitta information om din hälsa?	Do you use the Internet to find information about your health?
Vilka andra källor använder Du för att söka hälsoinformation?	What other sources do you use to search for health information?
<b>Övrigt</b>	<b>Other</b>
Något ytterligare Du vill lägga till om dina upplevelser och förväntningar med att kunna ta del av din hälsoinformation på nätet?	Something more you want to add about your experience and expectations about the opportunity to access your health information online?

***Interview guide for patients who have not read their EHR***

<b>Frågor till patienter i grupp B</b>	<b>Questions to patients in group B</b>
<b>Inledande frågor</b>	<b>Opening questions</b>
Ålder	Age
Hur länge har du haft en vårdrelation med Onkologen?	How long have you been a patient at the Oncology?
Har Du loggat in på tjänsten "Min journal på nätet"?	Have you logged in to the eHealth service "Journalen"

<p>a) Om ja - varför gjorde du det?</p> <p>b) Om nej - varför gjorde Du inte det?</p>	<p>a) If yes- Why?</p> <p>b) If no- Why?</p>
<b>Generella frågor relaterat till tjänsten Journalen</b>	<b>General questions related to the eHealth service Journalen</b>
Hur fick Du reda på att Du kunde läsa din journal på nätet?	How did you find out about the opportunity to read your EHR "Journalen" online?
<p>Har Du varit på väg att öppna tjänsten även om Du inte loggade in?</p> <p>a) Om ja, vad gjorde att du loggade in?</p> <p>b) Om nej, vad gjorde att Du inte loggade in?</p>	<p>Have you ever wanted to log in and read your EHR?</p> <p>a) If yes- Why?</p> <p>b) If no- Why?</p>
<b>Informationssäkerhet</b>	<b>Information security</b>
<p>Var säkerheten en av anledningarna till att Du inte vill läsa din information på nätet?</p> <p>Om ja, i så fall på vilket sätt?</p>	Was security one of the reasons that you do not want to read your information online? If yes, how?
Hur upplever Du säkerheten generellt med den här typen av tjänst?	How do you generally experience the security of this kind of eHealth service?
Vad anser Du om möjligheten att även närstående kan ta del av din information? Vad anser Du om att ha möjlighet att dölja viss information för närstående?	What do you think about the opportunity to share your information with relatives? What do you think about opportunity to hide certain information from relatives?
<b>Frågor relaterad till innehållet</b>	<b>Questions related to the content</b>
Vad är din uppfattning om att kunna ta del av medicinska uppgifter som kan vara oroande, misstanke om någon allvarlig sjukdom etc? Finns det några fördelar och nackdelar?	What is your opinion about taking part of the medical information that may be worrying. Are there any advantages and disadvantages?
Finns det några orosmoment med att nå din patientinformation via Internet	Do you have any concerns about accessing your patient information through the Internet?
Vilken information eller ytterligare tjänster skulle Du vilja ha tillgång till?	What additional information or eHealth services would you like to have access to?

Vilken information eller tjänst vill Du inte ha tillgång till?	Is there any type of information or eHealth services that you don't want to have access to?
<b>Hantering av din hälsoinformation generellt</b>	<b>Handling of health information in general</b>
Hur hanterar Du din hälsoinformation? Tex information om dina vårdbesök, information om din sjukdom och hälsa?	How do you handle your health information? For example, information about your healthcare visits, information about your illness and health?
Använder Du Internet för övrigt för att hitta information om din hälsa?	Do you use the Internet to find information about your health?
Vilka andra källor använder Du för att söka hälsoinformation?	What other sources do you use to search for health information?
<b>Övrigt</b>	<b>Other</b>
Något ytterligare Du vill lägga till om dina upplevelser och förväntningar med att kunna ta del av din hälsoinformation på nätet?	Something more you want to add about your experience and expectations about the opportunity to access your health information online?





## REFERENCES

- Aasen, E. M., Kvangarsnes, M., & Heggen, K. (2012). Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scandinavian Journal of Caring Sciences*, 26(1), 61-69.
- Abidi, S. S. R. (2005). Medical knowledge morphing: towards case-specific integration of heterogeneous medical knowledge resources. In *Proceedings of Computer-Based Medical Systems, 2005, 18th IEEE Symposium on* (pp. 208-213). IEEE.
- Abidi, S. S. R. (2008). Healthcare knowledge management: The art of the possible. In *Knowledge management for health care procedures* (pp. 1-20). Springer.
- Acharyulu, G. (2011). Information management in a health care system: knowledge management perspective. *International Journal of Innovation, Management and Technology*, 2(6), 534-537.
- Akobeng, A. K. (2005). Principles of evidence based medicine. *Archives of Disease in Childhood*, 90(8), 837-840.
- Alavi, M., & Leidner, D. E. (2001). Review: Knowledge management and knowledge management systems: Conceptual foundations and research issues. *MIS Quarterly*, 107-136.
- Alter, S. (2006). *The work system method: connecting people, processes, and IT for business results*. Larkspur, CA, Work System Press.
- Ambrosini, V., & Bowman, C. (2001). Tacit knowledge: Some suggestions for operationalization. *Journal of Management studies*, 38(6), 811-829.
- Aveyard, H., & Sharp, P. (2013). *A Beginner's Guide to Evidence-based Practice in Health and Social Care*. McGraw-Hill Education (UK).
- Baars, J. E., Markus, T., Kuipers, E. J., & Van Der Woude, C. J. (2010). Patients' preferences regarding shared decision-making in the treatment of inflammatory bowel disease: results from a patient-empowerment study. *Digestion*, 81(2), 113-119.
- Barnes, S. (2011). *Aligning people, process and technology in knowledge management*. London. Ark Group.
- Barratt, A. (2008). Evidence based medicine and shared decision making: the challenge of getting both evidence and preferences into health care. *Patient Education and Counseling*, 73(3), 407-412.
- Bates, M. J. (2002). Speculations on browsing, directed searching, and linking in relation to the Bradford distribution. In *Emerging frameworks and methods: Proceedings of*

- the Fourth International Conference on Conceptions of Library and Information Science (CoLIS 4)* (pp. 137-150).
- Beesley, L. G., & Cooper, C. (2008). Defining knowledge management (KM) activities: towards consensus. *Journal of Knowledge Management*, 12(3), 48-62.
- Bell, S. K., Mejilla, R., Anselmo, M., Darer, J. D., Elmore, J. G., Leveille, S., . . . Walker, J. (2016). When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient–doctor relationship. *BMJ quality & safety*.
- Ben-Tovim, D. I., Dougherty, M. L., O'Connell, T. J., & McGrath, K. M. (2008). Patient journeys: the process of clinical redesign. *Medical Journal of Australia*, 188(6), S14.
- Benbasat, I., Goldstein, D. K., & Mead, M. (1987). The case research strategy in studies of information systems. *Mis Quarterly*, 369-386.
- Berg, B. L. (2004). *Methods for the social sciences. Qualitative Research Methods for the Social Sciences*. Boston. Pearson Education.
- Bose, R. (2003). Knowledge management-enabled health care management systems: capabilities, infrastructure, and decision-support. *Expert Systems with Applications*, 24(1), 59-71.
- Butow, P., Harrison, J. D., Choy, E. T., Young, J. M., Spillane, A., & Evans, A. (2007). Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. *Cancer*, 110(9), 1937-1944.
- Caress, A., Beaver, K., Luker, K., Campbell, M., & Woodcock, A. (2005). Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. *Thorax*, 60(3), 199-205.
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681-692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651-661.
- Chen, E. T. (2013). *Knowledge management implementation in the healthcare industry. Proceedings for the Northeast Decision Sciences Institute*, 634-644.
- Chiu, C., Feuz, M. A., McMahan, R. D., Miao, Y., & Sudore, R. L. (2016). “Doctor, Make My Decisions”: Decision Control Preferences, Advance Care Planning, and Satisfaction With Communication Among Diverse Older Adults. *Journal of Pain and Symptom Management*, 51(1), 33-40.
- Clancy, C. M., & Cronin, K. (2005). Evidence-based decision making: global evidence, local decisions. *Health Affairs*, 24(1), 151-162.
- Coulter, A. (2010). Do patients want a choice and does it work? *British Medical Journal*, 341.
- Coulter, A. (2012). Patient engagement—what works? *The Journal of Ambulatory Care Management*, 35(2), 80-89.
- Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *British Medical Journal*, 318(7179), 318.

- Covell, D. G., Uman, G. C., & Manning, P. R. (1985). Information needs in office practice: are they being met. *Annals of Internal Medicine*, 103(4), 596-599.
- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35(2), 236-264.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage Publications.
- Davenport, T. H. (2013). *Process innovation: reengineering work through information technology*. Harvard Business Press.
- Davenport, T. H., & Prusak, L. (1998). *Working knowledge: How organizations manage what they know*. Harvard Business Press.
- Davis, S., Roudsari, A., Raworth, R., Courtney, K. L., & MacKay, L. (2017). Shared decision-making using personal health record technology: a scoping review at the crossroads. *Journal of the American Medical Informatics Association*, 24(4):857-866.
- de Lusignan, S., Mold, F., Sheikh, A., Majeed, A., Wyatt, J. C., Quinn, T., . . . Chauhan, U. (2014). Patients' online access to their electronic health records and linked online services: a systematic interpretative review. *BMJ open*, 4(9).
- de Silva, D. (2012). *Helping people share decision making*. The Health Foundation.
- Del Fiol, G., Workman, T. E., & Gorman, P. N. (2014). Clinical questions raised by clinicians at the point of care: a systematic review. *JAMA Internal Medicine*, 174(5), 710-718.
- Delbanco, T., Walker, J., Bell, S. K., Darer, J. D., Elmore, J. G., Farag, N., . . . Ralston, J. D. (2012). Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Annals of Internal Medicine*, 157(7), 461-470.
- Deming, W. E. (2000). *The new economics: for industry, government, education*. MIT press.
- Deng, Q.-W., & Tian, Y.-Z. (2008). *Modeling Knowledge Management Processes from Perspectives of Knowledge Agents*. In *Wireless Communications, Networking and Mobile Computing, 2008. WiCOM'08. 4th International Conference on* (pp. 1-5). IEEE.
- Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research*. Sage.
- Desouza, K. C. (2005). Knowledge management in hospitals. In *Creating Knowledge Based Healthcare Organizations*, N. Wickramasinghe, JND Gupta and SK Sharma (eds.), 14-28.
- do Rosário Cabrita, M., Cabrita, A. M., & Cruz-Machado, V. A. (2014). Healthcare Knowledge Management: Integrating Knowledge with Evidence-based Practice. In *Proceedings of the Eighth International Conference on Management Science and Engineering Management* (pp. 1121-1131). Springer, Berlin, Heidelberg.
- Edwards, A., & Elwyn, G. (2009). *Shared decision-making in health care: Achieving evidence-based patient choice*. Oxford University Press.
- Edwards, J. S., & Kidd, J. B. (2003). Bridging the gap from the general to the specific by linking knowledge management to business processes. *Knowledge and Business Process Management*, 118-136.
- Ekdahl, A. W., Andersson, L., Wiréhn, A.-B., & Friedrichsen, M. (2011). Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. *BMC Geriatrics*, 11(1), 46.

- El-Gayar, O., & Timsina, P. (2014). *Opportunities for Business Intelligence and Big Data Analytics in Evidence Based Medicine*. In *System Sciences (HICSS), 2014 47th Hawaii International Conference on* (pp. 749-757). IEEE.
- El Morr, C., & Subercaze, J. (2010). Knowledge management in healthcare *Handbook of Research on Developments in e-Health and Telemedicine: Technological and Social Perspectives* (pp. 490-510): IGI Global.
- El Sawy, O. A., & Josefek, R. A. (2004). Business process as nexus of knowledge. In *Handbook on Knowledge Management 1* (pp. 425-438). Springer, Berlin, Heidelberg.
- Elg, M., Stenberg, J., Kammerlind, P., Tullberg, S., & Olsson, J. (2011). Swedish healthcare management practices and quality improvement work: development trends. *International Journal of Health Care Quality Assurance*, 24(2), 101-123.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115.
- Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision making and motivational interviewing: achieving patient-centered care across the spectrum of health care problems. *The Annals of Family Medicine*, 12(3), 270-275.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., . . . Rollnick, S. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361-1367.
- Elwyn, G., Tilburt, J., & Montori, V. (2013). The ethical imperative for shared decision-making. *European Journal for Person Centered Healthcare*, 1(1), 129-131.
- Erlingsdóttir, G., & Lindholm, C. (2015). When patient empowerment encounters professional autonomy: The conflict and negotiation process of inscribing an eHealth service. *Scandinavian Journal of Public Administration*, 19(2), 27-48.
- Fahey, L., & Prusak, L. (1998). The eleven deadliest sins of knowledge management. *California Management Review*, 40(3), 265-276.
- Fennessy, G., & Burstein, F. (2007). Role of information professionals as intermediaries for knowledge management in evidence-based healthcare. *Healthcare Knowledge Management* (pp. 28-40). Springer.
- Fiksdal, A. S., Kumbamu, A., Jadhav, A. S., Cocos, C., Nelsen, L. A., Pathak, J., & McCormick, J. B. (2014). Evaluating the process of online health information searching: a qualitative approach to exploring consumer perspectives. *Journal of Medical Internet Research*, 16(10).
- Foley, G., & Timonen, V. (2015). Using grounded theory method to capture and analyze health care experiences. *Health Services Research*, 50(4), 1195-1210.
- Fowler, F. J., Levin, C. A., & Sepucha, K. R. (2011). Informing and involving patients to improve the quality of medical decisions. *Health Affairs*, 30(4), 699-706.
- Fraenkel, L., & McGraw, S. (2007). Participation in medical decision making: the patients' perspective. *Medical Decision Making*, 27(5), 533-538.
- Furukawa, M. F., King, J., Patel, V., Hsiao, C.-J., Adler-Milstein, J., & Jha, A. K. (2014). Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low in office settings. *Health Affairs*, 33(9), 1672-1679.
- Gartlehner, G., & Matyas, N. (2016). How contextual issues can distort shared decision making. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 118, 17-23.

- Gemmel, P., Vandaele, D., & Tambreur, W. (2008). Hospital Process Orientation (HPO): The development of a measurement tool. *Total Quality Management*, 19(12), 1207-1217.
- Gerard, M., Fossa, A., Folcarelli, P. H., Walker, J., & Bell, S. K. (2017). What patients value about reading visit notes: A qualitative inquiry of patient experiences with their health information. *Journal of Medical Internet Research*, 19(7).
- Glaser, B. G. (1992). *Basics of Grounded Theory Analysis*. Emergence Vs Forcing: Sociology Press.
- Glass, K. E., Wills, C. E., Holloman, C., Olson, J., Hechmer, C., Miller, C. K., & Duchemin, A.-M. (2012). Shared decision making and other variables as correlates of satisfaction with health care decisions in a United States national survey. *Patient Education and Counseling*, 88(1), 100-105.
- Godolphin, W. (2009). Shared decision-making. *Healthcare Quarterly*, 12, 186-190.
- Gonçalves, P. D., Hagenbeek, M. L., & Vissers, J. M. (2013). Hospital process orientation from an operations management perspective: development of a measurement tool and practical testing in three ophthalmic practices. *BMC health services research*, 13(1), 475.
- Gravis, G., Protière, C., Eisinger, F., Boher, J. M., Tarpin, C., Coso, D., . . . Viens, P. (2011). Full access to medical records does not modify anxiety in cancer patients. *Cancer*, 117(20), 4796-4804.
- Grünloh, C., Cajander, Å., & Myreteg, G. (2016). “The Record is Our Work Tool!”—Physicians’ Framing of a Patient Portal in Sweden. *Journal of Medical Internet Research*, 18(6).
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Technology Research and Development*, 29(2), 75-91.
- Hammer, M., & Champy, J. (1993). *Reengineering the corporation: a manifesto for business reengineering*. Nicholas Brealey Publ. London.
- Harrington, H. J. (1991). Business process improvement: *The breakthrough strategy for total quality, productivity, and competitiveness*. McGraw Hill Professional.
- Heisig, P. (2009). Harmonisation of knowledge management—comparing 160 KM frameworks around the globe. *Journal of Knowledge Management*, 13(4), 4-31.
- Hellström, A., Elg, M., & Lindmark, J. (2011). *Process orientation in healthcare services: tracking the patient’s journey through the healthcare system*. In *18th International Annual EurOMA Conference*, Cambridge UK.
- Hicks, R. C., Dattero, R., & Galup, S. D. (2006). The five-tier knowledge management hierarchy. *Journal of Knowledge Management*, 10(1), 19-31.
- Hoffmann, T. C., & Del Mar, C. B. (2012). Exploring the understanding of evidence-based concepts in people with type 2 diabetes. *International Journal of General Medicine*, 5, 781-786.
- Hoffmann, T. C., Légaré, F., Simmons, M. B., McNamara, K., McCaffery, K., Trevena, L. J., . . . Del Mar, C. B. (2014). Shared decision making: what do clinicians need to know and why should they bother. *The Medical Journal of Australia*, 201(1), 35-39.
- Hoffmann, T. C., Montori, V. M., & Del Mar, C. (2014). The connection between evidence-based medicine and shared decision making. *Jama*, 312(13), 1295-1296.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.

- Hägglund, M., & Scandurra, I. (2017). Patients' online access to Electronic Health Records—current status and experiences from the implementation in Sweden. *Studies in health technology and informatics*, 245, 723-727.
- Iroju, O., Soriyan, A., Gambo, I., & Olaleke, J. (2013). Interoperability in healthcare: benefits, challenges and resolutions. *International Journal of Innovation and Applied Studies*, 3(1), 262-270.
- Jabar, M. A., Sidi, F., Selamat, M. H., Ghani, A. A. A., & Ibrahim, H. (2009). An investigation into methods and concepts of qualitative research in information system research. *Computer and Information Science*, 2(4), 47.
- Jennex, M. E., Smolnik, S., & Croasdell, D. (2016). The search for knowledge management success. In *System Sciences (HICSS), 2016 49th Hawaii International Conference on* (pp. 4202-4211). IEEE.
- Jensen, P. E. (2005). A contextual theory of learning and the learning organization. *Knowledge and Process Management*, 12(1), 53-64.
- Jones, K., & Leonard, L. N. (2009). From tacit knowledge to organizational knowledge for successful. In *Knowledge Management and Organizational Learning* (pp. 27-39). Springer, Boston, MA.
- Jordan, J., Ellis, S., & Chambers, R. (2002). Defining shared decision making and concordance: are they one and the same? *Postgraduate Medical Journal*, 78(921), 383-384.
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, 94(3), 291-309.
- Joseph-Williams, N., Edwards, A., & Elwyn, G. (2016). Preparing patients ahead of time to share decisions about their health care. In *Shared Decision Making in Health Care: Achieving evidence-based patient choice*. Oxford University Press.
- Joustra-Enquist, I., & Eklund, B. (2004). SUSTAINS—direct access for the patient to the medical record over the Internet. *MEDINFO*, 400, 1673.
- Kaipio, J., Lääveri, T., Hyppönen, H., Vainiomäki, S., Reponen, J., Kushniruk, A., . . . Vänskä, J. (2017). Usability problems do not heal by themselves: National survey on physicians' experiences with EHRs in Finland. *International Journal of Medical Informatics*, 97, 266-281.
- Kambhampati, S., Ashvetiya, T., Stone, N. J., Blumenthal, R. S., & Martin, S. S. (2016). Shared decision-making and patient empowerment in preventive cardiology. *Current Cardiology Reports*, 18(5), 1-7.
- Kaplan, B., & Maxwell, J. A. (2005). Qualitative research methods for evaluating computer information systems. In *Evaluating the organizational impact of healthcare information systems* (pp. 30-55). Springer, New York, NY.
- Khosravi, A. (2016). Business process rearrangement and renaming: a new approach to process orientation and improvement. *Business Process Management Journal*, 22(1), 116-139.
- Kiraka, R. N., & Manning, K. (2005). Managing organisations through a process-based perspective: its challenges and benefits. *Knowledge and Process Management*, 12(4), 288-298.
- Knops, A., Ubbink, D., Legemate, D., de Haes, J., & Goossens, A. (2010). Information communicated with patients in decision making about their abdominal aortic aneurysm. *European Journal of Vascular and Endovascular Surgery*, 39(6), 708-713.

- Kohlbacher, M. (2010). The effects of process orientation: a literature review. *Business Process Management Journal*, 16(1), 135-152.
- Kothari, A., Rudman, D., Dobbins, M., Rouse, M., Sibbald, S., & Edwards, N. (2012). The use of tacit and explicit knowledge in public health: a qualitative study. *Implementation Science*, 7(1), 20.
- Krogstie, J., Sindre, G., & Jørgensen, H. (2006). Process models representing knowledge for action: a revised quality framework. *European Journal of Information Systems*, 15(1), 91-102.
- Kuhn, T. S., & Hawkins, D. (1963). The structure of scientific revolutions. *American Journal of Physics*, 31(7), 554-555.
- Labrecque, M., Lafortune, V., Lajeunesse, J., Lambert-Perrault, A. M., Manrique, H., Blais, J., & Légaré, F. (2010). Do continuing medical education articles foster shared decision making?. *Journal of Continuing Education in the Health Professions*, 30(1), 44-50.
- Leask, J. (2009). How do general practitioners persuade parents to vaccinate their children? A study using standardised scenarios. *New South Wales public health bulletin*, 20(8), 119-124.
- Légaré, F., Bekker, H., Desroches, S., Drolet, R., Politi, M. C., Stacey, D., . . . Coutu, M.-F. (2011). How can continuing professional development better promote shared decision-making? Perspectives from an international collaboration. *Implementation Science*, 6(1), 1.
- Légaré, F., & Witteman, H. O. (2013). Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Affairs*, 32(2), 276-284.
- Lenz, R., & Reichert, M. (2007). IT support for healthcare processes—premises, challenges, perspectives. *Data & Knowledge Engineering*, 61(1), 39-58.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Sage.
- Loermans, J. (2002). Synergizing the learning organization and knowledge management. *Journal of Knowledge Management*, 6(3), 285-294.
- Lott, J. P., Piepkorn, M. W., & Elmore, J. G. (2015). Dermatology in an age of fully transparent electronic medical records. *JAMA Dermatology*, 151(5), 477-478.
- Majchrzak, A., & Wang, Q. (1996). *Breaking the functional mind-set in process organizations*. Harvard Business Review, 3.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301-312.
- Mathews, A. L., Coleska, A., Burns, P. B., & Chung, K. C. (2016). Evolution of Patient Decision-Making Regarding Medical Treatment of Rheumatoid Arthritis. *Arthritis Care & Research*, 68(3), 318-324.
- Mathisen, E., & Krogstie, J. (2012). Modeling of Processes and Decisions in Healthcare-State of the Art and Research Directions. In *IFIP Working Conference on The Practice of Enterprise Modeling* (pp. 101-116). Springer, Berlin, Heidelberg.
- Mays, N., & Pope, C. (1995). Rigour and qualitative research. *British Medical Journal*, 311(6997), 109.
- McGlynn, E. A., Asch, S. M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A., & Kerr, E. A. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine*, 348(26), 2635-2645.

- McMullan, M. (2006). Patients using the Internet to obtain health information: how this affects the patient–health professional relationship. *Patient Education and Counseling*, 63(1), 24-28.
- Merriam, S. B. (1988). *Case study research in education: A qualitative approach*. Jossey-Bass.
- Mertins, K., Heisig, P., & Vorbeck, J. (2003). *Knowledge management: concepts and best practices*. Springer Science & Business Media.
- Mold, F., & de Lusignan, S. (2015). Patients' online access to their primary care electronic health records and linked online services: implications for research and practice. *Journal of Personalized Medicine*, 5(4), 452-469.
- Morton, S., Shih, S. C., Winther, C. H., Tinoco, A., Kessler, R. S., & Scholle, S. H. (2015). Health IT–Enabled Care Coordination: A National Survey of Patient-Centered Medical Home Clinicians. *The Annals of Family Medicine*, 13(3), 250-256.
- Mulley, A. G., Trimble, C., & Elwyn, G. (2012). Stop the silent misdiagnosis: patients' preferences matter. *British Medical Journal*, 345(1).
- Musen, M. A., & van Bommel, J. H. (1997). *Handbook of medical informatics*. Houten: Bohn Stafleu Van Loghum.
- Myers, M. D. (1997). Qualitative research in information systems. *Management Information Systems Quarterly*, 21(2), 241-242.
- Mühlhauser, I., Albrecht, M., & Steckelberg, A. (2015). Evidence-based health information and risk competence. *GMS German Medical Science*, 13.
- Nonaka, I. (1994). A dynamic theory of organizational knowledge creation. *Organization Science*, 5(1), 14-37.
- Nonaka, I., & Takeuchi, H. (1995). *The knowledge-creating company: How Japanese companies create the dynamics of innovation*. Oxford university press.
- Nordgren, S., & Fridlund, B. (2001). Patients' perceptions of self-determination as expressed in the context of care. *Journal of Advanced Nursing*, 35(1), 117-125.
- Nota, I., Drossaert, C. H., Taal, E., & van de Laar, M. A. (2016). Arthritis patients' motives for (not) wanting to be involved in medical decision-making and the factors that hinder or promote patient involvement. *Clinical Rheumatology*, 35(5), 1225-1235.
- O'Dell, C. S., Grayson, C. J., & Essaiades, N. (1998). *If only we knew what we know: The transfer of internal knowledge and best practice*: Simon and Schuster.
- Oates, B. J. (2005). *Researching information systems and computing*. Sage.
- Oh, S., Zhang, Y., & Park, M. S. (2016). Cancer information seeking in social question and answer services: identifying health-related topics in cancer questions on Yahoo! Answers. *Information Research - an International Electronic Journal*, 21(3).
- Oktay, J. S. (2012). *Grounded theory*. Oxford University Press.
- Pardon, K., Deschepper, R., Vander Stichele, R., Bernheim, J., Mortier, F., Schallier, D., . . . Deliens, L. (2011). Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. *Palliative Medicine*, 25(1), 62-70.
- Patel, V., Barker, W., & Siminerio, E. (2014). Individuals' access and use of their online medical record nationwide. *ONC Data Brief* (20).
- Pearce, C., & Bainbridge, M. (2014). A personally controlled electronic health record for Australia. *Journal of the American Medical Informatics Association*, 21(4), 707-713.

- Peleg, M. (2013). Computer-interpretable clinical guidelines: a methodological review. *Journal of Biomedical Informatics*, 46(4), 744-763.
- Peleg, M., Keren, S., & Denekamp, Y. (2008). Mapping computerized clinical guidelines to electronic medical records: Knowledge-data ontological mapper (KDOM). *Journal of Biomedical Informatics*, 41(1), 180-201.
- Perjons, E., Wangler, B., & Åhlfeldt, R.-M. (2005). Efficient and secure process and IT integration in healthcare using process manager technology. In *4th International Conference on Business Informatics Research, BIR 2005, 3 October 2005 through 4 October 2005, Skovde, Sweden* (No. 2, pp. 87-96). University of Skövde.
- Persson, A., & Stirna, J. (2007). Making IT Happen and Making IT Stick-A Successful Case of Implementing a Knowledge Management System in a Healthcare Organization. In *ECIS* (pp. 624-634).
- Persson, A., Stirna, J., & Aggestam, L. (2008). How to disseminate professional knowledge in healthcare: The case of Skaraborg hospital. *Journal of Cases on Information Technology*, 10(4), 41-64.
- Pitney, W. A. (2004). Strategies for establishing trustworthiness in qualitative research. *Athletic Therapy Today*, 9(1), 26-28.
- Polanyi, M. (1966). *The tacit dimension*. University of Chicago Press.
- Polanyi, M. (2009). *The tacit dimension*. University of Chicago press.
- Politi, M. C., Lewis, C. L., & Frosch, D. L. (2013). Supporting shared decisions when clinical evidence is low. *Medical Care Research and Review*, 70(1 suppl), 113S-128S.
- Pollard, S., Bansback, N., & Bryan, S. (2015). Physician attitudes toward shared decision making: a systematic review. *Patient Education and Counseling*, 98(9), 1046-1057.
- Pope, C., & Mays, N. (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal*, 311 (6996), 42-45.
- Protière, C., Moumjid, N., Bouhnik, A.-D., Le Corroller Soriano, A. G., & Moatti, J. P. (2012). Heterogeneity of cancer patient information-seeking behaviors. *Medical Decision Making*, 32(2), 362-375.
- Quinn, E., Huckel-Schneider, C., Campbell, D., Seale, H., & Milat, A. J. (2014). How can knowledge exchange portals assist in knowledge management for evidence-informed decision making in public health? *BMC public health*, 14(1), 443.
- Quintas, P., Lefere, P., & Jones, G. (1997). Knowledge management: a strategic agenda. *Long range planning*, 30(3), 385-391.
- Raghupathi, W., & Kesh, S. (2007). Interoperable electronic health records design: towards a service-oriented architecture. *E-service Journal*, 5(3), 39-57.
- Rahbek, N. J. (2013). E-record-access to all Danish public health records. *Studies in Health Technology and Informatics*, 192, 1121.
- Rapley, T. (2008). Distributed decision making: the anatomy of decisions-in-action. *Sociology of Health & Illness*, 30(3), 429-444.
- Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review*, 70(4), 351-379.
- Reichert, M. (2011). What BPM technology can do for healthcare process support. In *Conference on Artificial Intelligence in Medicine in Europe* (pp. 2-13). Springer, Berlin, Heidelberg.

- Reid, P. P., Compton, W. D., Grossman, J. H., & Fanjiang, G. (2005). *Building a better delivery system: a new engineering/health care partnership* (Vol. 2005, pp. 1-7). Washington, DC: National Academies Press.
- Reijers, H. A. (2006). Implementing BPM systems: the role of process orientation. *Business Process Management Journal*, 12(4), 389-409.
- Rentzhog, O. (1996). *Core process management*. Division of Quality Technology, Department of Mechanical Engineering, Linköping University.
- Rentzhog, O. (1998). *Processorientering: En grund för morgondagens organisationer*. Studentlitteratur.
- Robson, C., & McCartan, K. (2016). *Real world research*. John Wiley & Sons.
- Ross, S. E., Moore, L. A., Earnest, M. A., Wittevrongel, L., & Lin, C.-T. (2004). Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *Journal of Medical Internet Research*, 6(2).
- Ruland, C. M., & Bakken, S. (2002). Developing, implementing, and evaluating decision support systems for shared decision making in patient care: a conceptual model and case illustration. *Journal of Biomedical Informatics*, 35(5), 313-321.
- Russ, A. L., Saleem, J. J., Justice, C. F., Woodward-Hagg, H., Woodbridge, P. A., & Doebeling, B. N. (2010). Electronic health information in use: Characteristics that support employee workflow and patient care. *Health Informatics Journal*, 16(4), 287-305.
- Sackett, D. L., Rosenberg, W. M., Gray, J., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: what it is and what it isn't. *British Medical Journal*, 312, 71-72.
- Safford, M. M. (2017). A New Chapter in Patient-Centered Care: Sharing the Medical Note? *Annals of Internal Medicine* 168(4), 298.
- Sarlak, M. A. (2010). *The New Faces of Organizations in the 21st Century: A Management and Business Reference Book* (Vol. 2). NAISIT Publishers.
- Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: a worked example of a study of dental practices. *Medical Research Methodology*, 11(1), 128.
- Scarborough, H., Swan, J., & Preston, J. (1999). Knowledge management-the next fad to forget people. In *Proceedings of European Conference on Information Systems, Copenhagen* (pp. 668-678).
- Schroy, P. C., Emmons, K., Peters, E., Glick, J. T., Robinson, P. A., Lydotes, M. A., . . . Pignone, M. (2011). The impact of a novel computer-based decision aid on shared decision making for colorectal cancer screening a randomized trial. *Medical Decision Making*, 31(1), 93-107.
- SFS. (2014:821). *Patientlag [Patient Act]*. Socialdepartementet. Stockholm, Sweden.
- SFS. (2008:355) *Patientdatalag [Patient data Act]*. Socialdepartementet. Stockholm, Sweden.
- Shalom, E., Shahar, Y., Taieb-Maimon, M., Bar, G., Yarkoni, A., Young, O., . . . Liel, Y. (2008). A quantitative assessment of a methodology for collaborative specification and evaluation of clinical guidelines. *Journal of Biomedical Informatics*, 41(6), 889-903.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-75.

- Sheridan, S. L., Harris, R. P., & Woolf, S. H. (2004). Shared decision making about screening and chemoprevention: a suggested approach from the US Preventive Services Task Force. *American Journal of Preventive Medicine*, 26(1), 56-66.
- Shiffman, R. N., Michel, G., Essaihi, A., & Thornquist, E. (2004). Bridging the guideline implementation gap: a systematic, document-centered approach to guideline implementation. *Journal of the American Medical Informatics Association*, 11(5), 418-426.
- Shtub, A., & Karni, R. (2010). ERP: the dynamics of supply chain and process management: Springer Science & Business Media.
- Silber, D. (2009). The Internet and shared decision-making between patients and healthcare providers. *Presse medicale*, 38(10), 1491-1493.
- Silverman, D. (2006). *Interpreting qualitative data: Methods for analyzing talk, text and interaction*. Sage.
- Silverman, D. (2013). *Doing qualitative research: A practical handbook*: SAGE Publications Limited.
- Siminoff, L. A. (2013). Incorporating patient and family preferences into evidence-based medicine. *Medical Informatics and Decision Making*, 13(3), 1.
- Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmes-Rovner, M., . . . Thomson, R. (2011). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews*, 10(10).
- Straus, S. E., Glasziou, P. W., Richardson, S & Haynes, R. B. (2010). *Evidence-Based Medicine: How to Practice and Teach It*. Churchill Livingstone.
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. SAGE Publications.
- Swedish Ministry of Health and Social Affairs. (2006). *Nationell IT-strategi för vård och omsorg* [in Swedish]. Retrieved from <http://www.regeringen.se/49b69c/contentassets/fefdo1492f548c2ab1451e45b7f6463/nationell-it-strategi-for-var-d-och-omsorg-skr.-200506139>.
- Tan, S. S.-L., & Goonawardene, N. (2017). Internet health information seeking and the patient-physician relationship: A systematic review. *Journal of Medical Internet Research*, 19(1).
- Tang, P. C., & Lansky, D. (2005). The missing link: bridging the patient-provider health information gap. *Health Affairs*, 24(5), 1290-1295.
- Tello-Leal, E., Chiotti, O., & Villarreal, P. D. (2012). Process-oriented integration and coordination of healthcare services across organizational boundaries. *Journal of Medical Systems*, 36(6), 3713-3724.
- Thom, D. H., Wolf, J., Gardner, H., DeVore, D., Lin, M., Ma, A., . . . Saba, G. (2016). A Qualitative Study of How Health Coaches Support Patients in Making Health-Related Decisions and Behavioral Changes. *The Annals of Family Medicine*, 14(6), 509-516.
- Tiik, M., & Ross, P. (2010). Patient opportunities in the Estonian electronic health record system. *Studies in Health Technology and Informatics*, 156, 171-177.
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48(4), 388-396.
- Tuomi, I. (1999). Data is more than knowledge: Implications of the reversed knowledge hierarchy for knowledge management and organizational memory. In *Systems Sciences, 1999. HICSS-32. Proceedings of the 32nd Annual Hawaii International Conference on* (pp. 12-pp). IEEE.

- Walker, J., Meltsner, M., & Delbanco, T. (2015). US experience with doctors and patients sharing clinical notes. *British Medical Journal*, *350*, g7785.
- Walter, F. M., Emery, J. D., Rogers, M., & Britten, N. (2004). Women's views of optimal risk communication and decision making in general practice consultations about the menopause and hormone replacement therapy. *Patient Education and Counseling*, *53*(2), 121-128.
- Webster, J., & Watson, R. T. (2002). Analyzing the past to prepare for the future: Writing a literature review. *MIS Quarterly*, xiii-xxiii.
- Vera, A., & Kuntz, L. (2007). Process-based organization design and hospital efficiency. *Health Care Management Review*, *32*(1), 55-65.
- Vermeir, P., Degroote, S., Vandijck, D., Van Tiggelen, H., Peleman, R., Verhaeghe, R., . . . Vogelaers, D. (2017). The patient perspective on the effects of medical record accessibility: a systematic review. *Acta Clinica Belgica*, *72*(3), 186-194.
- Weske, M. (2010). *Business process management: concepts, languages, architectures*. Verlag Berlin, Springer.
- Wiljer, D., Urowitz, S., Apatu, E., DeLenardo, C., Eysenbach, G., Harth, T., . . . Records, C. C. f. P. A. H. (2008). Patient accessible electronic health records: exploring recommendations for successful implementation strategies. *Journal of Medical Internet Research*, *10*(4).
- Williamson, K. (2002). *Research methods for students, academics and professionals: Information management and systems*. Elsevier.
- Willis, J. W., & Jost, M. (2007). *Foundations of qualitative research: Interpretive and critical approaches*. Sage.
- Wilson, S. R., Strub, P., Buist, A. S., Knowles, S. B., Lavori, P. W., Lapidus, J., & Vollmer, W. M. (2010). Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American Journal of Respiratory and Critical Care Medicine*, *181*(6), 566-577.
- Winge, M., Johannesson, P., Perjons, E., & Wangler, B. (2015). The coordination hub: Toward patient-centered and collaborative care processes. *Health Informatics Journal*, *21*(4), 284-305.
- Wisker, G. (2007). *The postgraduate research handbook: Succeed with your MA, MPhil, EdD and PhD*. Palgrave Macmillan.
- Wolff, J. L., Darer, J. D., Berger, A., Clarke, D., Green, J. A., Stametz, R. A., . . . Walker, J. (2017). Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. *Journal of the American Medical Informatics Association*, *24*(e1), e166-e172.
- Vos, L., Chalmers, S. E., Dückers, M. L., Groenewegen, P. P., Wagner, C., & Van Merode, G. G. (2011). Towards an organisation-wide process-oriented organisation of care: A literature review. *Implementation Science*, *6*(1), 8.
- Yin, R. K. (2013). *Case study research: Design and methods*. Sage publications.
- Zwaanswijk, M., Verheij, R. A., Wiesman, F. J., & Friele, R. D. (2011). Benefits and problems of electronic information exchange as perceived by health care professionals: an interview study. *BMC Health Services Research*, *11*(1), 256.
- Åhlfeldt, R.-M. (2008). *Information security in distributed healthcare: Exploring the needs for achieving patient safety and patient privacy*. Doctoral dissertation, Institutionen för data-och systemvetenskap (tills m KTH)).

Åhlfeldt, R.-M., & Söderström, E. (2010). Patient Safety and Patient Privacy in Information Security from the patient's view: A Case Study. *Information Security in Distributed Healthcare*, 203.







## CHAPTER 8 THE PAPERS

Due to copyright the papers are not included in this document.



PUBLICATIONS IN THE  
DISSERTATION SERIES



## PUBLICATIONS IN THE DISSERTATION SERIES

1. Berg Marklund, Björn (2013) Games in formal educational settings: obstacles for the development and use of learning games, Informatics. Licentiate Dissertation, ISBN 978- 91-981474-0-7
2. Aslam, Tehseen (2013) Analysis of manufacturing supply chains using system dynamics and multi-objective optimization, Informatics. Doctoral Dissertation, ISBN 978- 91981474-1-4
3. Laxhammar, Rikard (2014) Conformal Anomaly Detection - Detecting Abnormal Trajectories in Surveillance Applications, Informatics. Doctoral Dissertation, ISBN 978-91- 981474-2-1
4. Alklind Taylor, Anna-Sofia (2014) Facilitation matters: a framework for instructor-led serious gaming, Informatics. Doctoral Dissertation, ISBN 978-91-981474-4-5
5. Holgersson, Jesper (2014) User participation in public e-service development: guidelines for including external users, Informatics. Doctoral Dissertation, ISBN 978-91- 981474-5-2
6. Kaidalova, Julia (2015) Towards a Definition of the role of Enterprise Modeling in the Context of Business and IT Alignment, Informatics. Licentiate Dissertation, ISBN 978- 91-981474-6-9
7. Rexhepi, Hanife (2015) Improving healthcare information systems – A key to evidence based medicine, Informatics. Licentiate Dissertation, ISBN 978-91-981474-7-6
8. Berg Marklund, Björn (2015) Unpacking Digital Game-Based Learning: The complexities of developing and using educational games, Informatics. Doctoral Dissertation, ISBN 978-91-981474-8-3.
9. Fornlöf, Veronica (2016) Improved remaining useful life estimations for on-condition parts in aircraft engines, Informatics. Licentiate Dissertation, ISBN 978-91-981474-9-0.
10. Ohlander, Ulrika (2016) Towards Enhanced Tactical Support Systems, Informatics. Licentiate Dissertation, ISBN 978-91-982690-0-0.
11. Siegmund, Florian (2016) Dynamic Resampling for Preference-based Evolutionary Multi-objective Optimization of Stochastic Systems, Informatics. Doctoral Dissertation, ISBN 978-91-982690-1-7.
12. Kolbeinsson, Ari (2016) Managing Interruptions in Manufacturing: Towards a Theoretical Framework for Interruptions in Manufacturing Assembly, Informatics. Licentiate Dissertation, ISBN 978-91-982690-2-4.

13. Sigholm, Johan (2016) Secure Tactical Communications for Inter-Organizational Collaboration: The Role of Emerging Information and Communications Technology, Privacy Issues, and Cyber Threats on the Digital Battlefield, Informatics. Doctoral Dissertation, ISBN 978-91-982690-3-1.
14. Brolin, Anna (2016) An investigation of cognitive aspects affecting human performance in manual assembly, Informatics. Doctoral Dissertation, ISBN 978-91-982690-4-8.
15. Brodin, Martin (2016) Mobile device strategy: A management framework for securing company information assets on mobile devices, Informatics. Licentiate Dissertation 978-91-982690-5-5
16. Ericson, Stefan (2016) Vision-based perception for localization of autonomous agricultural robots, Informatics. Doctoral Dissertation, 978-91-982690-7-9.
17. Holm, Magnus (2017) Adaptive Decision Support for Shopfloor: Operators using Function Blocks, Informatics. Doctoral Dissertation, ISBN 978-91-982690-8-6.
18. Larsson, Carina (2017) Communicating performance measures: Supporting continuous improvement in manufacturing companies. Informatics. Licentiate Dissertation, ISBN 978-91-982690-9-3.



HANIFE REXHEPI

Hanife Rexhepi has a background in information systems with a research specialization in healthcare. She holds a BSc in information systems, a BSc in nursing, a MSc in information systems and a Licentiate degree in information technology from the University of Skövde, Sweden. Her current research is in healthcare informatics.

In her thesis, she explores how evidence-based medicine and shared decision-making can be supported through information systems where the patient plays a more active role in healthcare decision-making. More specifically, she studies the information needs of both healthcare professionals and patients, and how information systems can be developed to deliver information in a way that makes it more accessible. She also explores how information systems can be used to inform and empower patients. Hanife argues that future healthcare information systems must support the core characteristics of evidence-based medicine and shared decision-making in an integrated manner, and that using the one without the other is not enough. Moreover, in her thesis she confirms that the challenges identified with regard to information system support are not exclusively technical. Organizational culture, and the attitudes of healthcare professionals to patient involvement are some of the biggest challenges facing healthcare organizations.