BRIDGING THE INFORMATION GAP
Supporting Evidence-Based Medicine and Shared Decision-Making through Information Systems

HANIFE REXHEPI
Informatics
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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 un-
able 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


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 processorierterat synsätt där patientens process är i fokus. Vidare har denna forskning påvisat att de tekniska utma-
ningarna 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.
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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


   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.


   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.

   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).*


   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.


   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.*

   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.


   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.


   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.
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INTRODUCTION
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 suppurative) 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 must 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, Ashvetchiya, 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.

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,

Figure 1: The core characteristics of EBM and SDM.
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 rescheduled, 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/documentated 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 infor-
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In order to make informed decisions, 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, & Myreteg, 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).
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).
The practice of EBM is thus a multistep process involving five essential steps:

<table>
<thead>
<tr>
<th>Steps in EMB</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>ASK a specific clinical question</td>
</tr>
<tr>
<td>2</td>
<td>FIND the best evidence with which to answer that question</td>
</tr>
<tr>
<td>3</td>
<td>CRITICALLY APPRAISE the evidence for its validity and usefulness</td>
</tr>
<tr>
<td>4</td>
<td>APPLY the results into clinical practice/patient care decisions</td>
</tr>
<tr>
<td>5</td>
<td>EVALUATE the process/steps</td>
</tr>
</tbody>
</table>

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

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 deci-
sion-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, & Tambeur, 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 interorganizational 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 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 di-
agnostic 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 pro-
cesses. 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 mechanistically, 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 (Tiiu & 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 (Tiiu & 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]
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 misunderstand 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, Focarelli, 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 EMB, 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.

<table>
<thead>
<tr>
<th>Steps in EMB</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ASK a specific clinical question</td>
<td>Form a relevant and answerable question based on the patient’s case</td>
</tr>
<tr>
<td>2. FIND the best evidence with which to answer that question</td>
<td>Choose relevant resources (e.g. different library resources, national medical guidelines) and perform a search</td>
</tr>
<tr>
<td>3. CRITICALLY APPRAISE the evidence for its validity and usefulness</td>
<td>Examine the evidence e.g. the articles to determine the validity and applicability to the patient’s case</td>
</tr>
<tr>
<td>4. APPLY the results into clinical practice/patient care decisions</td>
<td>Use the evidence in conjunction with clinical expertise, patients’ values and preferences to make a decision about care.</td>
</tr>
<tr>
<td>5. EVALUATE the process/step</td>
<td>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</td>
</tr>
</tbody>
</table>

**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 EMB 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, Mounjид, 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).
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 EMB) 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 cap-
tured, 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.](image)

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
METHODODOLOGY

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, particularly 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).
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 Bemmel (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:

1. 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.
2. 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.
3. 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 semi-
nars/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:


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.](image)

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).
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:


**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:


### 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 infor-
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 confirmability, 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, confirmability has been enhanced.
RESULTS
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.
CHAPTER 4 RESULTS

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.
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.
CHAPTER 4 RESULTS

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 infor-
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 document 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 deci-
sion-making, 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 devel-
oped.
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 EMB 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:
• Place focus on the patient process from the patient’s perspective,
• Place 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.

![Image]

**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 availa-
ble 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.
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 pa-
tients from jointly engaging in healthcare decisions. A holistic perspective is thus
missing. Furthermore, since evidence-based practice, where the healthcare profes-
sional 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 ef-
ective 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 con-
tribution 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 ba-
 lance 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 en-
ter 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 pro-
vide ideas for solutions that must be considered before work can begin with the de-
velopment of future healthcare information systems. This thesis has shown that in-
formation systems have the potential to reshape the practice of evidence-based med-
icine, by providing both patients and healthcare professionals with quick access to
patient information and high quality research evidence at the point of need. Howev-
er, to enable this, system developers must have an understanding of the characteris-
tics of EBM and SDM, or the solutions provided will remain ineffective. Further-
more, 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 devel-
opment 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 pa-
tient. 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.
APPENDIX
### CHAPTER 7

### APPENDIX

#### A INTERVIEW GUIDE – CASE STUDY ONE

<table>
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<th>Frågor till vårdpersonalen</th>
<th>Questions for healthcare practitioners</th>
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<tr>
<td>Frågor relaterade till ”handläggning av vårdbegäran”</td>
<td>Questions regarding the “processing of the referral”</td>
</tr>
<tr>
<td>Vilka ingångar är möjliga för en vårdbegäran?</td>
<td>In what ways can a referral be requested?</td>
</tr>
<tr>
<td>Hur går du tillväga när du registrerar vårdbegäran?</td>
<td>How do you register the referral?</td>
</tr>
<tr>
<td>Vilka kriterier existerar vid prioritering av vårdbegäran? Var kommer dessa kriterier ifrån?</td>
<td>What criteria exist for prioritizing the referral? Where do these criteria come from?</td>
</tr>
<tr>
<td>Vad innebär kompletterande remiss? Vilken typ av kompletteringar är det som behövs?</td>
<td>What does supplemental referral mean? What types of supplements are needed?</td>
</tr>
<tr>
<td>Hur prioriteras vårdbegäran?</td>
<td>How is the referral prioritized?</td>
</tr>
<tr>
<td>Frågor relaterade till ”planering av besök”</td>
<td>Questions regarding the “planning of patient visits”</td>
</tr>
<tr>
<td>Vad betyder ”gå igenom patientinformation”? Vad är syftet? Vilka system används? Vem gör det?</td>
<td>What does it mean to go through “patient information”? What is the purpose? What systems are used? Who does that?</td>
</tr>
<tr>
<td>Vad gör du när du planerar ett mottagningssbesök?</td>
<td>What do you do when you plan a patient visit?</td>
</tr>
<tr>
<td>Swedish</td>
<td>English</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Hur vet du vilka prover som behöver tas till mottagningsbesöket? Vilka svar krävs innan besöket bokas och planeras?</td>
<td>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?</td>
</tr>
<tr>
<td>Vad är “ELVIS” för typ av informationssystem? Är systemet integrerat med andra informationssystem som till exempel ”Melior”</td>
<td>What type of information system is “ELVIS”? Is the system integrated with other information systems such as “Melior”?</td>
</tr>
<tr>
<td>Vilken typ av information innehåller kalletsen som sänds till patienten inför ett besök?</td>
<td>What type of information is included in the notification that is sent to the patient prior to a visit?</td>
</tr>
<tr>
<td>Hur går ombokningsprocessen till?</td>
<td>How does the cancellation process work?</td>
</tr>
<tr>
<td><strong>Frågor relaterade till ”genomförande av besöket”</strong></td>
<td><strong>Questions regarding “carrying out the patient visit”</strong></td>
</tr>
<tr>
<td>Vem ansvarar för ankomstförfarandet? Hur går man tillväga?</td>
<td>Who is responsible for the arrival process? How is this process carried out?</td>
</tr>
<tr>
<td>Hur sker provtagningen vid ankomstförfarandet?</td>
<td>How is the sampling at the arrival carried out?</td>
</tr>
<tr>
<td>Vad händer när vårdteamet möter patienten?</td>
<td>What happens when the care team meets the patient?</td>
</tr>
<tr>
<td>Hur går patientmötet till? Vilken information behövs? Vilken tillgång på information har du vid detta tillfälle?</td>
<td>How is the patient meeting carried out? What information is needed? What kind of information do you have access to during the patient meeting?</td>
</tr>
<tr>
<td>Hur dokumenterar du patientbesöket? Hur skulle du vilja dokumentera i framtiden?</td>
<td>How do you document the patient meeting? How would you like to document the patient meeting in the future?</td>
</tr>
<tr>
<td>Vilken information behöver du för att göra din bedömning? Har du tillgång till något beslutsstödssystem? Finns det behov för beslutsstödssystem? Vilka är dessa behov?</td>
<td>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?</td>
</tr>
<tr>
<td>Hur sker dialogen med patienten idag?</td>
<td>How is the dialogue with the patient carried out today?</td>
</tr>
<tr>
<td>Hur sker den fortsatta planeringen? Hur skulle du önska att planeringen sker i framtiden?</td>
<td>How is continuing care plan carried out? How would you wish to conduct the planning in the future?</td>
</tr>
<tr>
<td>Hur används standardvårdplaner i det fortsatta planeringsarbetet?</td>
<td>How are standard care plans used in the continued planning?</td>
</tr>
<tr>
<td>Hur sker receptskrivningen? Vad finns det för fördelar respektive nackdelar med receptförskrivning?</td>
<td>How is the prescribing of medication carried out? What are the advantages and disadvantages?</td>
</tr>
<tr>
<td><strong>Frågor relaterade till ”planera fortsättning”</strong></td>
<td><strong>Questions regarding the “continued planning”</strong></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Question (Swedish)</th>
<th>Question (English)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hur planerar du för fortsatt behandling/fortsatt utredning? Hur skulle du vilja att det fungerade i framtiden?</td>
<td>How do you plan for the continued treatment / continued investigation and how would you prefer it to work in the future?</td>
</tr>
<tr>
<td>Vad innebär standardvården? Vad innefattar en standardvårdsplan?</td>
<td>What is a standard care plan? What type of information does a standard care plan include?</td>
</tr>
<tr>
<td>Hur sker uppföljning/återbesök?</td>
<td>How is the following up of a patient’s visit carried out?</td>
</tr>
<tr>
<td>Hur skrivs den slutliga dokumentationen? Vilken information anges i dokumentationen?</td>
<td>How is the final documentation written? What type of information is included in the documentation?</td>
</tr>
<tr>
<td>Hur hanteras svar till inremitterande instans? Finns det några integrationsproblemen?</td>
<td>How are the answers from the referring unit handled? Are there any integration problems?</td>
</tr>
<tr>
<td>Vilka kontaktytor finns med andra vårdgivare?</td>
<td>What kind of collaborations do you have with other healthcare providers? Which communication channels do you use?</td>
</tr>
<tr>
<td>Hur involveras patienten i planeringen av den fortsatta vården?</td>
<td>How is the patient involved in the planning of the continued care?</td>
</tr>
<tr>
<td>Hur skulle du vilja att patienten involveras i den fortsatta planeringen av vården i framtiden?</td>
<td>How would you like to involve the patient in the continued planning of care in the future?</td>
</tr>
</tbody>
</table>

**Frågor till patienter**

**Questions to patients**

<table>
<thead>
<tr>
<th>Questions regarding the “planning of patient visits”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hur upplever du kommunikationen med vården och vårdpersonalen som är involverad i din vård?</td>
</tr>
<tr>
<td>How do you experience communication with the healthcare and healthcare professionals involved in your care?</td>
</tr>
<tr>
<td>Hur upplever du tillgången till information inför ett besök?</td>
</tr>
<tr>
<td>How do you experience availability to information prior to a patient encounter?</td>
</tr>
<tr>
<td>Vilka informationsbehov har du?</td>
</tr>
<tr>
<td>What information needs do you have?</td>
</tr>
<tr>
<td>Vilka förväntningar har du inför ett läkarbesök?</td>
</tr>
<tr>
<td>What expectations do you have for a patient encounter?</td>
</tr>
<tr>
<td>Tillgodoses dina behov, förväntningar och önskemål av din läkare eller sjuksköterska under besöket?</td>
</tr>
<tr>
<td>Are your values, preferences and expectations taken into account by your physician or nurse during the patient encounter?</td>
</tr>
<tr>
<td>Hur ser du på att fylla i en hälsodeklaration innan ett vårdbesök?</td>
</tr>
<tr>
<td>What is your opinion about filling in a health declaration before a patient encounter?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questions regarding “carrying out the patient visit”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hur upplevde du patientmötet?</td>
</tr>
<tr>
<td>How did you experience the patient encounter?</td>
</tr>
<tr>
<td>Upplevde du att läkarna lyssnade på dig?</td>
</tr>
<tr>
<td>-----------------------------------------</td>
</tr>
<tr>
<td>Förstod du den information som läkaren gav till dig?</td>
</tr>
<tr>
<td><strong>Frågor relaterade till ”planera fortsättning”</strong></td>
</tr>
<tr>
<td>Hur planerar du för den fortsatta behandlingen och hur skulle du vilja att det fungerade i framtiden?</td>
</tr>
<tr>
<td>Hur sker den slutliga dokumentationen av patientmötet ut? Hur går den till? Ser du några fördelar eller nackdelar?</td>
</tr>
<tr>
<td>Vilka kontaktytor finns med andra vårdgivare?</td>
</tr>
<tr>
<td>Finns det ett intresse av att komma åt din journal?</td>
</tr>
<tr>
<td>Hur kan kommunikationen med vården bli tydligare och enklare för dig?</td>
</tr>
</tbody>
</table>

### B INTERVIEW GUIDE – CASE STUDY TWO

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

<table>
<thead>
<tr>
<th>Frågor till ansvariga för kunskapsportalen</th>
<th>Questions for managers responsible for the IT-based knowledge reposito-ry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vilka är kunskapsportalens målgrupper? Varför har denna målgrupp prioriterats?</td>
<td>Which are the user groups of the IT-based knowledge repository? Why has these user groups been prioritized?</td>
</tr>
<tr>
<td>Vilken struktur och teknisk lösning har valts för kunskapsportalen. Varför har dessa val genomförts?</td>
<td>What type of structure and technical solution has been selected for the IT-based knowledge repository? Why have these choices been selected?</td>
</tr>
<tr>
<td>Vad har du för organisatorisk modell för kontinuerlig förvaltning, inkl. ansvarsförråddan för kunskapsportalen?</td>
<td>What type of organizational model do you use for continuous management of the IT-based knowledge repository?</td>
</tr>
<tr>
<td>Hur utvärderas kunskapsportalen? Har kunskapsportalen fått genomslag i den aktuella mål-</td>
<td>How is the IT-based knowledge repository evaluated? Has the IT-based knowledge repository had</td>
</tr>
<tr>
<td>Frågor till chefer med ansvar för kompetensförsörjning och kompetensutveckling</td>
<td>Questions for managers responsible for competence maintenance and skills development</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Inledande frågor</strong></td>
<td><strong>Opening questions</strong></td>
</tr>
<tr>
<td>Vad ser du för utmaningar i att hålla verksamheten &quot;högkompetent&quot;?</td>
<td>What challenges do you see in keeping the organization &quot;highly skilled&quot;?</td>
</tr>
<tr>
<td>När anser du att verksamheten är högkompetent? Vilka kriterier arbetar du mot?</td>
<td>When do you think the organization is highly competent? What criteria are you working towards?</td>
</tr>
<tr>
<td><strong>Frågor relaterade till identifiering av kunskapsbehov</strong></td>
<td><strong>Questions related to the identification of knowledge needs</strong></td>
</tr>
<tr>
<td>Hur tar du reda på om verksamheten har den kunskap som behövs?</td>
<td>How do you work with finding out whether the organization has the necessary knowledge that is needed?</td>
</tr>
<tr>
<td><strong>Frågor relaterade till identifiering av kunskapskällor</strong></td>
<td><strong>Questions related to the identification of knowledge sources</strong></td>
</tr>
<tr>
<td>Hur arbetar du med att fånga in ny kunskap som behövs i verksamheten. Varifrån hämtar du ny kunskap?</td>
<td>How do you work with the capture of new knowledge that may be needed in the organization? Where do you capture new knowledge?</td>
</tr>
<tr>
<td><strong>Frågor relaterad till processer för att sprida och implementera ny kunskap</strong></td>
<td><strong>Questions related to the processes for dissemination and implementation of knowledge</strong></td>
</tr>
<tr>
<td>Hur arbetar du med att sprida och implementera ny kunskap i verksamheten?</td>
<td>How do you work with the dissemination and implementation of new knowledge in the organization?</td>
</tr>
<tr>
<td>Hur ser du på ett scenario där en datorbaserade hjälpmedlen spelar en roll för att sprida samt in-</td>
<td>How do you view a scenario where computer-based aids play a role in acquiring and disseminating</td>
</tr>
</tbody>
</table>
hämta kunskap. Vilka är möjli-
heterna och utmaningar med ett
datorbaserat hjälpmedel?

knowledge? What are the opportu-
nities and challenges with a com-
puter-based aid?

Om verksamheten erfar "best
practice" vilket ansvar tar du för
att sprida denna kunskap till öv-
riga i verksamheten (både inom
och utanför den egna verksam-
heten)?

If new "best practice “occurs in
your organization, what responsi-
bility do you take in disseminating
that knowledge to other people
(both within and outside the or-
ganization)?

<table>
<thead>
<tr>
<th>Typ av kunskap – Behov</th>
<th>Type of knowledge – Needs</th>
</tr>
</thead>
</table>
| Vilken typ av kunskap behöver oftast ”uppdateras” i verksam-
heten? | What knowledge in the organiza-
tion 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? |

Frågor till vårdpersonalen

<table>
<thead>
<tr>
<th>Frågor relaterade till identifiering av kunskap</th>
<th>Questions related to the identification of knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vad gör du om ett behov av att inhämta ny kunskap uppståar?</td>
<td>What do you do when you feel the need to acquire new knowledge?</td>
</tr>
<tr>
<td>Hur brukar du ta del av kunskaper och erfarenheer som redan finns inom organisationen?</td>
<td>How do you take advantage of the knowledge and experiences that already exists within the organization?</td>
</tr>
<tr>
<td>Hur brukar du ta del av den senaste forskningen och de senaste rönen inom ditt arbete?</td>
<td>How do you take advantage of the latest research and the latest findings within your field?</td>
</tr>
</tbody>
</table>

Frågor relaterad till processer för
att sprida och implementer av ny kunskap

Hur arbetar man i verksamheten med att implementera ny kunskap?

Hur ser du på ett scenario där datorbaserade hjälpmedlen spelar roll för att inhämta och sprida kunskap? Vilka möjligheter och utmaningar uppfattar du?

I den bästa av världar, hur skulle du vilja få tillgång till kunskap via din dator?

Frågor relaterade till identifiering av kunskapsbehov

Vilken typ av kunskap saknar du oftast? Varför är den kunskapen viktig anser du?

Hur skulle du vilja att den kunskapen görs tillgänglig och presenteras? Varför just så? Kan det finnas andra alternativ?

dissemination and implementation of knowledge

How is new knowledge implemented in the organization?

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?

How would you like to have access to knowledge through your computer?

Questions related to the identification of knowledge needs

What kind of knowledge do you miss most often? Why is this knowledge important for you?

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

Frågor till patienter i grupp A

Questions to patients in group A

Inledande frågor

Opening questions

Ålder

Age

Hur länge har du haft en vårdr relation 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”

a) Om ja - varför gjorde du det?

a) If yes- Why?

b) Om nej - varför gjorde Du inte det?

b) If no- Why?
<table>
<thead>
<tr>
<th>Question</th>
<th>Translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hur fick Du reda på att Du kunde läsa din journal på nätet?</td>
<td>How did you find out about the opportunity to read your EHR “Journalen” online?</td>
</tr>
<tr>
<td>Vilken betydelse (för- och nackdelar) har det för dig att kunna läsa din egen journal via nätet?</td>
<td>What advantages and disadvantages are there for you to read your EHRs online?</td>
</tr>
<tr>
<td>Hur lång tid anser Du att det är acceptabelt att vänta efter ett vårdbesök innan Du får dina journaluppgifter tillgängliga via nätet?</td>
<td>How long do you think it is acceptable to wait after a healthcare visit before your medical information is made available online through Jornalen?</td>
</tr>
<tr>
<td>Hur har tillgången till “Min journal på nätet” påverkat din relation med hälso- och sjukvården?</td>
<td>How has the access to the Journal affected your relationship with healthcare?</td>
</tr>
<tr>
<td>På vilket sätt anser Du att vårdpersonalen stöttar dej i att använda tjänster som “Min journal på nätet” och/eller andra Internettjänster.</td>
<td>In what way do you consider that healthcare professionals support you in using Journalen and other eHealth services?</td>
</tr>
<tr>
<td>I den mån Du kan bedöma, vilka tekniska brister anser Du att tjänsten har?</td>
<td>What technical flaws do you think the eHealth service Journalen has?</td>
</tr>
<tr>
<td>Vad anser Du om tjänstens användbarhet? Förstår Du hur den fungerar och hur Du ska använda den? År den ett stöd för dig i din kontakt med vården?</td>
<td>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?</td>
</tr>
</tbody>
</table>

**Frågor relaterad till innehållet**

<table>
<thead>
<tr>
<th>Question</th>
<th>Translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vad skulle Du göra om det står något i journalen som Du inte förstår? Vilka kanaler tar Du till hjälp?</td>
<td>What would you do if there is something in the Journalen that you do not understand?</td>
</tr>
<tr>
<td>Har Du läst något i journalen som gjort dig upprörd?</td>
<td>Have you read anything in Journalen that made you upset?</td>
</tr>
<tr>
<td>a) Om ja, hur upplevde Du det?</td>
<td>a) If yes, how did you experience it?</td>
</tr>
<tr>
<td>b) Om ja, var det information som Du tagit del av på annat sätt tidigare?</td>
<td>b) If yes, is it information that you have received earlier but in a different way?</td>
</tr>
<tr>
<td>Have you read something in the wrong journal?</td>
<td>Have you found any errors in Journalen?</td>
</tr>
<tr>
<td>a) Om ja, vad gjorde Du då?</td>
<td>a) If yes, what did you do about it?</td>
</tr>
<tr>
<td>Hur bedömer du innehållet i jou-</td>
<td>How do perceive the content in</td>
</tr>
<tr>
<td>Speglingen? 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?</td>
<td>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?</td>
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<tr>
<td>Hur har informationen i journalen påverkat dina möjligheter att följa ordinationer om behandling och vidta egna åtgärder för att förbättra välbefinnandet?</td>
<td>How has the information in Journal influenced your ability to follow through treatments and to take own actions in improving well-being?</td>
</tr>
<tr>
<td>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?</td>
<td>What is your opinion about taking part of the medical information that may be worrying. Are there any advantages and disadvantages?</td>
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<tr>
<td>Vilken information eller ytterligare tjänster skulle Du vilja ha tillgång till?</td>
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<tr>
<td>Vilken information eller tjänst vill Du inte ha tillgång till?</td>
<td>Is there any type of information or eHealth services that you don’t want to have access to?</td>
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<tr>
<td><strong>Informationssäkerhet</strong></td>
<td><strong>Information security</strong></td>
</tr>
<tr>
<td>Hur upplever Du säkerheten generellt med tjänsten?</td>
<td>How do you experience the safety of the eHealth service Journalen?</td>
</tr>
<tr>
<td>Vad anser Du om det tekniska säkerhetsskyddet? Har Du haft problem med att logga in etc?</td>
<td>How do you experience the technical security? For example have you had trouble logging in?</td>
</tr>
<tr>
<td>Har Du sett varningstexten när Du loggade in? Vad är din reaktion på den?</td>
<td>Have you seen the text warning when you log in? What is your reaction to it?</td>
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<tr>
<td>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?</td>
<td>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?</td>
</tr>
<tr>
<td>Finns det några orosmoment med att nå din patientinformation via Internet</td>
<td>Do you have any concerns about accessing your patient information through the Internet?</td>
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**Hantering av din hälsoinformation**

**Handling of health information in**
**Interview guide for patients who have not read their EHR**

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<td>Hur länge har du haft en vårderation med Onkologen?</td>
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<td>Har Du loggat in på tjänsten “Min journal på nätet”?</td>
<td>Have you logged in to the eHealth service “Journalen”</td>
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<tr>
<td>a) Om ja - varför gjorde du det?</td>
<td>a) If yes- Why?</td>
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<td>a) Om ja, vad gjorde att du log-</td>
<td>a) If yes- Why?</td>
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<tr>
<td>Var säkerheten en av anledningarna till att Du inte vill läsa din information på nätet? Om ja, i så fall på vilket sätt?</td>
<td>Was security one of the reasons that you do not want to read your information online? If yes, how?</td>
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<tr>
<td>Hur upplever Du säkerheten generellt med den här typen av tjänst?</td>
<td>How do you generally experience the security of this kind of eHealth service?</td>
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<tr>
<td>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?</td>
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<tr>
<th>Frågor relaterad till innehållet</th>
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<td>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?</td>
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<tbody>
<tr>
<td>Hur hanterar Du din hälsoinformation? Tex information om dina vårdbesöker, information om din sjukdom och hälsa?</td>
<td>How do you handle your health information? For example, information about your healthcare visits, information about your illness and health?</td>
</tr>
<tr>
<td>Använder Du Internet för övrigt för att hitta information om din hälsa?</td>
<td>Do you use the Internet to find information about your health?</td>
</tr>
<tr>
<td>Vilka andra källor använder Du för att söka hälsoinformation?</td>
<td>What other sources do you use to search for health information?</td>
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<tr>
<td>Övrigt</td>
<td>Other</td>
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<tr>
<td>Något ytterligare Du vill lägga till om dina upplevelser och förväntningar med att kunna ta del av din hälsoinformation på nätet?</td>
<td>Something more you want to add about your experience and expectations about the opportunity to access your health information online?</td>
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CHAPTER 8
THE PAPERS

TOWARDS EFFECTIVE AND EFFICIENT INFORMATION SYSTEM SUPPORT FOR HEALTHCARE PROCESSES – A HEALTHCARE PRACTITIONER PERSPECTIVE

Hanife Rexhepi, Rose-Mharie Åhfeldt and Anne Persson. University of Skövde, Informatics Research Centre, P.O. Box 408, SE-541 28, Skövde, Sweden

ABSTRACT
Healthcare processes require the cooperation of different healthcare providers and medical disciplines. In such an environment, the quality and safety of care rely heavily on the ability to exchange information from one software to another, and from one person to another. However, information systems that support a seamless flow of information along healthcare processes are not broadly used in healthcare environments. Usually, healthcare organizations have their own autonomously developed information systems that do not support the cooperation of different organizational units and medical disciplines. This has led to the fragmentation of the patients’ information in proprietary heterogeneous systems across healthcare organizations. The aim of this paper is to: (1) explore how healthcare practitioners’ in Sweden experience information system support in their daily work activities, and (2) present and illustrate how key design principles of a process support system prototype can support healthcare practitioners in their work practice. An important conclusion from this research is that a process support as the one described in this paper creates new opportunities to organize and coordinate healthcare.

KEYWORDS

1. INTRODUCTION
Delivering good quality care is a complex endeavor that is highly dependent on information and knowledge (Bose, 2003; Rezazadeh et al., 2014). Numerous studies have demonstrated positive effects when using information technology (IT) in healthcare (Lenz & Reichert, 2007). In particular IT, such as electronic health records (EHRs), decision support, electronic prescribing, electronic referral and other technologies that enable the exchange of information have been promoted as potential tools for improving the quality, safety and efficiency of the
healthcare system. Despite these potential benefits, IT has never been used to its full potential. Nowadays, the traditional single doctor-patient relationship is increasingly being replaced by one in which the patient is managed by a team of healthcare practitioners, each specializing in one aspect of care. For example, a frail older individual who sustains a hip fracture may require treatment from an orthopedic surgeon, hospital nurses, and a hospital physical therapist, home care nurses, home care physical therapists, a primary care physician and a nurse in the primary care setting (Coleman, 2003). In such an environment optimal process support becomes crucial. However, despite their widespread adoption in industry, IT systems that support a seamless flow of information along healthcare processes are not broadly used in healthcare environments. Usually, healthcare organizations have their own autonomously developed information systems (IS) that do not support the cooperation of different organizational units and medical disciplines. This has led to the fragmentation of the patients’ information in proprietary heterogeneous systems across healthcare organizations. Consequently, vital information stored in these systems cannot be easily accessed to present a clear and complete picture of the patient. This is worrying as, a seamless and shared care requires a high level of interoperability and information sharing among practitioners and care providers that are involved in the healthcare of a patient. In the absence of this information, a complex set of patient flows emerges where patient’s medical records necessary for care have to be transmitted between and across department boundaries, which often leads to a high administrative load of practitioners (Lenz & Reichert, 2007). Medical procedures can even become impossible to perform if information is missing, medical tests may be repeated or prior findings ignored, preparations may be omitted, or a preparatory procedure must be postponed (Lenz & Reichert, 2007; Reichert, 2011), and in emergency care lifesaving information may be unavailable.

The aim of this paper is to; (1) explore how healthcare practitioners’ experience information system support in their daily work activities, and (2) present and illustrate how key design principles of a process support prototype can support healthcare practitioners in their work practice. The key principles of the process support prototype have earlier been presented in the paper by Åhlfeldt, Persson, Krasniqi and Wåhlander (2013), where the patient perspective is taken into account. Therefore, this paper aims to report on the issues healthcare practitioners in Sweden experience with regard to current information system support and how a process support system (PSS) can resolve some of the issues identified.

The remainder of the paper is organized as follows. Section 1.1 describes the theoretical background. The research approach is presented in section 2. The study results are described in section 3, following a description and visualization of how a PSS can support healthcare practitioners. The findings are concluded in section 4.

### 1.1 Theoretical Background

During the last decade, the healthcare sector has tried to move from functional to process-oriented organizational forms. Yet, healthcare organizations are still characterized by an increasing number of medical disciplines and specialized units (Lenz & Reichert, 2007). Traditionally, hospitals have a functional organizational structure. The functional organization is based on grouping individuals into organizational units, according to the function they perform, such as orthopedics, surgery, physical therapy, etc. In a functional organization, people who share common expertise and responsibility are grouped into independent units.
Each unit works to achieve its organizational goals, independently of other units. A disadvantage of the functional organization is in its relationship with the patient. A patient is usually treated by various healthcare practitioners from different units and from different levels of care. During this process, the patient moves from unit to unit, receiving care from different practitioners as they go (Ben-Tovim et al., 2008). Since communication and collaboration between the various organizational units is deficient, due to the different goals, interests and background of the members of these organizational units, the patient may have difficulty receiving the care he/she needs (Shrub & Karni, 2010).

Moreover, the functional organizational structure has influenced how healthcare information systems have been developed. A common scene within most hospitals and primary healthcare centers is the distribution of patient information along several departmental information systems (see figure 1). As a result, patient information is organized and managed by several autonomous information systems, which contribute to the emergence of so-called islands of information. These information systems have been developed at widely differing points in time, by using different development paradigms as well as different software and hardware platforms. Therefore, current healthcare information systems suffer from a number of problems:

- They support single organizational units very well, but have trouble exchanging information between care units and between care providers and the community at large, e.g., social insurance offices, resulting in poor inter-organizational communication and collaboration (Ministry of Health and Social Affairs, 2006; Perjons et al., 2005).

- Electronic healthcare records (EHRs) have traditionally been developed mainly for managing patient information. They have also been developed separately from general medical knowledge. Therefore, knowledge, such as medical guidelines, is to a larger extent not integrated into EHRs. Instead, this knowledge is stored in numerous autonomous IT-based knowledge repositories at different levels (local, regional, national). Finding relevant medical knowledge at the point of care is therefore difficult (Krasniqi & Persson, 2012).

- They do not facilitate work activities. These activities, which may be helped by computerization are performed manually, and consume 50 to 80 percent of the physician’s time (Perjons et al., 2005).

- They lack established common user interfaces, making them difficult to navigate and use. Lack of “ease of use” prevents healthcare practitioners from achieving specified goals with effectiveness, efficiency, and satisfaction (Ministry of Health and Social Affairs, 2006).

- They cannot easily compile and communicate information to accounting and management systems at executive and principal levels, or to national registers, such as health data and quality registers (Ministry of Health and Social Affairs, 2006).

- They do not facilitate patient engagement. Patients themselves cannot easily access information about their care. Electronic communication with healthcare practitioners and the electronic booking of treatments and examinations is also limited (Ministry of Health and Social Affairs, 2006). Studies have shown that giving patients more access to their health information can encourage them to participate in their own care, self-manage their health condition, increase understanding of their medical issues, and improve patient–provider communication (Ricciardi et al., 2013; Delbanco et al., 2012).
To improve efficiency and quality of care delivery, it is necessary to overcome the traditional functional organization structure (Gonçalves, Hagenbeek & Vissers, 2013). This can be done by the implementation of a process-oriented organizational view with supporting information systems. A process-oriented approach with supporting information systems is an important foundation for achieving a system design that focuses on the patient process from the patient’s perspective and thereby sets the patients and their healthcare journey in the center of care (Åhlfeldt, Persson, Krasniqi & Wåhlander, 2013; Perjons et al., 2005). In a process-oriented organization, all the different disciplines involved in the delivery of patient care have to work together as a group and strive to achieve common goals (Vos et al., 2011), meaning that practitioners from different functions, such as orthopedics, surgery, physiotherapy, are all aligned towards satisfying the patients’ needs of care. In contrast, in a function-based organizational setting, the functions are disconnected from each other and from the process of satisfying patients’ needs (Kumar et al., 2009; Kohlbacher, 2010). Moving toward process orientation can according to Willaert et al. (2007) provide numerous benefits, including cost savings through a more efficient execution of work and improved customer focus. Process orientation has also been shown to reduce inter-functional conflict and increase interdepartmental connectedness and integration, both of which impact long and short-term performance (Willaert et al., 2007).

The starting point of a process-based organizational structure requires the identification of the core business process. The patient process is considered as one of the most important processes by many healthcare organizations (Åhlfeldt, 2008). An important aspect of a process-oriented organizational structure is thus that it focuses on the patients’ journey (process) through healthcare, instead of functional units. The patient process is according to Winge et al., (2007) defined as the sequence of treatments and other activities performed by health or social care personnel for the patient and in which the patient and his relatives 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 practitioners in order to promote health. Patients whose conditions necessitate complex care needs require care from a wide range of caregivers, 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 practitioners in a uniform and transparent way, anywhere and anytime, as required by the patient process. One example of a patient process and the care providers involved in the context of this process is presented in figure 2.

Figure 2. Example of a patient process and the care providers involved (Åhlfeldt, 2008).

Figure 2 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. 20 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). 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 et al., 2005).

In recent years, researchers have tried to resolve the information system problems that exist by proposing various architectures for realizing systems and services that support healthcare processes. For example, Winge et al., (2014) proposed a solution in the form of a Coordination Hub, 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. Raghupathi and Kesh (2007) have in their research 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 patient care processes. The research from, e.g., Winge et al., (2014) and Russ et al., (2010) focus on the communication needs of care providers 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 of this work. However, none of these have taken a holistic perspective where the patients’ whole process and the communication between healthcare providers and the patient within this process are taken into account. Moreover, the process support system presented in this paper is based on a unique solution which is not found in existing research, where the process support drives the process forward, ensuring that the process is carried out properly and hence supports users in performing their work activities.

2. RESEARCH APPROACH

The prototype presented in this paper is a result of a research project named Future Healthcare Information Systems (FHIS). The aim of the project was to develop a visualization of a process support system that demonstrates the requirements for future process-oriented information system support. The vision for process support system is that healthcare practitioners, from all levels of healthcare, and patients should have access to effective collaborative information system that supports a process-oriented care where the patient is a distinct and active collaborator. The process support system was developed in close collaboration between researchers and healthcare practitioners from a local hospital in the Region of Västra Götaland, Sweden. Since, addressing all the healthcare processes with related information systems seemed like an impossible task for the project, it was necessary to select an appropriate delimitation. Therefore, the project chose a healthcare process that repeats throughout the healthcare system and that can demonstrate patient and healthcare communication; initiating, planning, carrying out and following up a patient’s visit to healthcare providers. This process was termed “Patient meeting”. The first step in the prototype development was to collect data regarding 1) how current information systems support healthcare practitioners’ in their daily work practice with regard to availability of information, and to a certain extent availability of medical knowledge 2) how patients’ experience the information exchange with healthcare organizations and 3) identify user requirement for future process-oriented information system support. For this purpose, different data collection activities were conducted.

2.1 Data Collection Techniques

A current state analysis: This activity was carried out in close cooperation with healthcare practitioners as well as patients from an orthopedic clinic. Additional information was gathered from the cardiologist, eye clinics, emergency units 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 practitioners’ and patients’ information needs and (2) identify requirements for future information system support. For this purpose, interviews and direct observations were seen as adequate techniques for data collection (Berg, 2001). Eighteen semi structured interviews and direct observations of healthcare practitioners were conducted. The observations of the healthcare practitioners 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, 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 practitioners and patients were taped, transcribed and analyzed 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. An observation protocol was used to record information obtained during the observations of the healthcare practitioners and the patient meetings. A descriptive notes section for the description of activities was also included in the protocol (Creswell, 2007). In addition, the results from the observations and the interviews were discussed with the healthcare practitioners and the project team members. 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 meeting 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 domain practitioners and the project’s researchers. The method used for modelling of the chosen process and for the prototype development was the Visuera method (Visuera, 2014). The method was chosen for the following reasons:

- The Visuera method is a process modelling method that enables modelling 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 was to have healthcare practitioners 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 simulation/demonstrator of how a system will work and how it will look, without actually implementing the system. Since the objective was to develop a demonstrator it was a reasonable choice.

**Modeling the intended future state:** Based on the assessment of the current situation and the “As-Is” process models, work began on specifying the requirements of the proposed future state (To-Be models). Identification of the requirements began with an “idea seminar” with 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 for a number of idea seminars/workshops with healthcare practitioners. During these seminars/workshops, practitioners were asked to discuss objectives and ideas about 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 process models. The information content was sketched in forms with the Visuera Business Process Modelling 2007 tool (Visuera, 2014). Subsequently, the process models and the information content were validated by healthcare practitioners during workshop sessions, brainstorming meetings, seminars and lectures. Moreover, a patient representative from a patient organization provided feedback on the models.

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 towards in relation to user requirements identified through observations, workshops and interviews. In addition to this, identified user needs were also evaluated against in relation to the Swedish national strategy for e-health and in seminars involving healthcare professionals, patients and information system providers. Based on this evaluation, the prototype was refined.

2.2 Qualitative Analysis

The analysis of the transcribed interviews and the observation field notes have been conducted with inspiration from the Grounded Theory research method. The aim of the analysis was to find central core categories which, according to Robson (2011) is 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. The initial step of open coding stared by reading through the interviews several times in order to create a deeper understanding of the respondents’ statements. Subsequently the actual coding stared. Open coding of the transcribed data has involved line-by-line coding of words and phrases by highlighting (Strauss & Corbin, 1990). Each word or phrase was assigned a concept noted in the margin. Example of a concept that has been identified is “support in decision making”. At this stage the coding was conducted directly in the word document by using the function “insert comment”. When no more concepts could be identified, they were grouped into border categories. Example of a category that relates to the above concept is “Lack of a holistic IS”.

Axial coding involved further exploration of the categories and concepts that we re developed in the process of open coding (Oktay, 2012; Strauss & Corbin, 1990). Axial coding was the process of identifying the relationship between and within categories. Axial coding did provide depth to the description of the identified concept, which evolved into a deep understanding of e.g., how practitioners experience access to information in the patient process and how patients experienced information exchange with practitioners. It also gave a deeper understanding of the difficulties practitioners experienced with regard to availability of information and how they want future information system to support work practice and thereby improve the quality of care delivery.
3. RESULTS

In the sections below, the challenges with information system support are described, following a description and a visualization of how a process support system can support the availability of patient information in a way which seamlessly integrates with healthcare practitioners work practice.

3.1 How Healthcare Practitioners Experience Information System Support

1. Lack of a holistic system for information access: Interoperability of healthcare information systems does not only hamper access to patient information, it also results 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 a complete picture of the patient. In the absence of this information, a complex set of patient flows emerged where practitioners had to spend valuable time on locating and collecting relevant patient information. Patient’s medical record necessary for care was often transmitted between and across department boundaries, which resulted in a high administrative load of practitioners. Printed copies of the medical record were usually imported into the recipient’s IS by adding a scanned version to the system or by typing a summary in the system. This entailed problems of inefficiency and the risk of making errors. Delays in treatment’s were also common as practitioners had to wait for requested copies of the medical record, test results, medical list etc. Often patients even had to undergo similar test procedure because results of previous tests were unavailable at the point of care.

2. Manual handling of information: Much of the information managed in the healthcare processes was handled manually. For example, many of the information systems that were used during the patient meeting contained information that had been manually imported. The healthcare practitioner even told about situations where patient information had been missed to be imported into the IS or had been misinterpreted.

3. Nonstandard, unstructured information: In accordance with current research, unstructured information in the EHR has been identified as challenging. As the information in the EHR is recorded as free text, without limitations to the format or structure they were seen as time-consuming to review manually. The unstructured format also made it difficult for practitioners to extract important information. Another issue relates to terminology. One doctor may have one background and training, whereas another doctor has another background. Hence, they document differently and use different terminologies. Therefore, there is a need to “rationalize” the data – resolve the terminology into standard set of terms (Inmon & Nesavich, 2007).

4. Lack of care coordination between departments: Care coordination is defined in the Agency for Healthcare Research and Quality (2010) as the deliberate organization of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of healthcare services. Patients in greatest need of care coordination include those with multiple chronic medical conditions, concurrent care from several departments.
healthcare practitioners, and patients undergoing extensive diagnostic workups or transitions from one setting of care to another (Agency for Healthcare Research and Quality, 2010). As patients often receive medical care from different providers, enhanced care coordination becomes vital for the improvement of the quality of patient care. The healthcare practitioners emphasized that the coordination of patient care is a challenge due to interoperability issues. Another reason described is the functional organizational structure with task specialization. When each practitioner focuses on its function they usually fail to communicate critical elements of the care to the receiving department. Bottlenecks occurred as one department pushed the patient into another department that was not ready to take care of the patient. Lack of interoperable information systems and absence of electronic booking of treatments and examinations complicated the situation even more.

5. **Usability issues:** A common requirement among healthcare practitioners is that future information systems must meet the requirements for usability. Experiences such as, too much mouse clicking without feeling that they are getting closer to their goal were common complaints. In addition, interoperability problems resulted in double documentation, which in turn resulted in sub-optimal use of resources, and in worse cases it increased the risk for accessing different and contradictory patient information. The study result also confirms that current information systems do not support the users in the way they should be working. For example, while reading and/or writing in the EHR it is not technically possible for a physician to look at X-rays at the same time and in the same computer screen. Instead the physician must switch between different computer screens; between the X-ray and the EHR.

Moreover, the research study has shown that practitioners spend more time on trying to manage different information systems, to locate patient information, and to “figure out” how a specific IS works, instead of spending time with the patient. The study results confirm that 38 different system operations/ system transactions are made during a patient meeting, which means that the value creation time that needs to be applied on the patient is less than 20% of a patient encounter.

6. **Complex information flows:** The healthcare sector is an information and knowledge intensive organization comprising a large number of complex information flows. Healthcare practitioners found it difficult to orient themselves among these complex information flows. Interoperability issues complicated the situation even more.

7. **Incoming information from referrals is incomplete:** A recurring problem experienced among healthcare practitioners is related to the care request/referral. The problems are based on the following: (1) it is not possible for healthcare practitioners or patients to electronically fill in and send a care request, and (2) incoming care requests from primary care usually lack important information. Referrals that did not include required information where always sent back. The healthcare practitioners emphasized that this is one of the reasons why patients do not receive care within a reasonable time.

### 3.2 A Process Support System to Support Healthcare Practitioners

#### 3.2.1 Overall Architecture of the Process Support System

The vision for the process support system is that healthcare practitioners and patients should have access to efficient collaborative IS that supports a process-oriented care where the patient is a distinct and active collaborator. The words in bold are concepts that the FHIS project paid particular attention to, meaning that:
Appropriate parts of the process support system are available for both patients and practitioners taking 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 practitioners through the PSS.

The PSS can be viewed as a layer of abstraction or user interface above the various individual IS, enabling enactment of the process and interaction between patients and healthcare practitioners through computers and mobile devices without accessing each individual IS (Perjons et al., 2005). The process support system drives the process forward, ensuring that it is carried out properly and hence, supports users in performing their work tasks. The PSS also provides a user interface to the various systems involved in performing a work activity. The principle is described in Figure 3.

Moreover, the architecture makes it possible, at least in theory, to replace individual IT systems without 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 integration of medical guidelines and an IT-supported knowledge repository.

3.2.2 How the Process Support System can Support Healthcare Practitioners

The patient processes is in focus (support challenge 1, 2 and partly challenge 6):

A patient usually gets care from different healthcare practitioners. Each of these actors generates information that is needed by one another. Therefore, the PSS focus 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 information (e.g. medical record, lab-response, drug list) and administrative information (e.g. appointments) in a timely manner. The process support system follows the idea that all
information needed by practitioners when preparing for and carrying out a patient visit should be available, whether it is medical or administrative information. These types of information are currently separated in different information systems. The PSS also supports the patient's need for information and engagement. For example, the patient can send in an electronic care request to primary and secondary care, and book appointments with doctors online. When the patient submits a referral, a healthcare practitioner will be notified (see figure 4).

Figure 4. A patient has sent in a referral and a healthcare practitioner (a care planner who can be a nurse or a doctor) have received a notice in their process support system view (Åhfeldt, Persson, Krasniqi & Wåhlander, 2013)

The process support system is based on standardized information (supports challenge 3):

Having the right information when it is needed is a challenge. 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. The process support system can also ensure that healthcare practitioners always have access to relevant medical guidelines. For example, when the physician plans for medical examinations the PSS provides support by showing what medical activities that should be prioritized and also conducted with regard to the diagnosis or health issue (see figure 5).
Efficient information flows (supports challenge 6):

By adopting a process-oriented approach the information flows can be more efficient. The PSS can ensure that patients and practitioners always perform the correct activities during the different parts of the process. The challenge here, particularly in today’s decentralized healthcare, is to determine which healthcare provider that should be responsible for performing which work activities and who should provide a specific type of information to the PSS. Moreover, by structuring for example the referral, it is possible to ensure that all important information that is recorded in the referral follows the patient process.

A major advantage of a process-oriented approach and tools that supports the patient process is that the PSS drives the process forward. For example, when a work activity is completed, the process support system will present nearby activities that must be performed. For example, when a practitioner in secondary care has written and signed the final documentation for the patient record, the PSS automatically picks up the form “response to care request” that must be sent back to the referring physician from primary care. The process approach also minimizes duplication of documentation, as already registered information follows the process and therefore does not need to be registered again.
Digital booking and coordination of patient treatments and examinations (supports challenge 4):
The process support enables electronic booking and coordination of the patients’ 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 this visit can be cancelled in advance. In this way one prevents the patient to come to unnecessary meetings.

Enhanced security (is a prerequisite for all key design principles):
In the current version of the PSS no specific technical security solutions are implemented. Instead, the process support system is based on the current national system for secure identification and access controls, included existing secure infrastructure platforms.

Increased coordination with secure infrastructure (supports challenge 4):
Another step in improving security and increasing the coordination between different healthcare organizations is the outlined integration with national solutions such as the National Patient Summary (NPS), which contains excerpts from patient records kept by different healthcare providers. The NPS can be accessed by both patients and healthcare practitioners.

Electronic care request (support challenge 7):
The care request within the PSS is based on standardized checklists designed from national quality registers. In order to prevent incomplete referrals, the care request within the process support system is based on mandatory information that must be completed before it can be forwarded. The information in the referral is thus based on standardized checklists from predefined national medical pathways/care plans. The information displayed in the referral is in turn governed by the selected patient health issue or diagnosis.

Improved usability (supports challenge 5):
The perceived usability problems have been considered in the development of PSS. The process support system is more efficient to use as it takes less time to accomplish a particular task. The mouse clicks are significantly minimized as the PSS enables the user to look at several different screens simultaneously at the same time.

4. CONCLUDING REMARKS AND FUTURE WORK

Delivering good quality care is a complex endeavor that is highly dependent on patient information. The study results have confirmed that practitioners lack access to information about the patient when preparing and conducting patient visits, as well as when making decisions about the care of the patient. An important conclusion from this research is that a process support system 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 practitioners 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 also reduces double documentation and manual handling of information, which in turn reduces the risk of making errors. Since, healthcare practitioners no longer need to spend time in locating patient information or on managing non-user-friendly information systems, more time can be spent on meeting patients. However, much work remains before the suggested principles for the process support system can be fully implemented. One of the main challenges is that there
is no process owner of the patient process. A process owner is the person who has the authority to determine how a process operates, and have the responsibility to make sure it continues to meet patients and business needs today and into the future. Therefore, they play a vital role in sustaining process improvement, and are crucial for the organization. Other challenges are:

- To determine the ownership and responsibility of a process support system that crosses organizational boundaries and that supports a patient-centered care.
- Who should be responsible for the quality of the data that is generated by the process support system, and who should be the owner of this data.
- Which work activities within the process should the different levels of care be responsible for, which requirements can they impose on each other, for example if the patient seeks care in primary care because of hip pain and he/she is referred to the secondary care, who should do an x-ray? the primary care or the specialist care? These activities must be determined before the process support system can be implemented.
- What information should each level of care contribute within the process support system, and who should determine that?

Future research should study the above-mentioned challenges, as these are the major threats to a more process-oriented healthcare with supporting information systems. Further research is also needed regarding how future process-oriented information systems can be developed so they are more “patient inclusive” in a way that they enable patients to take control of their healthcare and thereby also empower them. More and more, physicians and patients are working together, increasing the exchange of information and sharing the decision-making. Therefore future research should examine what type of information patients want to access and why, how this information can be made available through a process support system, and how such a system can be developed so that patients themselves can provide information regarding their health, expectations, values and preferences. This information can complement the physician’s knowledge of the patients’ clinical situation. The effect of such solutions should also be studied.

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TOWARDS EFFECTIVE AND EFFICIENT INFORMATION SYSTEM SUPPORT FOR HEALTHCARE PROCESSES – A HEALTHCARE PRACTITIONER PERSPECTIVE


Web-based Knowledge Portals in Swedish Healthcare
– Overview and Challenges

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Abstract
Healthcare organizations are increasingly becoming dependent on knowledge management activities to improve the quality of care, to maintain a high level of efficiency and innovation as well as to flexibly adapt to rapid change. Utilizing knowledge management support systems - e.g. Internet based knowledge portals - to manage medical information and healthcare knowledge aimed to support the full spectrum of knowledge needs has become an important issue for all healthcare professionals. This paper reports on the main findings from analyzing the characteristics and challenges of 15 Swedish knowledge portals containing healthcare information. The analysis is based on inspection of the portals and interviews with their owners. The main challenges found concern fragmentation of knowledge, structuring of knowledge content, usability, interaction and resources for maintaining knowledge content. Future successful development and use of knowledge portals to disseminate healthcare knowledge depend on addressing these challenges, which requires portal owners to have a long-term strategy as well as a systematic way of working.

Keywords
Knowledge management, knowledge portal

1. Introduction
Knowledge Management (KM) has established itself as good management practice for modern organizations that strive to be efficient and competitive, since it helps getting the right knowledge to employees when they need it [1]. Healthcare organizations are increasingly becoming dependent on knowledge management (KM) activities to improve the quality of care, to maintain a high level of efficiency and innovation as well as to flexibly adapt to rapid change. Utilizing knowledge management support systems (KMS) to manage medical information and healthcare knowledge aimed to support the full spectrum of knowledge needs has become an important issue for all healthcare professionals [2, 3]. On the other hand, adopting KM is a complex process. In the past, many KM initiatives and projects have not been successful and even the more successful ones have struggled to make a broader impact. Often it can be observed that KM approaches, methods, and tools are tried out but the results are unimpressive or they do not meet exceptions. One of the reasons for these problems is that the implementation process of KM system is too ad hoc and unplanned [4].

Healthcare organizations are knowledge-rich, yet healthcare knowledge is largely under-utilized at the point-of-care and point-of-need. It is well known that new healthcare knowledge is being generated at a rapid pace and its utilization can profoundly impact patient care and health outcomes. However, this growth of knowledge, dispersed across different mediums, is making it extremely difficult for healthcare professionals to be aware of and to apply relevant knowledge to make the ‘best’ patient care decisions. Recent research has shown that the inability of physicians to access and apply current and relevant knowledge, leads to the delivery of suboptimal care to patients [3]. It is often difficult to ensure that healthcare professionals use the latest and newest healthcare knowledge. Education is one way of spreading knowledge. However experience shows that education must be supplemented by other systematic efforts to ensure sustainable uptake of knowledge. Furthermore, knowledge that has been captured and packed as written knowledge in some form usually resides in repositories, manuals, the intranet, etc. An important issue identified is that knowledge shared through manuals may be difficult to absorb since the documents, in essence, are not adapted to the target group. A further complicating factor is that healthcare professionals need to relate to national, regional and local knowledge bases dispersed across different mediums. One way of accommodating a single point of access to knowledge is through so-called knowledge portals, often Internet based.

The goal of this paper is to report on an analysis of a representative number of Swedish Internet based knowledge portals. The second author of this paper has been involved, since many years, in developing methods and tools to create and maintain KMS, in particular Internet based knowledge portals, implementing them in both business and public organizations, e.g. in healthcare. A successful case of implementing such a system was reported in [4]. The experiences from this case form the basis of the analysis.
The remainder of the paper is organized as follows. In section 2 the method is presented, while section 3 contains the results. The results consist of a number of observations about the characteristics and challenges of the analyzed knowledge portals. In section 4 the results are discussed and some concluding remarks are given.

2. Method

The analysis has been made according to the following steps:

Firstly, we selected a number of portals to analyze. We aimed at collecting a variety of portals which would demonstrate the multitude of approaches to creating knowledge portals. We took as a starting point the national projects initiated by the National Board of Health and Healthcare, e.g. Kunskapsguiden (www.kunskapsguiden.se). We then selected portals that have been initiated on a national basis, e.g. Vårdhandboken (www.vardhandboken.se) and Svenskt demenscentrum (www.demenscentrum.se). Finally we searched the Internet for portals initiated on a regional or local level, e.g. Särwebben (www.vgr.se/skrasarswebben), using a snowballing approach. All analyzed portals, 15 in total, contain healthcare knowledge. Swedish healthcare organizations, authorities and associations have created them. The following 15 portals were analyzed:

- Kunskapsguiden
- Vårdhandboken
- Internetmedicin
- Ungdomsmottagningen på nätet UMO.se
- 1177.se
- Svenskt demenscentrum
- IPULS-projektet METIS
- Nationella riktlinjer för Sjukdomsförebyggande metoder: Tobak, alkohol, fysisk aktivitet och matvanor
- Virtuellt Särcentrum
- Sårvårdsboken Örebro
- Särwebben
- Föräldrawebb Fyrbodal
- PS Young Support
- Nationellt kkompetenscentrum Anhöriga
- Vårdaktörsportalen i Västra Götaland

Secondly, we documented the selected portals according to the following aspects:
1. Type of content
2. Target group/s
3. Structure of the knowledge content
4. Technical platform
5. Possibilities for communication between users and portal owners
6. Organizational model for maintenance of the portal
7. Model for evaluating the effects of the portal
8. Possibilities and challenges relating to the portal

To collect the data two methods were used: 1) inspection of the portals and 2) telephone interviews with managers of the portals.

Thirdly, we analyzed the data to identify general patterns. All portals were analyzed by the first author of the paper and the overall analysis was made by both authors.

3. Results

The main findings of the analysis are presented organized according to the general patterns that we found.

3.1 Focus

A general pattern among the analyzed portals is that most of them are developed based on the need to disseminate knowledge about a particular medical specialty to particular target groups with particular needs of information, knowledge and learning. Considering an employee that needs to access knowledge about several specialties, i.e. a district nurse, or a patient with several health problems, this situation is sub-optimal. A person then has to access several portals. Since there is no standardized way of structuring a knowledge portal this means that knowledge is fragmented and usability on the overall level, over several portals, is low. Also, learning and exchange of experiences is hindered by this fragmented approach. From this situation we conclude two things. Firstly, it is clear that a more conscious strategy is missing in healthcare organizations about how knowledge should be structured and disseminated through knowledge portals. Secondly, portal developers do not properly consider the needs and characteristics and usage situation of the target user group/s. One particular aspect of this is that portal developers in most cases neglect that the users of their portal will most likely use other portals as well.

Among the analyzed portals there is a dominance of portals focusing on mental illness, particularly in young adults. We also observe several portals addressing lifestyle related disease, e.g. related to alcohol. We can only hypothesize the reasons for this focus, but one can be that the Swedish government has prioritized knowledge dissemination in these areas.

3.2 Intended users

Among the analyzed knowledge portal we find three types of intended user groups:

- Healthcare professionals
- Patients and/or citizens
- Both of the above user groups
We believe that the Swedish National strategy for e-health\(^1\), initiated by the Swedish government, has motivated several of the analyzed portals. The strategy focuses on the introduction, use and benefit of information technology in healthcare. The goal is to create actual benefit for three main target groups: the citizen, healthcare professionals and decision-makers in healthcare and social services. Two particular areas in the strategy are related to the analyzed portals:

- Useful and available information – decision support for healthcare professionals, and
- Knowledge management, innovation and learning.

### 3.3 Structure of the knowledge content – a usability issue

As previously stated, most portals have different structures and they also have a varying degree of usability.

The knowledge is often structured in a hierarchical and linear manner, comparable to that of a book or report. As a consequence, the use of multi-media such as moving pictures (film and animation) and sound is hardly ever seen.

We often find usability problems related to the book type of structure. E.g., when a large amount of information is presented to the user at once, she is often confused and experiences difficulties in filtering unnecessary information, which leads to problems to manage situations when choices need to be made [5]. Also, this type of structure focuses on gathering of information rather than on learning. This problem emphasizes that portals need to be developed using a governing method for how knowledge should be captured and structured. We have found a small number of portals that have a clearly identifiable structure that is systematically implemented throughout the portal, and that truly take the user situation into account, but they are unfortunately a select few.

The target group of some portals is broad, e.g. both healthcare professionals and patients. This is a particular challenge in terms of designing the user interaction and structuring the knowledge content, something that many of the portal owners experience.

### 3.4 Interaction through knowledge portals

Very few knowledge portals include facilities to support interactive meetings – between healthcare professionals and citizens or between citizens - through the Internet. Several evaluations (see e.g. [6]) have concluded that this is a feature that should be prioritized. However, such interaction through the Internet can be sensitive, which requires that personal integrity can be managed in a secure way. On the other hand, security and integrity issues must be balanced with the benefit that the interaction can give the users. Also here it is necessary that there are guidelines and strategies that govern how this interaction can take place. This could be functions for moderating discussion forums, e.g. in order to remove improper material.

### 3.5 Technical platform

The general patterns is that Internet based knowledge portals are seen as web-pages that are created through a traditional publishing process where texts are produced, reviewed and published. Therefore, the pre-dominant technical platform is traditional web-publishing tools such as Microsoft SharePoint\(^2\). One challenge related to this type of platform is to manage overview when the amount of knowledge increases and knowledge “chunks” in the portal becomes increasingly linked, internally and externally to other portals and sources on the Internet.

### 3.6 Processes and resources for maintaining knowledge portals

One of the problems with knowledge repositories in general is that their use decreases over time, often because their contents become out of date and hence becomes less relevant for its users. A common reason for this is that processes and responsibilities for continuously updating the content do not work in the organization [1].

One aspect of this is that decision-makers may be willing to invest in the creation of a knowledge portal, but fail to see that keeping the portal up-to-date and useful over time requires that more resources are continuously invested.

The majority of analyzed portals follow this pattern. Their owners find it challenging to manage them over time, particularly in terms of resources. E.g. several important and useful portals targeting young adults are at risk since financial resources are lacking.

Situations where several organizations collaborate to create/maintain a knowledge portal are particularly challenging. In these cases it has shown to be very difficult to agree on common standards, e.g. for structuring the knowledge content. This is the same pattern of difficulties that can be observed regarding standardization of IT solutions in Swedish healthcare as a whole.

### 4. Discussion and concluding remarks

Internet based knowledge portals 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 prevention and treatment of health problems by supporting both healthcare professionals and citizens with the knowledge that they need and when they need it. However, in order for knowledge portals to live up to expectations a number of challenges need to be addressed, some of which has been discussed in this paper. These issues have impact on the survival of a knowledge portal over time.

From the implementation projects that we have been involved in (list included in [4]) we conclude that there are critical success factors that can make or break the long-term survival of a knowledge portal:

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1. [http://www.nationellehalsa.se/English/Default.aspx](http://www.nationellehalsa.se/English/Default.aspx)
• The portal is important enough for management to champion it
• The value to its users is high
• The usability of the portal is high
• The knowledge structure is robust but still flexible enough to cater for changes over time
• Processes and resources for maintaining the portal over time is in place
• There is a strategy in place for the future developments of the portal

The portals that we have analyzed have several weak spots related to these factors. From what we see it is quite common that portals are developed and maintained by healthcare professionals, while managing several of the factors (e.g. usability and knowledge structure) is clearly outside their expected expertise. Portal development projects therefore need to also involve other categories of competencies, such as usability experts, experts in knowledge structuring and IT experts.

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CHALLENGES TO IMPLEMENTING IT SUPPORT FOR EVIDENCE BASED PRACTICE AMONG NURSES AND ASSISTANT NURSES: A QUALITATIVE STUDY

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INTRODUCTION

Internationally, evidence based medicine (EBM) has been a priority for many years. Both the World Health Organization and the European Commission emphasize that health and social services should be based on the best research evidence (Stokke, Olsen, Espehaug & Nortvedt, 2014). Delivering good quality care is a complex endeavor that is highly dependent on patient information and medical knowledge. It is widely recognized that the main benefits of using evidence based medical knowledge are to improve and update clinical practice and to enhance the quality of care and outcomes for patients (Veeramah, 2016). EBM is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients (Sacketta, 1997). It aims to improve quality and safety of care by eliminating decision-making based on more traditional methods in favor of using (a) current best evidence in conjunction with (b) patient values and preferences, and (c) individual clinical expertise (Houser & Oman, 2011, p. 3) (Fig. 1). Following the principles of EBM practitioners are required to formulate questions based on patients’ medical history, current clinical problems, values and preferences, search the literature for answers, evaluate the evidence for its validity and usefulness, and finally apply the information to patients (Lenz & Reichert, 2007).

Practicing EBM is challenging. One reason is inability to access patient's past and current medical history due to interpretability issues. It is also complicated, as healthcare practitioners usually do not have time to search for medical knowledge while the patient is in the office. Therefore, literature search usually takes place offline (Lenz & Reichert, 2007). Practitioners who search for knowledge all too often find that existing knowledge is not accessible in real time and may not necessarily map to the issue at hand (Clancy & Cronin, 2005). Some practitioners may even choose not to actively look for the needed knowledge as textbooks may be out of date, information in journals is too difficult, if not impossible, to translate into daily work practice and current information systems (IS) such as IT-based knowledge repositories are not widely used as they are not developed to meet practitioners' knowledge needs (Krasniqi & Persson, 2012). To alleviate this untenable situation, systematic reviews and medical guidelines are continuously developed. It is, however, still challenging to ensure that healthcare practitioners actually apply the latest medical knowledge, as there is no single point of access to the needed knowledge. Medical guidelines and other important medical knowledge are contained in numerous autonomous IT-based knowledge repositories at different levels (local, regional, national). Each of them is developed based on the need to disseminate knowledge about a particular medical specialty to particular target groups with particular needs of knowledge. Considering that a
A practitioner, such as a nurse within municipality care, needs to access knowledge about several specialties, the situation is sub-optimal, as the individual is forced to access several repositories in order to find the needed knowledge (Krasniqi & Persson, 2012).

The Swedish Ministry of health and social affairs have in their IT-strategy for Swedish healthcare (2006) emphasized the need to develop decision support systems and other knowledge-based support systems that provide timely and easy access to relevant medical knowledge. This is important since studies have supported the conclusion that patient outcomes are substantially improved when healthcare is based on evidence versus tradition or clinical expertise alone (Houser & Oman, 2011). The perceived benefits are faster dissemination of new knowledge, e.g., new treatment methods, and continuous competence development of healthcare practitioners. However, bringing evidence to the point of care requires more than investments in IT support. To realize the full potential of information technology that helps practitioners to access, use and share medical knowledge, knowledge management processes (KM) must be embedded in organizational processes, activities and relationships. The question that this paper addresses is how well the reality of current Swedish healthcare practice can live up to the national strategy.

The paper is based on a research project carried out in Swedish healthcare. The goal of the project was to investigate the possibilities to develop an IT-based knowledge repository that was intended to function as a single point of access to knowledge for healthcare practitioners in primary, secondary and municipality care. The target groups of this “knowledge portal” were nurses and nursing assistants. Physicians were excluded due to the results from a previous study (Krasniqi & Persson, 2012), which showed that the majority of the IT-supported knowledge repositories in Sweden had physicians as the main target group, while nurses and particularly assistant nurses were to a large extent neglected.
As part of the project, the current knowledge management processes in the healthcare organizations of a region of Sweden comprising 15 municipalities, 4 hospitals and a large number of primary care units were studied. The aim of investigating these processes was to evaluate the healthcare organization’s readiness to adopt an IT-based knowledge repository as a tool in daily healthcare practice. The results are reported in this paper. Extensive international research has been conducted regarding access to medical knowledge within the healthcare sector. However, little is known about how nurses and assistant nurses experience the availability of medical knowledge. In particular, no study has, to the best of our knowledge, addressed the problems experienced with availability of medical knowledge by healthcare practitioners within the three levels of healthcare at the same time; primary care, secondary care and municipality care. Therefore, the aim of this paper is to explore (1) how the three levels of healthcare worked with the process of managing knowledge, and (2) how practitioners experience access to medical knowledge (such as theoretical knowledge, systematic reviews, medical guidelines, scientific papers, and clinical expertise etc.), where and when they needed it. Attitudes towards using IT-based sources to access knowledge were also important to capture, since the goal of the project was to develop an IT-based knowledge repository.

The remainder of this paper is organized as follows. First, a description of the theoretical background is given, followed by a presentation of the research approach and the main findings. A discussion of the findings is given in the last chapter of the paper.

THEORETICAL BACKGROUND

In this section we present the theoretical background to the research reported in the paper.

Knowledge management in healthcare

In today’s increasingly complex environment, it is rapidly becoming essential for healthcare organizations to effectively manage both internal knowledge and externally generated knowledge in order to provide the best possible healthcare, achieve operational excellence, and foster innovation. Wahle and Groothuis (2005) argue that healthcare is information intensive, since it uses multiple knowledge areas, such as those of medicine, and policies that assist healthcare practitioners in making decisions. These multiple knowledge areas and the large number of interdependent disciplines make the healthcare organization a knowledge intensive organization. Additionally, since the healthcare organization is traditionally divided into different levels, primary, specialist, and municipality care, it has resulted in the development of small but very specialized areas of practice. As a result, the specialized healthcare practitioners have unique tacit and explicit knowledge that has to be captured, disseminated and utilized by other practitioners (Wahle & Groothuis, 2005). Healthcare practitioners are also facing greater demands from patients that are increasingly interested in participating in decision-making regarding treatment choices and care possibilities (Desouza, 2005). El Morr and Subercaze (2010) further emphasize that any knowledge created by practitioners, irrespective of healthcare level, is of utmost importance to all others, in order to provide good quality care. Efficient interaction and exchange of knowledge among these actors is therefore a key issue for creating the best conditions for the practice of EBM (Nicolini et al., 2008). Effective
collaboration in turn requires that relevant medical knowledge is made available, as needed, at any time of the day and without technical difficulty (Wickramasinghe, Gupta & Sharma, 2005; Abidi, 2007).

KM is a conscious strategy of getting the right knowledge to the right people at the right time and helping people to share and put knowledge into action in ways that strive to improve healthcare services (Alajmi, Marouf & Chaudhry, 2016). It involves processes for capturing, storing, sharing and applying knowledge. Within healthcare, KM is about managing the knowledge that is critical to providing high quality care to patients. Knowledge in this context includes both the experiences and understanding of practitioners (tacit knowledge) and the information available inside and outside the organization such as, medical guidelines (explicit knowledge). KM in the context of EBM creates a learning environment and ensures that “best practice” is systematically captured and disseminated.

It is clear that healthcare organizations can profit from many advantages that KM provide, such as: improved patient care, safety and satisfaction, team-building across organizational boundaries and more informed decision-making by learning from others and building on individual experiences etc. (De Brún, 2007). The Swedish healthcare system, similar to other countries, faces significant challenges of delivering high-quality care, at lower costs. At the same time, there is growing recognition that healthcare organizations are knowledge-intensive and are suffering from information overload (Chen, Liu & Hwang, 2011). Healthcare organizations, thus need to embrace KM strategies, processes, IT tools and techniques as it can support them to create greater value by delivering higher care quality more cost effectively (Wickramasinghe, Gupta & Sharma, 2005).

General challenges related to IT in the healthcare sector
In this research focus is on investigating the conditions under which IT support for EBM can be introduced and used, in particular by nurses and assistant nurses. However, there are general challenges related to the introduction and use of IT in the healthcare sector that are important to be aware of in order to understand the context of such IT support.

Information systems play a crucial role in the practice of EBM, by allowing healthcare practitioners to access clinical evidence and information about the patients’ health, as they formulate their patient-care strategies (Wells, 2007; Del Fiol, Workman & Gorman, 2014). However, current IS are not meeting the expectations and rarely fulfill these requirements (Iroju, et al., 2013). Usually, healthcare organizations have their own autonomously developed IS that do not support the cooperation of different organizational units and medical disciplines. This has led to the fragmentation of the patients’ information in proprietary heterogeneous systems across healthcare organizations. Consequently, vital information that is stored in separate IS cannot be easily accessed, in order to present a clear and complete picture of the patient. Therefore, all too often healthcare practitioners have to make decisions about patient care without knowledge of the problems addressed by other healthcare practitioners from another unit, including services provided, medications prescribed, or preferences expressed in the previous healthcare setting (Ben-Tovim et al., 2008). Medical procedures can even become impossible to perform if information is missing, medical tests may be repeated or prior findings ignored, preparations may be omitted, or a preparatory procedure must be postponed (Lenz & Reichert, 2007), and in emergency care lifesaving information may be unavailable.
In making decisions about patient care, healthcare practitioners 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 practitioners, many of them remain unanswered (Del Fiol, Workman & Gorman, 2014) as existing IS do not provide the support that is needed. Medical questions that cannot be answered may lead to suboptimal patient-care decisions. In critical situations, lack of patient information and medical knowledge may even lead to late or wrong decisions (Reichert, 2011; McClellan et al., 2008; Del Fiol, Workman & Gorman, 2014).

The knowledge management framework used in the research

In this work a general model of KM has been used as a framework to study how the organizations involved in this study work with managing knowledge and how healthcare practitioners perceive availability of medical knowledge when and where it is needed. The model of the KM cycle presented by Persson & Stirna (2007) as described in Fig. 2 was the model chosen. It covers the whole lifecycle of knowledge in an organization and is adapted from O’Dell, Grayson & Essaides (1998). Knowledge creation involves developing new knowledge or replacing existing knowledge with new content. Creating knowledge can be done in many different ways – running day-to-day business operations, improving existing work routines, restructuring the organization, planning organizational strategies for the future, etc. While organizations create new knowledge and learn, they also forget (i.e., do not remember or lose track of the acquired knowledge). Therefore, the knowledge needs to be captured in one way or another. The capturing of knowledge should according to Persson and Stirna (2007) be done in a participative and collaborative way, which enhances one’s individual view. When knowledge is captured, the organization and its employees are aware of its existence. If the captured knowledge is relevant, the next step is to package and store it so that it is available and can be used by those who need it in the organization. Explicit knowledge, thus represents everything that can be tracked, documented and saved. We can find it written in books and loaded into databases. On the contrary, tacit knowledge exists within people, and is a consequence of what we know, what we observe and how we process this knowledge (Karamitri, Talias & Bellali, 2015). This type of knowledge is often seen as the most important knowledge in an organization. Therefore, it is essential to capture who knows what, where the knowledge sources are, and how to access it. This also becomes an important part of the organizational/memory/knowledge repository/base (Persson & Stirna, 2007). After knowledge is properly documented and stored, it needs to be shared and applied. This probably is the most important task in KM. It has been reported that knowledge sharing in healthcare is very complex and often fraught with various types of barriers such as poor individual relationships and lack of motivation (Huang et al. 2016). Therefore, it is not enough to install and fill a knowledge base and expect the organization to suddenly start sharing knowledge. Particular attention should be paid to building a knowledge sharing culture in the organization supported by organizational leadership. Information technology can only play a supporting role in knowledge sharing and application by making sharing easier and more effective. Successful as well as an effective knowledge sharing and application also stimulate innovation - improvement of existing knowledge and creation of new knowledge. In order to assess whether or not new knowledge and practices are
actually applied, different types of measurement procedures need to be developed and implemented. This essentially closes the knowledge cycle (Persson & Stirna, 2007).

**RESEARCH APPROACH**

The research was set up as a qualitative study consisting of three steps:

1. A preliminary review of literature describing related research was first conducted, targeting literature from different research domains related to EBM and KM.
2. An interview study was then carried out. Sixty two semi structured interviews were conducted with managers, nurses and nursing assistants from primary, specialist, and municipality care (Fig. 3). A letter requesting participation in the research project was sent to managers within each municipality. A request was also sent to managers in primary care and to different units at specialist care. The letter contained requests to interview one manager, two nurses and two nursing assistants with varying experiences of working in the healthcare sector. The inclusion criteria also included factors such as different age range and gender. The managers then suggested one or two individuals who were willing to participate in the study. One of the authors of the paper was responsible for carrying out the interviews. When the researcher started to gather information from interviewees, the researcher was referred to others who could be contacted for interviews. 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, we conclude that managers in fact have been successful in recommending healthcare practitioners who were also willing to share the KM difficulties that the organization experienced. The interviews were taped and transcribed, and lasted one to two hours each. The interview guide with associated questions was developed based on the KM cycle, which means that the following aspects were addressed:
   - Processes for capturing and creating knowledge and
   - Processes for packaging, storing, sharing, applying knowledge, and measurement of innovation and transformation.
The interview guide also included questions about the potential lack of medical knowledge in specific clinical situations and how the situation is managed in those cases. The interviewees represented two perspectives in the KM process:

- The management perspective (unit managers), assuming that they have the overall responsibility for ensuring that their unit apply the best available knowledge.
- The employee perspective (nurses and assistant nurses), assuming that they are responsible to access and apply the best available knowledge.

3. The recordings were transcribed into written documents. Analysis of the documents was inspired by grounded theory (Strauss & Corbin, 1990), and has been conducted in two steps:

- 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 started by reading through the transcribed interviews several times, in order to create a deeper understanding of the respondents’ statements. The actual coding then 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 a concept that was identified 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 “knowledge explosion”. Moreover, 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 and 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 are 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 (Strauss & Corbin, 1990). It was 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 information exchange with healthcare providers. It also gave a deeper understanding of the difficulties practitioners experience with regard to availability of information and how they want future IS to support their work practice and thereby improve the quality of care delivery. 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 (Sbaraini, et
al., 2011; Glaser, 1992). These categories were then mapped into the KM process cycle (Fig. 2).

![Figure 3. Overview of the conducted interviews](image)

We argue that the extensive empirical material together with the rigorous analysis method makes a strong case for the reliability of the results presented in this paper.

**FINDINGS**

The findings from the interview study are presented according to the knowledge cycle (Fig. 2).

**Capturing and Creating Knowledge**

Knowledge creation involves developing new knowledge or replacing existing explicit and tacit knowledge within the organization (Alavi & Leidner, 2001). Practitioners within primary, secondary and municipality care exchanged tacit knowledge through informal and formal networks, involving day-to-day interaction between people e.g., in a clinical situation, during breaks, and during joint activities such as meetings. They shared tacit knowledge by, e.g., assisting each other in terms of providing practical insights into “what solution will work in a particular situation, why it will work, and how to make it work”. Through interaction practitioners obtained new insights that resulted in the creation of new knowledge. In other cases tacit knowledge was transferred from one member to another through discussions. Usually, important tacit knowledge that was transferred from one practitioner to another was not captured despite that the knowledge could be captured and were of importance to the organization as a whole. However, if practitioners converged to solve a complex clinical situation requiring an immediate solution, this knowledge was usually documented. The organizations had thus failed to establish a common space for creating and capturing tacit knowledge. There were, for example, no dialogue meetings or collaborative settings in place where individuals could share experiences, which later on could be captured. Another significant problem is lack of collaborative relationships with practitioners from other units within and outside the organization where practitioners could
share experiences, gain new insights, create new tacit knowledge and capture explicit knowledge. The problem was particularly evident in municipality care and secondary care. A majority of the nurses, assistant nurses and managers asked for cross-communication and collaborative settings. There was a clear need to share experiences about “how others solve a specific clinical situation”. Collaborative settings were especially important for nurses in municipality care as they usually work alone in their function that comprises treatment, counselling, supervision, and caring, with limited opportunities of daily contact with physicians.

The situation is somewhat different in secondary and primary care where the clinical situation requires close collaboration between nurses and physician. Furthermore, several of the nurses within the three levels of healthcare expressed a concern regarding the lack of a culture among nurses and assistant nurses to share knowledge and collaborate between departments within and outside the organization. They also expressed a feeling of injustice since they believe that the organizations prioritize physicians to connect and share tacit and explicit knowledge. Even managers argue that there is a tradition among physicians, that is not found among nurses and assistant nurses, “to connect people”, to develop and cherish collaborative relationships with other practitioners by e.g., holding lectures, educating and sharing new research findings among each other. It is also common that physicians have internal training 1h/week where experiences are shared through face-to-face interactions and where tacit knowledge is converted to explicit knowledge and shared among other practitioners, an approach that is missing among nurses and assistant nurses. Additionally, managers emphasize that the effect of joint activities, especially seminars and conferences is not ideal, due to delays in knowledge creation, capture and knowledge transfer. They further argue that physicians and nurses are good at sharing tacit knowledge during joint activities, but less efficient at knowledge sharing in the day-to-day practice, and if knowledge sharing occurs, it is usually among colleagues within the department, and not entirely surprising knowledge is often shared between individuals within the same professional category. However, during this study, some nurses in secondary care gave examples of physicians who saw the importance of sharing their experience with nurses and assistant nurses, but these examples were few.

Capture of explicit knowledge within and outside the organization, especially within municipality care was seen as challenging. Not knowing what knowledge that flows through the organization and what knowledge is critical was considered problematic. Additional problems concerned, capturing of explicit knowledge from outside the organization. Not knowing where to find relevant knowledge and what type of knowledge that was relevant for the organization were evident. Capturing of explicit knowledge in the three levels of healthcare was mainly done through (1) individual responsibility of managers and practitioners and through (2) the “medical nurse in charge” (MNC). Individual responsibility means that each individual is responsible for capturing relevant knowledge in their subject area from inside and outside the organization and disseminate it among the organizational members. Nurses in municipality care and secondary care experienced capturing of new knowledge as challenging and time-consuming as the knowledge is dispersed and stored in various autonomous IT-repositories. Moreover, as these repositories are not comprehensive, nurses expressed concerns that important knowledge may be overlooked. To simplify access and ensure application of knowledge
that guides practitioners in delivering high quality care, practitioner expressed an urgent need to integrate knowledge such as medical guidelines with EHRs and to develop one comprehensive IT-supported knowledge repository, which also is integrated with the EHR. Some also requested integration of reminders within current IS. Nurses and nursing assistant within municipality care and specialist care also emphasized the need for IT that supports sharing of tacit knowledge between practitioners within and outside the organization. Furthermore, nurses, particularly in municipality care, experience stress and worry about not being able to capture and access relevant knowledge at the right time, at the right place and in the right format as only one of ten municipalities paid for access to scientific databases. This was more pronounced among nurses within municipal care than for nurses in secondary care and primary care, due to the fact that the latter groups work closely with physicians and hence have better access to scientific medical knowledge. A nurse explains:

“Working evidence-based requires that we have access to scientific research, and scientific databases. To only use Google to find such knowledge is impossible [...]. Then I ask myself the question how can I educate and inform our assistant nurses on the ward when I cannot keep myself updated”

Another nurse in municipality care explains that the technology is not adapted to the work processes as the need for knowledge, usually occurs during the patient encounter. Therefore, accessing knowledge at the point of care is impossible:

“We have a computer in the office, but usually you want to search for information when you are at home with the patient because that’s where the questions usually arise, in the meeting with the patient. It may be that I am unsure of the showing symptoms and then I want to check it out, but you can’t because you don’t have the technology to support you”

Nurses in primary care have a national web-based knowledge portal that they use to acquire explicit knowledge. Therefore, the individual responsibility for capturing explicit knowledge was not perceived as problematic. Also, capturing of explicit knowledge, based on an individual responsibility within secondary, primary and municipality care occurs sporadically because of lack of enablers such as IT and culture, lack of time (to capture and document lessons learned), effort, interest and skills needed to find relevant knowledge. Assistant nurses also have an individual responsibility for capturing knowledge. Unfortunately, 89% of those interviewed felt that their individual responsibility for capturing knowledge, particularly evidence based research, is not relevant to their profession. Instead, they rely on knowledge derived from experience and/or on nurses and managers to provide them with relevant knowledge. An assistant nurse explains:

“As an assistant nurse I do not think that it is important to search for the research. I've been working for 20 years, so I have a lot of experience [...] It is
rare that I feel I need knowledge, and usually we have nurses who print out papers on things and put it in folders, which we then read, or the manager emails links with information, for example about dementia"

The results show thus that assistant nurses seldom incorporate research findings into their practice, and they tend to use knowledge derived from experience. However, not all assistant nurses share this view. Two assistant nurses in municipality care argue that their colleagues (assistant nurses) must have a more positive attitude towards EBM and see the value of evidence for patients. They believe that having knowledge and taking part in evidence based practice working groups may be an important approach to change current attitudes:

"If we are to raise the status of assistant nurses and improve the care we provide to patients, then it is important that we try to keep abreast of the latest research"

An additional obstacle to nursing assistants’ individual responsibility is (1) lack of knowledge and experience in searching for scientific medical knowledge and (2) lack of knowledge of what characterizes a scientific source. The nursing assistant who felt that the acquisition of knowledge is just as important for a nursing assistant as for a nurse or physician believes that the organization has failed to create an environment that supports capturing and sharing of knowledge.

The “Medical nurse in charge” is a nurse who has the primary medical responsibility of the department. She is also responsible for capturing, storing and disseminating explicit and tacit knowledge that may be relevant to other nurses and nursing assistants. The created and captured knowledge is often packaged in a document, stored on the intranet and/or printed and saved in a binder. Managers also have an important role in capturing, storing and disseminating knowledge. Knowledge outside the organization was captured, e.g., by following central directives and through organization-wide collaborations. It is evident that there is a tendency among both managers and practitioners to focus on the capturing of explicit knowledge from outside the organization. The tacit and explicit knowledge inside the organization does not seem to get as much attention. Perhaps the knowledge inside the organization is taken for granted? There was only one department at secondary care who consciously worked with the capture and creation of knowledge from inside the department.

Packaging and Storing Knowledge

While organizations capture, create new knowledge and learn they also forget acquired knowledge. Therefore, the storage and retrieval of organizational knowledge constitute an important aspect of KM (Alavi & Leidner, 2001). The interview results have demonstrated difficulties with the packaging, storing and access of knowledge. Knowledge is usually packaged in documents and then published on the intranet. This knowledge is difficult to absorb since the documents often are not adapted to the target groups. The use of multi-
media such as film, animation and sound is hardly ever seen, even though this is often a feasible way to package tacit knowledge. A further complicating factor is that information is stored in variable form and in various places, e.g. on the computer, on the intranet, in different knowledge repositories and in paper folders. Hence, medical knowledge is inaccessible when needed. Some practitioners even choose to not actively look for the knowledge as existing tools are not adequate for answering the questions that arise and those who search for knowledge find that the provided knowledge usually do not map to the issue at hand. A nurse explains:

“Finding the right knowledge is difficult because you don’t know if it is it stored on the intranet, on the computer, in the summaries of medical guidelines, in folders, news archives, on different web pages and so on”

Sharing and Applying Knowledge

An important part of KM is the sharing and use of knowledge. This process is not always simple as organizations often do not know what they know and/or they have weak systems for locating and retrieving knowledge that resides in them (Alavi & Leidner, 2001). Knowledge can be shared through different channels, such as meetings. However, informal channels such as unscheduled meeting and informal seminars aimed for sharing knowledge are rare among nurses and assistant nurses. Training is a common way of disseminating knowledge, but practitioners claim that it must be supplemented by other systematic efforts to ensure sustainable uptake of knowledge. The most common method used is that one practitioner is trained in a specific subject and is then expected to train their colleagues. This practice has proven to be problematic as knowledge gained from training often remains within the person who was first trained and tends not to reach other individuals in the organization. Experiences and insight from the training are usually presented orally and rarely documented. Additionally, it is difficult for managers to determine how much of the tacit knowledge gained from training is shared among individuals. Hence it is difficult to see the effect of such training.

IT is used within the three levels of healthcare as a “push-pull” approach. The push approach is characterized by a desire to capture knowledge in central repositories and then push it out to the organization, in this case by email, intranet and in conjunction with meetings. If a manager captured knowledge, e.g., from an external repository a web link was sent to employees by email and/or published on the intranet. Additionally, sharing is also dependent on the “pull” approach. This approach expects people to seek the knowledge they need, when they need it. As discussed previously the practitioners’ lack of interest, time, skills and lack of adequate IT-support prevents a successful “push-pull” approach. This is worrying, as a successful and effective knowledge sharing and application is critical for transformation and innovation of knowledge - improvement of existing knowledge and creation of new knowledge (Persson & Janis, 2007). Moreover, managers in secondary care and to some extent in primary care express difficulties to assess whether employees have applied the disseminated knowledge. A manager even mentioned that explicit knowledge that has been captured from the outside organization is comparable to rain:
"Explicit knowledge is like a temporary and sudden rain of knowledge that washes through the organization without anyone knowing if someone has embraced it”.

Another argues:

"There we have a huge problem because we measure very badly how knowledge is assimilated or if the implemented knowledge, such as guidelines has contributed to any advantages to the patients. We have no feedback loop for how knowledge grows and is assimilated. Hence we don’t know if it exists."

Also, managers in municipality care perceive that monitoring the compliance to new knowledge is difficult. The majority of the municipalities have no specific processes developed for this. Sporadic follow-ups are common, and are conducted through verbal feedback from the nursing staff regarding her/his experience of how other medical staff follow new medical guidelines.

**ORGANIZATIONAL IMPACT OF THE STUDY**

The results of this study have made the leaders of the participating organizations aware of the problematic situation. They now realize that the KM processes needed for the successful implementation of an IT-based knowledge repository is simply not there. It is evident that just implementing an IT-based knowledge repository will most probably not improve on the situation, as the main KM problems were related to people and to the organizational culture.

As a result of this study, the 15 involved municipalities have decided to develop basic support for managers to start assessing the knowledge needs in their own units and to start thinking in general about systematizing their KM processes. The authors of this paper provided guidance in the process.

The support is based on the knowledge cycle (Fig. 2) and includes simple discussion and reflection questions and ways of working in each part of the cycle. They constitute a small first step towards the vision of having an IT-based knowledge repository as a single point of access to relevant medical knowledge.

The knowledge cycle was adapted in order to simplify for the managers and did not rely on any IT tools. The names of the steps in the knowledge cycle were rephrased using terminology that the managers could easily relate to. Guiding questions were also formulated to help the managers to go through the steps in the cycle. The resulting steps were:

1. **Reflect and follow up**: In this step managers are first supposed to state the goal they want to achieve. It can e.g. be to improve care in general in their unit or it can be something more concrete such as making sure that a specific patient’s needs are catered for. After that they evaluate whether there are some shortcomings in the knowledge needed to meet the goals. e.g. there can be shortcomings with regard to knowledge about the latest medical guidelines.
2. **Find relevant knowledge**: In this step the managers identify the relevant sources of knowledge. To support them, they are provided with different suggestions as to which potential sources there are. It is worth pointing out that not all relevant knowledge needs to be evidence based since an important part of evidence practice is also the experience based knowledge of the staff and the preferences and experience of the patient.

3. **Adapt knowledge to target group and package it**: In this step managers reflect about who in the organization that needs the knowledge and what is the best way to package the knowledge so that the target group can understand it. The goal here is to make the knowledge useful to those who need it.

4. **Share and implement the knowledge**: In this step the managers identify the means by which to make the knowledge accessible. It could, e.g., be by training, by written or oral information or by computerized access if possible.

5. **Reflect and follow up**: The cycle is closed by coming back to the first step where managers assess whether or not the goal they set up has been met. Has the knowledge led to any improvements? If not, a new goal needs to be set and the cycle starts again. If yes, new situations will mean that new goals are set and the cycle starts again. In essence, this step keeps the cycle in motion.

Training sessions were organized with groups of managers to make it possible for them to discuss with other managers and to share experiences. The managers brought practical cases from their own units. The sessions were also a way to create a network between managers in order to facilitate future development of an IT-based knowledge repository. The model has been well received among the managers. It has been considered easy to understand. In particular, it has facilitated the understanding of how they in a reasonably practical and easy manner can implement evidence practice in their units. When the managers introduced this way of working in their units, it has also been well received by the staff as a way of talking about introducing new knowledge in their unit. In general the managers’ report that there are challenges in finding the relevant needed knowledge sources. There are many different sources and evaluating their relevance can be difficult. Also the implementation of knowledge is challenging as described previously in this paper.

**DISCUSSION AND CONCLUSION**

A crucial role in the practice of EBM is healthcare practitioners’ possibility to access evidence based medical knowledge at the time when they need it. This study has confirmed that practitioners lack access to medical knowledge when preparing and conducting patient visits, as well as when making decisions about the care of the 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. For example, insights regarding which knowledge flows through the organization and how it flows, what information is critical for which process, and how it is used as well as who uses it, is missing. Moreover, the findings have confirmed that the main barrier hindering the adoption of KM is related to people and organizational culture. There seem to be difficulties related to getting people to share,
participate and understand the roles and responsibilities that support KM and its importance and contribution to the organization. In addition, practitioners lack access to adequate IT-support for accessing and sharing knowledge. To simplify access and ensure application of knowledge that guides practitioners in delivering high quality care, practitioners expressed an urgent need to integrate medical guidelines and relevant knowledge sources with Electronic Health Records. There is also an urgent need for IT that supports sharing of tacit knowledge between practitioners within and outside the organization. However, as shown by this study, the participating organizations did not have the KM processes and culture needed for the successful implementation of an IT-based knowledge repository. Therefore, they needed to first focus their attention on fostering awareness among managers of the importance of having systemized KM processes and then to develop and introduce such processes. The simple tool described in the section “organizational impact of the study” is an attempt to get managers to move in this direction.

In conclusion, current Swedish healthcare practice, at least in the studied region, is far away from being able to live up the national IT-strategy as concerns IT-based knowledge support. We have no reason to believe that the situation is any different in other Swedish regions. The study has been carried out in Swedish healthcare and the more general applicability of the results could therefore be questioned. The second author has been involved in several international studies of KM in various types of organizations and seen similar gloomy patterns there. We would, therefore, not be surprised if healthcare organizations in other countries experience the same problems. This needs to be further studied as we have not been able to find any studies to compare with.

REFERENCES


Patients’ Experiences of Communicating with Healthcare – an Information Exchange Perspective

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Aims: To explore on how patients experience the information exchange with healthcare organizations and how this relates to the six areas that constitute good quality care.

Method: A qualitative approach inspired by Grounded Theory was adopted. Seven interviews with patients were carried out in the homes of patients.

Conclusion: Healthcare does not always meet the requirements of Health and Medical Services Act with regard to good quality health. An effective exchange of information between health professionals and patients was found as a key issue for creating the conditions for good quality care.

Keywords
Good quality health, information exchange, IT in healthcare, patient process

1. Introduction

Healthcare is increasingly dependent on information. The rapid success of new treatments and patients’ ability to choose health center, have changed information needs. Often different healthcare professions are involved in the care of one patient. A successful treatment outcome and good quality care is therefore dependent on having access to relevant, correct and up-to-date information about the patient at the right time [1]. There are numerous examples of health related injuries that are caused by deficient information exchange between different actors in the care process. Besides safe and efficient information exchange between healthcare providers, it is equally important for good quality care, that information exchange between providers and patients is effective. The patient must therefore be able to easily access information concerning him or her and in an efficient manner get in contact with health services [2], [3], [4], [5].

Information technology (IT) has enormous potential to improve the quality of healthcare with regard to safety, effectiveness, and efficiency. IT also has the potential to make care patient-centered, to enhance equity and to improve timeliness of care. However, present IT-support does not yield the expected positive effects. In Sweden, e.g., IT systems used by different healthcare providers do not communicate across operational and organizational boundaries [2], [3].

The aim of this paper is to explore how patients experience information exchange with healthcare organizations and how this relates to the six areas that constitute good quality care according to the Swedish Health and Medical Services Act [6]. Today there is a gradual development in healthcare, where the focus is on improving the care given to patients through IT. This ongoing development also includes a gradual change in the
relationship to the patient. In the past, the emphasis has been on improving and enhancing the efficiency of care services on the basis of assessments by healthcare professionals of what constitutes efficient healthcare. The new approach is based on citizens’ and patients’ actual needs and emphasizes the value of active patient participation [2], [3]. Previous research has focused on healthcare professionals’ experience of the information exchange and patients’ experience has largely been neglected. Since patients’ participation in their own care is stressed, at national and international levels, it is important to study how patients experience the exchange of information with healthcare and how these experiences relate to the concept of good quality care.

2. Research Approach

The research was conducted in three steps:

1. **Literature review**
   A preliminary review of literature describing related research was made, targeting literature from different research domains related to IT in healthcare and good quality care.

2. **Collection of empirical data**
   The research reported in this paper is part of a larger research project, The Future Healthcare Information System (FHIS), which aims to develop a prototypical process support (PPS) that demonstrates requirements for future IT support in healthcare. The PPS has been developed in close collaboration between researchers at the University of Skövde, Sweden, a local hospital in Region Västra Götaland, Sweden, and other healthcare organizations in the said region.

   Seven interviews with patients were carried out in their homes, following a previous doctor consultation at the hospital. The consultation and the conversation that then took place between patient and doctor was observed by a researcher. The interviews were recorded and lasted approximately two hours each. The purpose of the interviews was to explore how patients experienced the information exchange with healthcare organizations and how they perceived their health status to be affected by the nature of that exchange.

3. **Data analysis**
   The recordings were transcribed into written documents. Analysis of the documents, inspired by grounded theory [6], was then conducted in three steps:

   - **Open coding**: Generated concepts/categories and a deeper understanding of the interview documents [6].
   - **Axial coding**: Categories that emerged from open coding were reviewed in detail [6]. When an understanding of the categories occurred, a description of each category was made.
   - The six quality areas for good quality care were reviewed in detail and compared with the six quality areas.

3. **Good quality care**

In this section we discuss the concept of good quality care, mainly based on sources published by Swedish and International healthcare authorities.

Section 2 of the Swedish Health and Medical Services Act [7] states that the overall goal of the health and medical care services is to have a healthy population and to provide healthcare on equal terms. According to reports by the National Board of Health and
Welfare [5], patients are overall satisfied with the care provided, although they perceive that information about the care provided is defective. Insufficient and/or lack of information cause stress and anxiety among patients. Patients also often complain about long waiting times and that there is no continuity in the care. Receiving care perceived to be defective can give a feeling of not being genuinely cared for and about, which in turn can aggravate state of health [8]. Better co-operation and consensus are seen as the fundament of good quality care. Citizens and patients expect good quality care and easily accessible care. The six areas of good quality care have been defined in [9] by the Swedish National Board of Health and Welfare, based on [10], as follows:

- **Effective healthcare**
  Care must be based on scientific knowledge and best practice.

- **Safe healthcare**
  Safe care is a basic dimension of good quality care. Healthcare Management and professional care must be organized to insure safe healthcare and to prevent healthcare related injuries.

- **Efficient healthcare**
  Resources should be used efficiently in order to reduce waiting times and sometimes harmful delays for those who receive and those who give care.

- **Equitable healthcare**
  Healthcare should be delivered with respect for all human beings and with the equal value of all people in mind. Individuals who are in most need of health services must be prioritized.

- **Timely healthcare**
  No one should wait unnecessarily for health services. It is a human right to receive medical evaluation and treatment as soon as possible. Timely healthcare is also about patients and citizens being aware of where to turn and to be able to quickly come in contact with healthcare when it is needed. Access to care is an issue that relates to opening hours and waiting times but also to the possibility to communicate and to be able to access comprehensive information about diagnoses, patient rights and available services.

- **Patient-centered healthcare**
  Healthcare staff must provide care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

IT has enormous potential to improve the quality of healthcare with regard to all six areas [10]. Its potential as a means for information sharing has successfully been demonstrated although numerous challenges still exist. IT systems used by different healthcare providers often do not communicate with each other, and users are not satisfied with their functionality. To achieve good quality care, healthcare professionals need timely patient information (i.e., current diagnosis, medication list, medical history) from various sources at the point-of-care.

Another important problem is that patients often lack the possibility to follow their own care processes, e.g. the status of a referral, or to access relevant information, e.g. diagnoses and planned treatments [2], [3], [10]. The patient process is defined in Åhfeldt and Söderström [11] as the process that follows the patient during an event of illness. During this process important patient information must follow the patient in order to ensure good quality care [12]. Also, patients have limited possibilities to communicate electronically with healthcare professionals [3]. Individuals in their roles as citizen, patient, and relative must have easy access to quality assured information about health, treatments and medical services. In order for individuals to experience participation, influence and self-treatment on their own terms, it is important that they are offered interactive e-services that enable, e.g., booking or changing of, renewal of prescriptions or contacts about specific problems with their doctor. It is equally important to enable access to information concerning medical history, diagnoses as well as planned...
investigations and therapies [2], [3]. Several reports from government authorities indicate that patients’ participation in planning and conducting their own care and treatment improves the outcome of care [5].

Information exchange between providers of care and patients need thus to be more effective and efficient in order to increase patients’ possibilities to influence and actively take part in their care. Improved participation can give patients a feeling of empowerment, which in turn can lead to better health, in the form of better wellbeing, as well as increased decision power [13], [14].

4. Findings
4.1 Patients’ experiences of information exchange in healthcare

The analysis of the interviews resulted in the identification of two main categories: (1) the absence of a holistic view from a patient perspective, and (2) uncertainty is a source of insecurity, as well as nine sub-categories (Figure 1). Category 2 is a consequence of category 1 and its associated sub-categories.

![Figure 1](image-url)
The absence of a holistic view from a patient perspective

IT in healthcare has never been used to its full potential. The reasons for this according to [3] are; (1) it has been difficult to agree on the specific requirements for interoperable IT solutions, (2) electronic communication between different healthcare professionals and units was underdeveloped in the past, (3) developing IT systems is costly. Therefore, development and implementation of IT systems in the Swedish healthcare have until now been confined to delimited areas of the healthcare system, which is why interoperability between different systems is limited [2].

When the information does not follow the patient process, the lack of an overall holistic approach becomes clear. This lack contributes to a number of consequences for the patient. These impacts are defined as sub-categories, which are further divided into three groups: the patient's role in the care process, meetings between doctor and patient and waiting times in healthcare. Within each group there are relationships between the sub-categories (Figure 1). In the following, quotes from the patient interviews are included in order to strengthen the argumentation for each sub-category and to illustrate how the patients experience their situation.

Identified sub-categories

1: Patients role in the care process

The patient as a carrier of information
Since IT systems in healthcare often do not communicate across operational and organizational boundaries, patients are forced to act as "information carriers". Patients experience that it is their responsibility to communicate their healthcare history between care units, which means that patient safety can be in jeopardy. Patients, however, want to play an active role and are open to participation and influence. This does not mean that the patient should be responsible for transferring information between different care providers.

"I was recommended to go to the emergency. There, they knew nothing about me and I had to sit there and explain my medical history" (Patient F)

"There is a new doctor every time. Then I have to repeat the same history for each doctor" (Patient G)

The sick but active patient
Patients role as "information carrier" together with the Swedish decentralized healthcare system requires that the patient is active despite of being ill or injured. While waiting, e.g., patients are expected, despite of their illness, to actively contact the hospital and in some cases play an active role in obtaining test results, new appointments with healthcare professionals and to ensure that their treatment history as well as newly and previously prescribed medicines are communicated between healthcare units.

"I have been active. I have to be healthy in order to be sick" (Patient G)

"If I haven’t been active then I wouldn’t be half way through my care process" (Patient F)

Lack of influence over their own care process
As shown, the patient must be active despite being ill or injured. The majority of patients are, however, experiencing their forced active role as a waste of time and strength, since in practice they have little or no influence in their own care process. All patients perceive that they must accept what they are offered, or resign to not having any convenient appointments for treatments and/or investigations. This is frustrating to them.
"I was terrified to miss the show in figure skating and I did too. I got an appointment for the surgery so I missed the show by four days. It would be great if you as a patient can book or change appointments with healthcare professionals, treatments, operations" (Patient B)

2: Meetings between the doctor and patient

Doctor-patient relationship or patient-doctor relationship

The doctor-patient relationship has traditionally been paternalistic, which means that the doctor was perceived as the expert (the active) and the patient as the passive. Over the years, patients' role in their own care process has been strengthened, meaning that the relationship have changed from being a physician-patient to a patient-doctor relationship. A good relationship between patient and doctor assumes that the physician respects the patients’ values, autonomy and patients’ empowerment in questions about diseases, interventions and treatments. The analysis of the interviews reveals that patients sometimes feel that doctors do not take their health related problems seriously. The doctors seem, according to the patients, to be satisfied with some interventions without considering the patients’ perception of their own illness. In addition, they feel that they have no participation and influence in matters affecting their health. Being listened to is something that the majority of patients ask for. Doctors’ ability to listen is not only essential to obtain information about the patients’ medical condition. It is also essential for patient satisfaction and to establish a good patient - doctor relationship.

"It is important that the doctor listens to the patient. During these five years, nobody has taken my pain seriously" (Patient E)

"They should listen to the patient. Sometimes they only suggest that the patient should eat pills without listening" (Patient B)

Language difficulties - technical language Swedish/ second language

The meeting between care professionals and patients is the core of all healthcare. It is the responsibility of each individual healthcare professional to ensure that patients receive information about their care process. Patient safety, participation and influence requires that patients can follow and get an overview of relevant medicines and previous contacts made. The analysis indicates that the communication of information based on each patient's circumstances and needs is a complicated process due to “language problems”. Patients have problems getting individual information about treatment, interventions and diagnosis and in some cases understand the information that is communicated. These problems arise partly because the doctors do not adapt their language to each patient's health status, ability and experience, and partly because some doctors do not speak Swedish well enough. This, combined with the lack of empowerment and information imply that patients do not feel that they understand what is happening and what will happen in the future. A sense of insecurity is created.

"I usually get treatments by doctors who don´t speak Swedish and it’s difficult because communication problems arise" (Patient B)

"The first doctor was talking in Latin" (Patient G)

"What did the doctor say?"

Patients’ ability to receive information may be impeded due to health status, health professionals’ inefficient ability to convey information to the individual and/or the use of inefficient aids for communication that are not adapted to each patient's individual needs. In order to increase participation, the information must be perceived correctly. However, communication between patients and health professionals is perceived as inadequate partly also because patients do not remember what was communicated during the
meeting. The situation is frustrating for the patients and anxiety seems to be a common consequence.

"I brought a friend during the visit to the doctor so that you can remember everything" (Patient D)

3: Waiting times in healthcare

"Care guarantee” and accessibility are not the same

Improved accessibility to healthcare is fundamental for good quality care. However, it is often argued that the accessibility of Swedish healthcare is its greatest weakness. The aim of the Swedish “care guarantee” is to ensure that every patient receives timely healthcare. The analysis indicates that the care guarantee works but that accessibility to healthcare must be improved. Citizens must have easy, trouble-free and secure access to healthcare. A great deal of information on health and elderly care is already available electronically on a large number of national, regional and local government websites [3]. However, the information is neither easily accessible nor comprehensively presented. Furthermore, patients cannot, themselves, easily access and read their health records or information compiled about them by care professionals. Electronic booking services are also limited [2]. Those who wish to book or change appointments with healthcare professionals must often use the telephone. A major problem with this service is long telephone queues. This requires great commitment from the patient's side, especially when the problem is repeated continuously at almost every healthcare contact.

"[...] I sat one hour on hold. They said you are on hold and we will answer your call as soon as possible, but it was not very fast” (Patient E)

Long waiting times

Five out of six patients also complain about long waiting times. Long telephone queues are also perceived as problematic.

"[...] I am irritated when the put you on hold when you are trying to make an appointment” (Patient A)

"[...] When you are at the orthopedics and you have an appointment, you will not be submitted on time. If you go to get an inspection of your car you have your time and you will get help in time but when you are at the orthopedist you have to wait. Easy to wait for one hour” (Patient C)

"Have I been forgotten?"

Patients perceive accessibility to information during and after a treatment as defective. Lack of clear instructions and information is often the case. Patients feel that they do not receive information during the care process. The feeling of having been forgotten increases, which causes anxiety. The situation also creates frustration and forces the patient, despite being ill, to act in order to obtain the necessary information.

"I'm not sure if it will be keyhole surgery or not. If I do not hear something soon so then I have to contact the hospital” (Patient B)

"I waited for three weeks without receiving any reply. Therefore, I have to call myself” (Patient C)

Uncertainty is a source of insecurity

As shown in the above section, patients feel that they do not receive adequate information about their health. Some patients also find the information provided to be insufficient and/or not suited to the individual's ability and capacity to absorb information.
Language, transmission media, and other aids of communication are not adapted to each patient's health status and maturity. Lack of adequate information about important aspects of healthcare, causes a feeling of uncertainty and uneasiness about the future.

"It takes a long time to get answers. I have had this problem for five years and tried to find out what is wrong. Is it possible to fix it or not" (Patient B)

In addition, lack of participation/influence is another important characteristic causing anxiety and feelings of not being safe. E.g., in situations where the patient is unable to influence scheduling, the combination with inadequate access to information about time of treatments and/or planned healthcare interventions and with patients' anxiety causes a sense of uncertainty which later on is developed into insecurity.

Some important questions that patients’ ask themselves are whether Swedish healthcare is safe and if it can deliver good quality healthcare. Because patients often have to be active despite being ill questions are raised whether healthcare in practice is patient-centered and equal. Patients’ role as carrier of information also raises questions about patient safety. Furthermore, since healthcare professionals, according to the patients, do not consider patients' perception of their own illness create a sense of insecurity.

4.2 Patients' experiences of information exchange related to the six characteristic of good quality health

The following section presents how patients’ experience of information exchange in healthcare relates to the six areas of good quality care (figure 2).

![Figure 2 Identified categories and their influence on good quality care](image-url)
4.2.1 Patient-centered healthcare

Existing evidence suggests that healthcare does not always meet the requirements of the Health and Medical Services Act with regard to informing patients and providing an opportunity to discuss health and medical care interventions and/or treatment [14]. The evidence suggests that exchange of information between patients and health professionals are not functioning optimally and that efficiency of care services has been improved based on healthcare professionals perceptions of what constitutes efficient healthcare. The analysis indicates that patients are satisfied with certain aspects of care although many areas need improvement, more specifically participation and influence.

Also, exchange of information between doctor and patient is deficient. Patients emphasize that information (about their health) from health professionals is unsatisfying. An important prerequisite for achieving patient-centered care is that care should be planned and implemented in consultation with the patient. When the patient lack understanding, knowledge and insight, they are not given the opportunity to participate in and influence their own health, care and treatment. Research demonstrates that a patient-centered approach has a positive impact on patient health and welfare [14].

Other identified dimensions that show limitations and shortcomings with patient-centered healthcare, is patients’ statements about language difficulties and the difficulty to remember what healthcare professionals communicate to them. These experiences show that a deficiency in information management between health professionals and patients increases puts the patients at risk if the information is given in a form that is not suited for them. Especially important is the communication of information to vulnerable groups such as the elderly and the foreign-born [14].

4.2.2 Efficient healthcare

Efficient healthcare means that resources should be used efficiently in order to reduce, sometimes, harmful delays. Efficiency can be improved by working towards a holistic view on the care process, by introducing cost-effective treatments and by improving the competence of healthcare professionals and their division of tasks [14]. Since differences in IT deployment and use by county councils and municipalities respectively hinders effective exchange of information with healthcare units [3] patients have to undergo repeated and unnecessary interventions, which in the long run contributes to an excessive consumption of resources. Not having access to a patient’s EHR and medical history, ongoing treatments and courses of medication can also lead to harmful delays.

4.2.3 Safe healthcare

Deficiencies in information exchange and communications are, in accordance with previous research, some of the most common causes of health related injuries. The analysis of the interviews with patients demonstrates that patients are unable to participate in healthcare based on individual circumstances. The interviews indicate that patient participation in the care process is limited in practice. It is likely that the number healthcare related injuries could be reduced by increasing patients’ participation.

Another important feature of a safe care is collaboration and communication between different professional groups and different healthcare services. Patient safety requires that the information follows the patient and, if necessary, is available to authorized healthcare providers. When the information does not follow the patient process, the patient is forced to act as “carrier” of information [3]. Today, it is thus on the patients’ responsibility to communicate important information about their own care between clinicians, healthcare units and healthcare providers. Possible risks which may arise due
to lack of integration and data transfer includes health related injuries because of medication interaction, delayed in prescribing medication and prolonged periods of care.

4.2.4 Timely healthcare

Care accessibility has been identified as a significant problem among all patients who participated in the study. Deficiencies in availability are described as long waiting times and limited opportunities for communication and access to comprehensive information on diagnoses, the status of the referral and treatment choices. Although the care guarantee is held to operate satisfactorily, care must be coordinated, which is necessary to achieve accessibility. Furthermore, processes and procedures should be optimized based on a patient perspective in order to make healthcare available to all patients [14].

Furthermore, timely healthcare implies that different types of technologies should be used in order to offer citizens different aids to learn more about health concerns, illnesses, symptoms, medicines and self-treatments, to book or change appointments with health professionals, to renew prescriptions and to get information about the status of a referral [3]. The interviews, however, prove negative experiences among patients in this respect. For example, it is normal for patients to feel neglected by healthcare, which is why the frustration and anxiety among these patients is common.

4.2.5 Equitable healthcare

Based on the analysis of the interviews it can be concluded that Swedish healthcare, partly, fail to meet the objective to provide good quality care on equal terms. There are differences between patients regarding the treatments and tests carried out but also differences in waiting time. E.g. patients who try to take charge of their patient process may have greater opportunities to influence their treatment and/or interventions. However, there are no major differences between men and women in this respect. E.g., the majority of patients experience difficulties in convincing doctors about their perception of their illness. Patients who are active and dare to take charge of their healthcare process usually succeed to convince the doctor to trust their experience of illness. They often also succeed to convince the doctor to carry out different healthcare interventions. Withdrawn patients however, are in the opposite situation, which affects their confidence of healthcare negatively. Finally, we can thus conclude that healthcare must be designed so that equal care is equally accessible to all.

4.2.6 Effective healthcare

Care must be based on scientific knowledge and best practice. In order for healthcare to be based on scientific knowledge, the knowledge must be reviewed, valued and consolidated. Also, the healthcare professionals’ collective experiences, skills and dialogue with patients are important. The dialogue is a precondition for the staff to explain the effect of certain treatments. Furthermore, it is also an important requirement for staff to be able to understand and respond to patients’ expectations [14]. In order to meet each patients’ individual needs, healthcare staff must use the best available knowledge in the meeting with the patient and in the planning of health services. An important part of effective healthcare is also the coordination and cooperation between different care providers. Access to information relating to the individual patients’ personal circumstances is an important knowledge base but since the patient must take on the role of “information carrier”, the Swedish efficient healthcare can to some extent be questioned.
5. Discussion and Conclusion

The purpose of IT in healthcare is to improve the quality of care. In order for healthcare to provide good quality care, healthcare must be available and provide patients with comprehensive and accessible information about healthcare services, care quality and information compiled about them by care professionals [3], [15], [16]. Also, healthcare should be delivered with respect for all human beings and allow patients to influence their care [2]. IT has enormous potential to improve the quality of healthcare with regard to all six characteristics of good quality care. In the areas of safety and effectiveness there is growing evidence that EMRs and automated order entry systems can improve the quality of the care given and reduce unnecessary resource consumption by double work [10]. In the areas of patient-centered and equal healthcare it has been stated that IT can increase patients’ empowerment by offering access to understandable and reliable Internet-based medical information. Internet-based health communication that offers e.g. booking of appointments with healthcare professionals and discussions with doctors etc., can also improve the timeliness of healthcare. Furthermore, the use of systems such as DSS can improve efficiency by making it possible for healthcare professionals to make decisions that are based on scientific knowledge [10].

Although IT has enormous potential to improve quality of healthcare, the results concludes that deficiencies in information exchange between healthcare professionals and patients’ prevent the fulfillment, to the extent that is possible, of the six areas that constitute good quality care. Swedish hospitals demonstrate good medical outcomes but unfortunately it is still far too many patients who do not receive care in a timely manner and who are not given the opportunity to influence and participate in their own health, treatments and interventions. When the exchange of information does not function properly patients’ health status is also affected. Effective exchange of information between healthcare professionals and patients is therefore a key issue for creating the best conditions for good quality care and to give patients a sense of empowerment in their own health and care process.

Until now, development of IS to support healthcare processes in Sweden has been heavily focused on the needs of healthcare professionals, whereas the needs of patients have not been prioritized. This has been identified by the Swedish authorizes, resulting in a national strategy for e-health that puts more emphasis on patient needs [2]. This should provide an opportunity to improve the situation described in this paper, although the work in this direction has only started.

References


Cancer patients’ attitudes and experiences of online access to their electronic medical records: A qualitative study

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Abstract
Patients’ access to their online medical records serves as one of the cornerstones in the efforts to increase patient engagement and improve healthcare outcomes. The aim of this article is to provide in-depth understanding of cancer patients’ attitudes and experiences of online medical records, as well as an increased understanding of the complexities of developing and launching e-Health services. The study result confirms that online access can help patients prepare for doctor visits and to understand their medical issues. In contrast to the fears of many physicians, the study shows that online access to medical records did not generate substantial anxiety, concerns or increased phone calls to the hospital.

Keywords
electronic medical records, medical information, patient access, patient empowerment

Introduction
Engaging patients and their relatives to play an active role in their healthcare process is a critical element of patient-centred care, yet patients are an underused resource in the healthcare system.1 In an effort to provide more patient-centred care, some healthcare organizations worldwide have offered patients online accesses to their electronic medical record (EMR) using a secure Internet...
portal, also called e-Health portal. e-Health portals are gaining traction among healthcare institutions as mechanisms to improve the safety and quality of healthcare delivery, as well as modalities to activate and involve patients to a greater degree in managing their own health. e-Health portals can be defined as “applications that allow patients to access health information that is documented and managed by a healthcare institution” (p. 63). There is great variation in the features and functionality of available e-Health portals. Most portals allow access to selected health information from the EMR and enable patients to perform certain administrative tasks, such as appointment scheduling and prescription refills. Besides providing sole access to health information, e-Health portals may also offer additional services such as secure messaging between a patient and an institution. Studies have shown that giving patients’ online access to health information from, for example, their EMR can encourage them to participate in their care, to manage their health condition, increase understanding of their medical issues and improve doctor–patient communication. This is often denoted as patient empowerment, which is a situation in which the patients’ role is changing from a patronized patient to an informed and engaged patient. Patient empowerment is in this article defined as “patients having the ability to understand health information and make effective use of it, as well as to gain control over and participate in a meaningful way in the disease management process in an equal partnership with healthcare professionals.” The definition revolves around three empowerment dimensions: patient knowledge, patient control and patient participation. There is evidence in the literature that individual’s ability to access and use their online medical records serves as a cornerstone of national and international efforts to increase patient empowerment and improve health outcomes. Having access to information about personal health is seen as an important precondition for patients to make informed decisions about treatment options. It also allows patients and their families to better cope with their conditions and their implications. Research has also shown that online access to medical records can increase patients’ ability to prepare for healthcare visits, improve communication with healthcare practitioners and increase the accuracy of information given to healthcare providers. However, there seems to be a disagreement in the literature regarding the effects of making medical records available for patients, especially when it comes to anxiety and concerns. Some studies have reported that patient-accessible medical records can generate anxiety or concerns whereas others have concluded that having full access to a medical record neither decreased nor increased anxiety.

Giving patients’ access to their EMR is not a novel idea. Nonetheless, many still primarily rely on verbal communication between healthcare practitioners and patients. Hassol et al. have in their study concluded that patients and physicians differed substantially in their preferred means of communication, with patients preferring e-mail communication for most interactions followed by in-person communication, whereas physicians preferred in-person communication followed by telephone communication (p. 512). Some researchers argue that the quality of verbal communication is limited due to the lack of time when visiting a physician and due to difficulties of recalling information provided during a visit. Therefore, it is apparent that it would be beneficial to use multiple channels for communication, including written notes, brochures and online access to information that is available in the medical record. At the same time, healthcare practitioners have had several concerns about giving patients online access to their medical record.

In Sweden, the County Council of Uppsala (LUL) was the first county to introduce online access to medical records by giving all patients over 18 years of age access to their personal EMR, together with several other e-Health services in the autumn of 2012. The online medical record and other e-Health services are accessed through a national e-Health portal called “1177.se.” Online access to medical records enables patients in LUL to access and read their EMR containing information on appointment bookings, medical notes, drug prescriptions, medical laboratory results, diagnoses, referrals and log lists with names of the healthcare practitioners who have accessed the record.
interactive services such as providing a healthcare declaration, changing address information, editing information about relatives and sharing the medical record with a next to kin are also provided to the patients. In the year 2015, patients were given the possibility to annotate medical notes by attaching a comment. However, healthcare practitioners are according to terms not required to keep track and/or read any of these comments. Sweden is not the only country that is providing patients with online access to their EMR. Since 2003, patients in Denmark have had access to their EMR through a national e-Health portal called www.sundheds.dk. Even Estonia provides its citizens with access to their full personal health records. Physicians and patients have thus equal viewing access. Malta has recently introduced a Government portal for online access to health records. The portal is called Minu e-tervis (Engl. myHealth (www.digilugu.ee)). Patients and the doctors can choose who can access health data through this portal. However, to the best of our knowledge, there are no other countries except Denmark which offer patients access to all the information sets described above.

In Sweden, the patient accesses the online medical record using an e-ID or alternative secure login options. This is the same level of security that Swedish banks offer their customers for Internet transactions. Before patients can read their EMR, they are required to answer a question regarding what kind of information they want to access. They can choose to only read medical notes and laboratory results verified and approved by physicians, or they can choose to read all information, including notes, which have not been double-checked by their physician, and risking receiving information (including disturbing or worrying findings and diagnoses) before the physician has contacted them. This means that, for instance, cancer patients in LUL can see their test results before a scheduled appointment with a doctor or any other contact with healthcare. In spite of the asserted risks, currently 98 percent of the patients in LUL choose to read all available information, including notes that have not been checked by their physician. Although the Swedish Ministry of Health and Social Affairs has emphasized the importance of providing patients with a secure personal online access to their own medical records, an overview of relevant medicines and previous contacts with healthcare,¹⁴ many physicians in Uppsala and in other parts of the country have expressed concerns that reviewing the medical record may worry and confuse patients, especially if seriously ill individuals such as cancer patients are given access to their records. Since the evidence and qualitative understanding of the impact regarding cancer patients’ access to medical records has remained inconclusive in this research, a case study of cancer patients was conducted in the County of Uppsala in 2013–2014. The case study is a part of the Deployment of Online Medical Records and e-Health Services (DOME) research project.¹⁵ Consequently, the aim of this article is to provide in-depth understanding of cancer patients’ attitudes and experiences of online medical records, as well as an increased understanding of the complexities of developing and launching e-Health services based on a direct access to patients’ EMR.

**Research approach**

Data were gathered using a semi-structured interview approach. So far, a large number of the studies on patients reading their EMR are based on surveys. In contrast to the earlier efforts, we could identify a lack of comprehensive qualitative understanding of how specific patients interact with the EMRs in a specific context. Unlike quantitative surveys, the qualitative research methodology approach allowed us to capture and explain what is going on in real organizations.¹⁶ However, this approach also has some limitations. The qualitative interview approach with a focus on in-depth understanding means that the results are transferable through the readers’ own interpretations to other settings. Another limitation is that the study is based on a convenience sample of patients with some apparent interest in the EMRs, because they were engaged enough to volunteer to participate in the study. In spite of these limitations, we argue that the material and chosen methods
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are appropriate in the context of the study as they provide relevant in-depth insights into the cancer patients’ experiences and views of reading their EMRs.

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 EMR online, whereas in the second group (B) they had not used the service. Thirty patients (15 in each group) who had volunteered to participate in the study were contacted and subsequently interviewed by three researchers from the DOME project. The interviews were conducted in the patients’ homes or at the premises of the Department of Oncology at the Uppsala University Hospital. The cancer patients were under treatment during the period that the interviews were conducted. They were also in different stages of their cancer. Some of the patients were diagnosed with cancer recurrence and had been ill for a longer time. Others were newly diagnosed. Several of the patients suffered from advanced cancer and were given palliative treatment. The patients were in the age between 30 and 92 years. Among the 30 patients, 9 were men. The length of the interviews was 45–60 min. The semi-structured interview approach meant that in addition to predefined questions, the researchers asked spontaneous follow-up questions. The interviews were transcribed by a professional and then analyzed by four researchers from the DOME project. A question–answer matrix was produced on the basis of the transcribed interview data for an analysis on a question-to-question basis. Significant phrases and quotes were coded in a separate document that was used in a thematic analysis. The quotations presented in this article have been directly extracted from the interview texts. Some passages have been rephrased to make them easier to understand.

Findings

In the analysis of the interview material of the two groups (patients from groups A and B) emerged thematic categories of reasons for why patients want to access their online medical records and potential benefits of providing online access. These themes are described in the sections below.

Why patients want to access their online medical records

*Increased understanding of medical issues and increased sense of control.* Patients from group A emphasized that they want to read their health information because they want to learn more about their health condition. Patients also emphasized that they use the EMR in order to know whether they have understood the information from the physician correctly or not. Other patients emphasized that EMRs helped them feel more in control of their care. The feeling of control is thus achieved first when the patient is given access to test results and medical notes, regardless of whether the information is disturbing or not. The feeling of control is perceived as crucial for well-being. Hence, for some patients, access to the medical records has had an important and crucial role in the management of their disease.

*Accessing test results is crucial for well-being.* Patients from the interview group A reported that the ability to have direct access to clinical test results is one of the main reasons why they have chosen to read their EMR. The patients emphasized that the healthcare system is causing them considerable anxiety because they have to wait at least a couple of weeks and at the most a couple of months, before receiving the results of a laboratory test, such as a cancer diagnosis. It was also common that patients had to wait for additional days, or weeks, before receiving laboratory results from their physician. According to the patients, the delays have a negative impact on their health. Therefore,
those patients who have chosen to access their EMR argue that accessing their laboratory tests before being contacted by a doctor is a promising way to reduce anxiety and other unpleasant emotions related to waiting times. According to the interviewees, having to wait for laboratory results causes much more anxiety than accessing the results through the online medical record, even if the results would be alarming. One of the patients who read her EMR explains:

Accessing test results, it is a tremendous difference, and it really means a lot to me. To get the information at once so you do not have to wait. It’s so difficult to wait, whether it is bad or good news, it’s very good to know.

All patients from group B were positive about the possibility of reading medical records online and perceive it as an important tool to increase patient engagement. In all, 13 of the 15 patients were interested in reading their medical records in the future, including information that can be worrying. The remaining patients indicated a preference to first talk with the physician. Access to information and increased patient safety appears to be two important factors that create curiosity for online medical records. The study findings also show that 14 of the 15 patients from group A, in accordance with the patients from group B, want to access all types of information, including worrying information such as cancer diagnoses. These patients argue that “to be diagnosed with cancer is worrying no matter how you get that information.” Therefore, many of the patients want to decide themselves how they should receive that information, by talking to the physicians or by reading about it in the medical record. One of the patients explains:

I think the information that you have been diagnosed with cancer is worrying no matter how you get it. [...] I actually got my diagnosis by telephone, but it was my own choice that I got the information. I think that we should be free to choose how to get access to that information.

Another patient considers the following:

If we can manage to have all these cancer diseases and to live with it, then we can handle reading about it.

Two patients from group A have received their cancer diagnosis by reading about it in their EMR, and not from talking to their physician or nurse. This was a conscious choice made by these patients. One of the patients argues that “it is easier to break down at home where you are surrounded by family, than at the doctor’s office.” The other patient claims that she decided to be notified about the cancer diagnosis by reading about it in the EMR as this was much easier than having to wait for information from the physician. Thus, it seems that the patients experience more anxiety when having to wait for verbal information regarding laboratory results from their physician, then accessing the results through the online medical record, even if the results would be alarming. Some patients argue:

I’d rather sit and cry at home and fix myself in the head so I can get back on track, rather than having to sit in front of a doctor, shocked without the ability to ask questions.

For me it was good to read about my cancer diagnosis through the online medical record. It was more difficult having to wait for information.

I want to know even if it’s bad news. It does not get any easier just because you get the same information two days later verbally from a doctor or because someone says: “it is not so dangerous and so on.” No, I want clear answers.
Suspect inaccuracies. In contrast to the physicians’ predictions, few patients reported being worried, confused or offended by the notes they read. Only two patients reported that they have read their EMR because they suspected incorrect entries. In all, 6 of 15 patients who had individual experiences of accessing their EMR reported that they had found inaccuracies in their medical record, and none of them, however, had filed for a correction because they did not want to be a burden for the healthcare practitioners. Moreover, all the patients who had read their EMR emphasized that when medical notes raise concerns, they usually wait to ask questions until the next patient visit instead of calling a physician. This indicates that patients are both respectful of doctors’ time and resourceful in addressing questions that notes raise.

Moreover, the study findings show that 13 of 15 patients from group A have not become upset or offended after reading their medical records. When they had become upset, it was because they had found errors. However, as stated above, none of them considers the inaccuracies critical enough to require corrections. Moreover, three patients from group A argued that the access to the medical records have made the disease more evident and this has made them upset. However, they emphasize that it is not the e-Health service itself that contributed to these feelings, but the fact that they have been diagnosed with cancer. One of the patients explains: “I was upset about my cancer situation, but not for entering and reading my medical record.” Moreover, one of these three patients had made an active choice to refrain from reading the medical record. Another patient, however, argues that unpleasant feelings related to the disease also occur during the patient encounter when the physician gives upsetting information, such that the patient is suffering from terminal cancer. Therefore, unpleasant feelings are according to the patient not necessarily only related to situations in which patients read their online medical record.

The importance of being able to read the medical record

Better preparation for future visits. All patients from group A emphasize that access to medical records enables them to become better prepared for their doctor visits. For example, patients from group A argue that access to the medical record prepared them for the upcoming visit. The patients prepared their doctor visits by writing down questions. It seems that those patients who prepared themselves and asked questions become more actively engaged in their healthcare and were more satisfied with the patient encounter. A patient tells the following:

> When you are visiting the doctor you get quite blocked. You can’t remember. Here I have the opportunity based on what I read in my medical record to write down the questions I want to ask my doctor otherwise I might not think of them during the meeting.

All patients from group B also believe that access to their online medical records can help them to prepare for a doctor’s visit.

Physician–patient relationship. In all, 3 of the 15 patients from group A felt that the preparation for future visits brought a number of other benefits, including improved physician–patient communication and increased appreciation of the physician’s skill. According to these patients, being prepared for a doctor’s visit contributes to more efficient communication and dialog between patient and doctor, which, in turn, seems to affect the physician–patient relationship positive. Only one of the patients, however, felt that their trust for the physician has decreased after having identified inaccuracies in the record. The remaining 11 patients do not believe that the record has affected their physician–patient relationship. Another patient stresses that the preparations have enhanced the shared decision-making with her doctor.
One interesting observation is that patients from group B argue that they have a good relationship with their physician and that they receive the information they need. This is according to the patients’ one of the main reasons for why they currently do not want to access their EMR.

Another interesting observation is that patients from both groups, A and B, explained that healthcare practitioners have not informed them about the opportunity to read their medical records online. Instead, many of them have received information about the e-service through newspapers.

**Aiding memory.** Most patients from group A and B reported that the medical record could work as an important memory aid. Some patients from group A emphasized that it is difficult to remember all the information that was conveyed during the patient encounter. Therefore, they liked having the medical record available as a reminder before and after doctor visits. Having easy access to information about personal health when and where it is needed also seems to increase the patients’ feeling of safety:

I think you get a much better mental preparation when you have the opportunity to return to your medical record instead of just relying everything on these occasional doctor visits that are so short and so confusing sometimes.

I’m curious about my case and I think it is good to have something to go back to. When you talk to a doctor, you will not always remember everything, therefore it can be good to be able to go back to the medical records.”

**Improved access to information when and where it is needed.** All patients from group A emphasized that having access to medical records helps them receive information in a timely manner. Particularly, the availability of information regarding test results is considered to be crucial. Also, the patients from group B emphasize that access to the medical record may improve access to information when and where it is needed.

Furthermore, 14 of 15 patients from group A argue that medical information such as test results should be made available to the patient the minute they are available for the healthcare practitioners. They also argue that delays of publishing medical notes are more acceptable than the delay in providing access to test results. However, they argue that the delay of publishing medical notes should be no longer than 3 days. One patient from group A and two from group B do not want to take part of the test results through the EMR before they have spoken to the physician.

**Learning more about their medical issues.** Patients from group A reported that access to their medical records helped them understand their medical issues. Especially, by reviewing the records, they have learned more about how and when the cancer started, what treatment they have received and why and what is planned for the future. They appreciated being able to keep track of the progress of their cancer and the therapies they have received. Another patient appreciates that she is able to learn more about her medical issue in “peace and quiet” when reviewing the record. The patient argues: “I want to be able to understand my illness a little better in silence.”

Moreover, patients from group A found some parts of the medical records difficult to understand. This is, however, not perceived as a major problem as the patients believe that they still have a comprehensive understanding of the content. They also argue that the understanding of the content is facilitated by the fact that they usually read their EMR after a patient visit. When the content of the medical records is not understood, 13 of 15 patients use the Internet to find information and receive answers to their questions. In some cases, the patients turn to relatives and friends who have some form of healthcare professional background. Two patients mentioned that they used
other sources such as dictionaries. An interesting observation is that patients did not tend to take any additional contacts with their healthcare providers to ask questions. If the patient is unable to answer their questions by using the Internet or by asking relatives and friends, they wait until the next doctor visit.

**Security and privacy.** The majority of the patients from group A believe that the e-Health service is reliable and find the security satisfactory. Only one patient expressed concerns that unauthorized individuals can share the information in her EMR. Since the service has been implemented with an equivalent level of security to Internet banking, most of the patients believe that this service is not less insecure than any other national e-services. There is also an underlying expectation that these services maintain a high level of security.

I assume that the security is very high. If not, then it should not be available to patients. It must be 110% secure so that no one but me, and those who are authorized can access and read the information.

Similar to patients in group A, patients in group B expect that the level of security of the online service is high. Only one patient expressed concerns that the security might not hold the required levels and also perceives his or her own information as sensitive. In spite of the isolated concerns, the respondent from both groups, A and B, shares an attitude that their health information is not interesting for others. One patient argues: “There are no secrets in my records and it does not bother me at all if anyone else sees my records.” One patient from group B is, however, concerned about unauthorized access. The patient believes that it is important to protect the privacy of individual patients and have confidence that healthcare practitioners care for protecting it.

As presented previously, when patients access their EMR, they are required to answer a question regarding what kind of information they want to access. A warning is hence displayed regarding sensitive/worrying information. In all, 13 of 15 patients had noted the warning during the login process. Some patients even experience the warning as silly as having to answer the same question at every login is perceived as frustrating.

Moreover, only one patient has chosen to share the medical records with a family member. The patient perceives the function to be important; however, from the study one can conclude that it is seldom used. Other patients argue that they do not share their medical records as they usually read their EMR together with family members. Patients from group B have similar views as patients from group B regarding this functionality. More than half of the patients are positive to the technical possibility to share their medical records with family and friends, while others believe that they want to keep the access for themselves. Those who are positive believe that it can be useful to share the records when one is old and sick. Allowing relatives to read the EMR seems to be a way for patients to involve them in their care, and consequently to increase relatives’ engagement.

**Discussion and future work**

Accessing medical records is a controversial issue. When medical records were made accessible online for patients in Uppsala, it raised discussions and concerns of security and ethics, both in the media and among healthcare practitioners at hospitals in the region. Many worried about the workload of the healthcare practitioners and about how patients would handle the information. One of the prominent aspects of concern was that cancer patients would be accessing test results and medical notes without being able to discuss with healthcare practitioners on possible upsetting matters right away. The possibility to receive a cancer diagnosis online was seen as especially problematic. However, little was known about why cancer patients want to read their own medical records and
how they manage their personal health information. The results from this study deepen our understanding of cancer patients’ attitudes and experiences of online medical records. Similar to earlier research, the study results confirm that online access can help patients prepare for doctor visits, which, in turn, seems to improve the communication with practitioners. It can also help patients learn more about and understand their medical issues. An interesting aspect of the results is that the study participants had not experienced the negative aspects of online access anticipated by physicians. For example, in contrast to fears of many physicians, online access to medical records did not generate substantial anxiety, concerns or increased phone calls. In accordance with this research, it seems that patients are more respectful of doctors’ time in addressing questions that the medical records raise 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. The study findings support the urges that it is crucial to include the patients’ perspective in the development of e-Health services, since they have experiences and opinions unknown for healthcare practitioners. Another interpretation of the results is that the healthcare sector needs to consider patients as a heterogeneous group of people, who have different needs and habits. Access to medical records is appropriate and possibly beneficial for some patients but not for all. Therefore, there is a need to consider and respect the differences between individuals and develop e-Health services that are based on the needs of the individuals. Therefore, it may be relevant to identify the characteristics of those patients who experience anxiety and to determine which patients are and are not suited for comprehensive information through e-Health services. Moreover, when it comes to security and privacy issues, there are two important reasons why patients do not seem to be worried about unauthorized access to medical records: (1) patients expect that the e-Health service has a high level of security and (2) patients perceive their own information as non-sensitive. Despite the fact that their own information is not deemed sensitive, there is a recognizable expectation among patients that their patient information should only be made available to authorized healthcare practitioners.

Because of the limitations of this study, it is not possible to reach definitive conclusions about the outcomes discussed above. Further qualitative research with a larger sample size regarding patients’ access (both seriously ill patients and other patient groups) to the EMR is needed. This study is, however a step toward that direction. Future research should also focus on studying in what way the information can be adapted and improved so that patients who want can become more involved gain increased knowledge and gain better control over their own healthcare, that is, to become empowered. In addition, there is a need for further research on the development of related e-Health services and on the premises and methods for facilitating improved and secure communication between patients and healthcare.

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Supporting Active Patient and Health Care Collaboration: A Prototype for Future Health Care Information Systems

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Abstract
This article presents and illustrates the main features of a proposed process-oriented approach for patient information distribution in future health care information systems, by using a prototype of a process support system. The development of the prototype was based on the Visuera method, which includes five defined steps. The results indicate that a visualized prototype is a suitable tool for illustrating both the opportunities and constraints of future ideas and solutions in e-Health. The main challenges for developing and implementing a fully functional process support system concern both technical and organizational/management aspects.

Keywords
e-health services, patient-centred care, process-oriented approach, process support systems, prototype development

Introduction
Health care processes are characterized by their high complexity and the large amount of data they have to manage. To provide high-quality care, health care processes require cooperation among different organizational units and medical disciplines, as well as their cooperation with patients. Process orientation is therefore crucial. However, despite its widespread adoption in industry, the process-oriented approach, with supporting information systems (IS), is not widely used in health care.1,2 Instead, organizations typically have their own autonomous IS that support...
internal processes. These types of systems usually work well for the single unit but do not support inter-institutional cooperation and, hence, cause delivery of suboptimal care. Furthermore, the needs of patients tend to be neglected in these systems. Taking a process-oriented approach can streamline the flow of information and ensure that information is available where and when it is needed. Sharing information that is of high quality efficiently is a fundamental part of an integrated health care system.

IS have enormous potential to improve the quality of health care, in terms of safety, effectiveness and efficiency. They also have the potential to make care patient-centred. However, present IS do not yield the expected positive effects. The current situation regarding the availability of IS that support patient-centred health care is still far from satisfactory. Often, different care providers are involved in the care of one patient, which requires collaboration for a successful treatment outcome. A key issue in supporting collaboration is the need for information sharing between different care providers. However, for a long time, there have been concerns that the communication between health care professionals, regarding co-treated patients, has been delayed, incomplete or erroneous. There are numerous examples of health-related injuries that are caused by the deficient exchange of information between different actors in the care process. Furthermore, communication between patients and health care providers has major shortcomings.

Today, shared patient information is hampered by the existence of numerous IS, so-called stovepipe solutions. Another important factor is the decentralized health care system. In addition, decentralization hinders solutions that take a holistic approach to the problem, from a patient perspective. Furthermore, current IS cause a suboptimal consumption of health care resources and force the patient to act as a ‘carrier’ of their health care information. To achieve a seamless and secure transfer of information between care providers, a more process-oriented approach, with supporting IS, must be considered. A process-oriented approach is an important foundation for achieving a system design that focuses on the care process from the patient’s perspective and thereby sets the patient process in focus. The patient process is defined in Åhlfeldt and Söderström as the process that follows the patient during an event of illness. During this process, important patient information must follow the patient in order to ensure good quality care. The process-oriented approach can streamline the flow of information and ensure that health care professionals work with the right tasks in the different parts of the health care process as well as always have access to the right patient information when they need it. Having access to patient information at the right time is crucial for providing the best possible care. However, for information to be a usable and useful resource in the long term, it must have a uniform, nationally established structure, hence, be placed under a common regulatory framework. (For information technology (IT) systems to manage and exchange information, the information must have a nationally defined and consistent information structure. This allows IS to more effectively and efficiently manage and exchange information. A unified national information structure is thus based on a standardized use of terms, concepts and classifications. This is an important prerequisite for both patient safety and follow-up care.) This will allow different IS to manage and exchange information more efficiently and securely. Furthermore, patient safety and the ability to follow up on care activities are contingent on a uniform information structure based on established terminologies and classifications. Structured information and standardized terms and concepts will also facilitate transparent audits and comparisons between health care processes and outcomes, as well as provide support data for quality development. Furthermore, the Ministry of Health and Social Affairs emphasizes that future IS need to support, involve, motivate and empower individuals/patients by enabling greater accessibility to health care and social services. This provides the prerequisites for empowerment and self-determination and strengthens individuals’ perceived benefit, participation and insight into the interventions that concern them.
The aim of this article is to present and illustrate the main features of a proposed process-oriented approach for patient information distribution in health care, by using a prototype. The remainder of this article is organized as follows. Section ‘Research approach’ describes the research approach. Section ‘Key principles for a future IS’, discusses the key principles for developing the prototype, while section ‘Results and print screen examples’ presents the resulting prototype. Section ‘Discussion’, discusses the results and, finally, some concluding remarks are stated in section ‘Concluding remarks’.

**Research approach**

The prototype presented in this article is a result of a research project, Future Healthcare Information Systems (FHIS). The aim of the project was to develop a visualization of a process support system (PSS) that demonstrate the requirements for future process-oriented IS support in health care. The PSS was developed in close collaboration between researchers and practitioners in the Region of Västra Götaland in Sweden.

Since the overall health care process is extremely complex and demanding, to tackle it all within one project would clearly not be feasible. Therefore, one of the first tasks of the project was to select a suitable sub-process for the work to focus on. Some criteria used for the selection included that the chosen sub-process should

- be one in which the patient can play a truly active role,
- be relevant for more than one level of care (primary care, hospital care and municipal home care), in order to demonstrate general applicability,
- be relevant for more than one health care profession,
- be complex enough, particularly in terms of information flow, to demonstrate a substantial difference between the existing way of working and the proposed future way of working,
- be used often enough for the changed way of working to have a substantial impact on both health care professionals and patients.

The project selected the process of initiating, planning, carrying out and following up a patient’s visit to a health care provider. This process was termed ‘Patient Visit’ and was limited by involving only ambulatory care. It is a process which occurs frequently and exists in both 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. In addition, the chosen process was also suitable to demonstrate the intricacies of the communication between a patient and health care providers. In order to make the demonstrator concrete and illustrative, two scenarios of the ‘Patient Visit’ process were chosen for implementation (see section ‘Results and print screen examples’).

Firstly, a current state analysis was conducted, involving both health care professionals and patients. The main research activities included observations of patient visits; interviews with health care professionals, health care administrators, patients and patient organizations, as well as workshops involving professionals from a broad range of disciplines.

Following the current state analysis, earlier research results mentioned above and in conjunction with the results from the workshops, a number of goals were identified for the future state: increased access to information, both from professionals’ and patients’ perspective, increased coordination of both clinical and administrative information based on the patient process, a holistic approach based on the patient’s perspective, increased patient involvement, and improved quality of care.
Based on the assessment of the current situation and As-Is process models, work began by sketching the proposed future state (To-Be models). First, the overview of the general patient visit was elaborated, in order to identify the sub-processes and information flows involved. Then, process models of the different sub-processes, comprising activities, roles and information flows, were created. An important part of this work was to identify the detailed contents of the information needed for the various activities in the process models. The information content was sketched in forms using the Visuera Business Process Modeler 2007 tool. Process models and information content were validated by various professionals from both primary care and specialist care in workshops, brainstorming sessions seminars and lectures, which also took patient input into account. Key design principles were identified and after a number of iterations, to ensure the quality of processes and information content, a prototype of a PSS was developed to visualize the key principles.

Finally, the resulting prototype (see section ‘Discussion’) was evaluated in relation to user requirements identified through observations, workshops and interviews. In addition to this, identified user needs were also evaluated in relation to the Swedish national strategy for e-health and in seminars involving health care professionals, patients and IS providers.

The choice of which health care providers to involve in the development and evaluation of the PSS was partly governed by the fact that the research project was commissioned by Region Västra Götaland. They chose the sub-region on which the main portion of the research was to focus. In addition, the researchers chose to involve a convenient sample of other referenced health care providers and patient organizations, based on the researchers’ existing contacts in the region. Within the respective organizations, the involved individual stakeholders were selected to reflect a broad spectrum of stakeholder perspectives. In the evaluation phase, the circle of involved stakeholders was widened to also include the national perspective. For example, feedback was collected during the main Swedish professional conference and exhibition on health care and IT.

The approach used for modelling the chosen process and for prototype development was the Visuera method, chosen for the following reasons:

- The Visuera method is a process modelling approach that enables the modelling 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 the concepts used in the process. Since the general focus of our research is to enhance the support that information can provide to health care processes, this was considered an important feature.
- It is fairly easy for non-experts to understand the models produced with the method. Since an important part of the work was for health care professionals to 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 related information flows and ‘translate’ it into simulation/demonstrator of how a system will work and how it will look, without actually implementing the system. Since the objective was to develop a demonstrator, it was a reasonable choice.
- The researchers in the project had previous experience with the method and its supporting tool.

The method contains five steps:

1. **Analysing 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 performed manually.
   (ii) Removing manual or automated tasks with no significance for activities later on in the process.
   (iii) Improving the quality of activities in the process.
   (iv) Making sure that the end result of all the activities has 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 supporting IS if technological change is necessary, based on To-Be process models.

4. **Deploying the new process and IS.** In this step, employees affected by the IS are educated.

5. 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. The process models can be abstracted or detailed into an unlimited number of levels. The prototype, presented in this article, acquired all of its sample data and flow logic directly from the process model.

**Key principles for a future IS**

**Overall architecture of PSS**

The vision for PSS is that health care providers and patients should have access to effective collaborative IS that supports process-oriented care in which the patient is a distinct and active collaborator. This means that

- Appropriate parts of the PSS are available to both patients and professionals taking into account usability for different user groups.
- Involved roles interact through the PSS. The underlying approach is process oriented.
- Various, relevant individual IS interacts with patients and professionals through the PSS.

The PSS may be viewed as a layer of abstraction or user interface above the various individual IS, enabling enactment of the process and interaction between patients and professionals through computers and mobile devices, without accessing each individual system. The PSS drives the process forward ensuring that it is carried out properly and, hence, supports the users in their work. The PSS also provides a user interface to the various systems involved in performing a task. The principle is described in Figures 1 and 2.

Furthermore, this architecture makes it possible, at least in theory, to replace individual IT systems without necessarily significantly affecting the user.

The PSS connects the following aspects:

- Relevant patient information, both medical and administrative.
- Process control providing integrated support for the user.
Figure 1. The principle of the PSS (adapted from Perjons et al.14).

Figure 2. Communication between user, PSS and IS (adapted from Visuera Integration AB20).
• Medical knowledge through integrated links to internal and external sources of medical knowledge and other kinds of decision support.

In the PSS, process data can be collected, regarding how each instance of the process is executed. This enables various types of quantitative evaluation of processes, for instance, the waiting time between activities can be traced in order to identify bottlenecks.

**Key design principles for PSS**

This section describes the key design principles for PSS and how they are related and implemented in the PSS.

**The patient process in focus.** Due to the lack of a holistic approach from the patient’s perspective, for example, information that does not follow the patient satisfactorily between health care providers, the PSS has been designed to follow the patient’s path through the health care system. This is visualized by showing how the patient sends an own care request to primary care, participates in an appointment in primary care, is referred to specialist care and participates in an appointment in specialist care.

Another important key principle was to include both medical information (e.g. medical record, lab-response, drug list) and administrative information (e.g. appointments) in the PSS, following the idea that all information needed by patients and professionals when preparing for and carrying out an appointment should be at hand, regardless of whether it is medical or administrative. Medical and administrative information is currently often separated in different systems.

When the patient leaves the consultation room, it is not always easy to remember what was decided during the visit. Often the patient goes directly to the nurses in the waiting room and asks, ‘What did the doctor say?’ Therefore, the PSS enables the physician to briefly document the patient’s disease and the medical actions taken for the patient. This can be in paper or electronic form. In the latter case, it can be accessed later through the patient view in the PSS.

**Shared goal for the patient visit.** To overcome the lack of a common vision for the patient visit, the PSS provides an opportunity for patients to state their expectations beforehand. It is important to emphasize that just because the patient indicates his/her expectations it does not mean that they will be fulfilled. Instead, the aim is that the patient’s expectations should be made clear to the professional involved so that the expectations can be addressed and discussed.

**PSS is based on standardized information.** Having the right information when it is needed is a challenge in the health care context. To make this possible, it is essential that the information is standardized and structured. In order to achieve this in the PSS, the information content of the national quality registers for selected diagnoses has been used. The types of information stored in quality registers have been transformed into checklists for each diagnosis. A further challenge was to provide the correct information for each level of care.

**Efficient information flows.** Using a process-oriented approach, the information flow can be more efficient. The PSS can ensure that patients and professionals carry out the appropriate activities in different parts of the process. The challenge here is to define, in today’s decentralized health care, which health care provider should be responsible for which activity and what information should be provided to the PSS.
Furthermore, it is important to ensure that certain necessary information sets are completed. The PSS should ensure that such information is not omitted.

A major advantage of a process-oriented approach and tools to support the process is that the PSS drives the process forward. When a task is completed, it will initiate and show nearby activities. For example, when the professionals in specialist care have written and signed the final documentation for the patient record, PSS automatically picks up the form ‘response to care request’ that will be sent back to primary care.

The right information at the right time, in the right place and for the right person is a vision strongly related to patient safety. By using the PSS that drives the process forward to the right person (predefined roles), place (e.g. the right level of care) and time (no unnecessary intermediate storage or manual handling), while the right information (standardized checklists designed according to the national quality register) follows throughout the whole process, a more efficient information flow can be achieved. Another consequence of the above approach is that it minimizes duplication of documentation. Already registered information comes with the whole process and does not need to be entered again.

**Digital booking and coordination of patient treatments and examinations.** In the PSS, it is possible to book treatments and tests and to see the status of these activities. When, for example, a plan is made for a hip osteoarthritis patient, the PSS provides support for prioritization using checklists showing obligatory and recommended treatments/tests. Furthermore, another care provider in the process should be able to view made orders including the status. If some activities, such as lab tests, are not completed before the scheduled visit, they can be cancelled in advance. This saves the patient the inconvenience of coming to the consultation and then being sent home.

**Enhanced security.** In the current version of the PSS, no specific technical security solutions are implemented. Instead, it is based on the assumption that the current national system for secure identification and access controls, including existing and secure infrastructure platforms, has been implemented. Implementation of national security solutions is required for systems that deal with information which follows the patient in his/her care process. Otherwise, they will not operate under existing laws and regulations. However, patient safety is further improved when information management is controlled by a PSS in a standardized manner. The PSS can, based on the information content, ensure that sensitive information is not disclosed.

**Increased coordination with secure infrastructure.** Another step towards improving security, and also towards increasing the coordination between different health care organizations, is the outlined integration with national solutions, such as the National Patient Summary (NPS), which contains excerpts from patient records kept by different health care providers. In the patient’s view of the PSS, the patient can access their own NPS. It is also possible for both professionals and patients to access NPS in their PSS views.

**Results and print screen examples**

This section describes the resulting PSS.

**PSS design**

To clarify the future PSS function and usage, two scenarios were designed: one for a hip osteoarthritis patient and one for an angina patient. In both scenarios, the patient first seeks admission to
the primary health care centre, after which he/she is referred to specialist care with a following visit. This means that each scenario implements two patient visits, one at the primary care and one at specialist care. Sending and planning the ‘care request’ precede both visits. The scenarios were developed in collaboration with doctors and nurses at a local hospital in the Region of Västra Götaland in Sweden.

**Hip osteoarthritis scenario**

The hip osteoarthritis scenario concerns a 55-year-old man who has been a sportsperson for many years and has accumulated pain for a long time. The patient cannot currently play tennis due to hip pain. In addition, he is self-employed and does not want to be on sick leave for long periods.

**Angina pectoris scenario**

The angina pectoris scenario concerns a 67-year-old man, a former mechanic who is married and has two children. He has worked for 43 years and has taken early retirement for labour market reasons. The patient has previously been treated for chest pain and takes medicine for high blood pressure.

**Views for different roles in the future state process**

There are three general views in the PSS, representing the main roles in the target process: the Patient View, the Care Planner View and the Patient Visit Leader View. Patient Visit Leader is defined as the professional (e.g. doctor or nurse) who is responsible for the patient visit. Care Planner is defined as the professional (e.g. nurse or secretary) who prioritizes patients and plans the upcoming visit. These views are repeated in both primary care and specialist care.

**Patient View**

The Patient View (Figure 3) should be accessed through a national health portal. The idea is that the patient logs in with secure identification and strong authentication mechanisms using national solutions for secure infrastructure. Patients also have the option to upload their profile. In the upper part of the view to the left, credentials showing the patient’s name and social security number are presented. To the right, a direct link to the NPS in which the patient can see the nationally stored patient information, as well as an entrance for creating a new care request, has been made available. The process starts by creating a care request and selecting the care unit. An inbox with unread and untreated messages is found in the left part of the view. There is also storage provision for processed messages. In the middle of the view, there is a message box where the patient receives the messages displayed. In the lower part of the view, there is a task management field which allows the patient to see his/her upcoming visits as well as history from completed ones. The field of active cases are colour coded. Yellow illustrates waiting, for example, for an upcoming visit (Figure 3). This indicates that more information will be given, for example, confirmation of the appointment. Red illustrates action – the patient should give some response, for example, fill in a health declaration. Green illustrates that the visit is ready to be carried out – all necessary planning and information gathering has been completed before the patient visit. Figure 3 shows a picture of the Patient View in which the patient, Tommy Johansson, is logged. He has made two visits, one at the health care centre in Lerum and one at the orthopaedic clinic at a local hospital. The message field displays information from the last visit. The digital documentation that Tommy asked for is
now available in the message field. The upcoming visit field shows that Tommy has a surgical appointment. This field is also highlighted in yellow, indicating that further information to the patient about the surgery will come later.

**Care Planner View and Patient Visit Leader View**

The layout of the Care Planner View and Patient Visit Leader View is basically the same as in the Patient View, but in a simpler form. The upper left part of the view shows the credentials of the person who is logged on. In the PSS, only the roles of care planners and patient visit leader are implemented. The left part of the view contains an inbox with unread read and untreated messages. Processed messages can also be accessed. In the middle of the view, there is a message box which displays received messages.

**Snapshot of the patient’s ‘care request’**

Figure 4 illustrates how the PSS, in this case the ‘own care request’, is based on standardized checklists designed from national quality registers.

When the patient fills in the symptom/disease, for example, hip pain, the patient is requested to provide specific information related to the hip pain, depending on his/her situation and reality. When the patient has submitted the ‘own care request’ to primary care for further planning, the role of Care Planner checks the information and plans for further actions. This information then follows the patient throughout the entire care process, regardless of the level of health care organizations.
involved in the patient process. It should be noted that only health professionals involved in the patient’s care have access to the information.

A more detailed description of each part of the patient visit process, primary and specialist care follows.

**Part 1: primary care.** The process begins when the patient from the PSS patient view electronically fills in his/her ‘own care request’ and forwards it to primary care. At primary care, the ‘own care request’ is planned and prioritized by the role of Care Planner. A confirmation is then sent back to the patient who is prompted to complete the health declaration for the upcoming primary visit. Patients can also fill in their expectations for the visit. The patient subsequently enters the health care centre and the patient visit starts. The role of Patient Visit Leader, that is, the professional (e.g. doctor or nurse) that meets with the patient, has had the opportunity to access information about
upcoming visits in the Patient Visit Leader view of the PSS and can there see clearly which patients are ready for their visit. The Patient Visit Leader can also access the patient’s ‘own care request’, the submitted health declaration and any expectations that the patient has stated.

During the patient visit, the Patient Visit Leader concludes that the patient needs to be referred to the next level of care, which in these scenarios is specialist care. The Patient Visit Leader therefore completes, in the PSS, a care request (referral) to specialist care, and assesses what other measures should be taken. Thereafter, documentation is provided to the patient digitally through the PSS Patient View or in written form. It is also possible for the Patient Visit Leader to begin documentation during the visit through the Patient Visit Leader View of the PSS. Thereafter, the patient visit is concluded and documentation in the patient’s health record is completed and signed. The information is transferred automatically to the underlying individual IS (Figure 1).

When the patient comes home, he/she may access his/her patient record via the Patient View of the PSS. Information about upcoming visits and treatments can also be accessed from the Patient View.

**Part 2: specialist care.** At specialist care, the care request is planned and prioritized. Confirmation of the date for the visit is then sent to the patient, together with necessary information about the patient’s condition, through the Patient View. Also, a new health declaration, targeting the specific information that specialist care needs, is made available to the patient through the Patient View. The patient completes the health declaration which is then made available to specialist care through the Care Planner View.

The Patient Visit Leader may in his/her view see upcoming visits, whether the patient is ready for the visit, and access available information about the patient. When the patient arrives for the visit, health related actions to be initiated are considered. The Patient Visit Leader will also continue the process by documenting in the patient record via the PSS and write the documentation that is provided to the patient. As the patient visit ends, the documentation is finalized by the Patient Visit Leader who chooses whether to dictate the note using noted information as a support or to write the additional information directly in the PSS. The next step in the process is to verify and sign the documentation. Thereafter, the Patient Visit Leader writes a ‘care request response’, which is sent via the PSS back to the health care unit that originally sent the request for care in this case the primary care.

**Discussion**

The following aspects are linked together in the PSS:

- Relevant patient information, both medical and administrative.
- Process control providing integrated support for the user.
- Medical knowledge through integrated links to internal and external sources and other kinds of decision support.

In the PSS, so-called process data collected about each instance of the process is executed. This provides opportunities for different types of a more quantitative follow-up. For example, waiting times between different activities can be followed up to identify bottlenecks.

Much work remains before the above presented suggested principles for a PSS can be fully implemented. We have identified the following main challenges for developing a fully functioning PSS.
The interfaces between PSS and the underlying IT systems need to be developed

The PSS requires standardized information exchange between individual IT systems and the PSS. Perhaps the biggest challenge is that concepts used are frequently defined and written in different formats in different systems. This is particularly difficult for key concepts. One example is the social security number that is sometimes written in different ways in the existing systems. It is not just a question of how this is technically possible, it is also a question of information quality. Poor information quality causes unnecessary risks for the patient.

PSS usability for the patients, need to be secured

In the PSS, certain documentation is made available to the patient after the visit. This means that documentation in the patient record will have a new, more communicative role in the patient process. One challenge will then be to ensure that the patient is able to assimilate the information. This relates to the fact that patients perceive problems in communication with health care, in terms of language barriers.\(^4\)

Inclusion of all patients in using the PSS

The question whether all patients can be expected to make use of a computerized solution for communication with health care has been raised during the validation. It is worth noting that this has never been the purpose in the design of PSS. Since patients have different requirements and conditions for communicating with health care, several options must be available to patients. However, from a patient perspective, there are considerable benefits in having a secure, computerized channel of communication.

Cross-organizational responsibility for managing the PSS

Besides detailing how the various design principles can be implemented efficiently in the PSS, development and further research must, above all, be carried out in terms of ownership and responsibility of a PSS that crosses organizational boundaries and supports patient-centred care. For example, who owns all the process data generated in the PSS, who takes responsibility for the quality of the process data, who will be the process owner of the entire patient process? If the technical challenges can be solved, this will be the biggest challenge for implementing the PSS.

Concluding remarks

This article has presented a prototype that visualizes the future of information management as a solution to the problems identified in earlier research. However, we can conclude that a visualized prototype is a suitable tool to illustrate both the opportunities and constraints of future ideas and solutions. Nevertheless further research is clearly needed, particularly addressing the identified challenges, for instance, the responsibility for PSS, that cross health care organizational boundaries, the ownership of process data and the quality of information flows both for professionals and patients.

Health care information management is a complex task which forces IS to be able to manage this complexity. Reliable health care information is also an important condition for obtaining high-quality care. Therefore, future IS need to support both patients and professionals in carrying out their respective roles. This requires that health care IS are more process oriented from the perspective of
the patient process, structured, standardized and, above all, are more patient-centred. A PSS, as proposed in this article, is one step towards that direction.

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PROCESS ORIENTED INFORMATION SYSTEMS – A KEY TO EVIDENCE BASED MEDICINE

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ABSTRACT
The primary and basic component of healthcare is information. Being a healthcare practitioner involves using medical knowledge and patient information to deliver the best possible care. When decisions about the care of the patient are made they must as far as possible be based on research-derived evidence rather than on clinical skills and experience alone. This decision process is complex as evidence is infrequently available in a form that can be acted upon at the time decisions must be made. The aim of this paper is to present and illustrate how a prototype visualization of a process support system can support the availability of relevant medical knowledge in a way which seamlessly integrates with healthcare practitioners work practice, and thereby enables healthcare practitioners to work in accordance with EBM. An important conclusion from this research is that a process support as the one described in this paper can reshape the practice of EBM.

KEYWORDS
Medical guidelines; Medical decision support; Process Support Systems; Process Oriented Approach; Knowledge Management Systems; Evidence Based Medicine.

1. INTRODUCTION
Delivering good quality care is a complex endeavor that is highly dependent on patient information and medical knowledge (Bose, 2003; Rezazadeh et al., 2014). When decisions about the care of a patient are made, they must, as far as possible, be based on research-derived evidence rather than on clinical skills and experience alone. Evidence based medicine (EBM) is the conscientious and judicious use of current best medical evidence in conjunction with clinical expertise as well as patient values and preferences to guide healthcare decisions, see figure 1.1 (Sackett et al., 1996; Sackett et al., 2000). Clinical expertise refers to the practitioner’s cumulated experience, education and clinical skills that the individual acquires through clinical experience and clinical practice. The patient brings to the encounter his or her own personal preferences and unique concerns, expectations, and
values that 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., 2000). The purpose of EBM is to provide a stronger scientific foundation for clinical work, in order to achieve consistency, quality, and safety in care (Timmermans & Mauck, 2005). The evidence based medical knowledge does not, by itself, make the decision, but it can help support the practitioner in the decision-making.

Following the principles of EBM, practitioners are required to formulate clinical questions based on the understanding of the patient’s clinical condition. The patient’s condition can be understood by the past and present diagnosis, as well as laboratory and administrative data (El-Gayar & Timsina, 2014). After the patient’s condition has been identified and synthesized into clinical questions, the practitioner proceeds with the search of the literature for answers, evaluates the evidence for its validity and usefulness, and finally applies the information to patients (Lenz & Reichert, 2007; Mayer, 2009). The degree to which the clinician can practice EBM is thus dependent upon the availability of information about the patient (such as diagnosis, prognosis and therapy) and medical knowledge (such as medical guidelines). Patient information is a precondition for medical decisions and it is evidence based medical knowledge, clinical expertise as well as patient values and preferences that guide these decisions. The full integration of these components into clinical decisions enhances the opportunity for improved quality and safety of care.

Nevertheless, practicing EBM is challenging. One reason is the lack of information systems (IS) that support a seamless flow of patient information (both medical and administrative information) along the care process. This is highly disturbing, since the traditional single, doctor-patient relationship is increasingly being replaced by one in which the patient is managed by a team of healthcare practitioners, each specializing in one aspect of care (Bose, 2003, p. 61). Such seamless and shared care critically depends on collaboration and the ability to easily share information between healthcare providers (Iroju et al., 2013; Bose, 2003). Collaboration between healthcare providers and the patient is also essential in ensuring the proper delivery of the most appropriate care, since both parties share vital information. The healthcare practitioner offers evidence based treatment options, as well as their risks and benefits, while the patient offers his/her experience of the medical condition, values and expectations (Oshima Lee & Emanuel, 2013). Considering and incorporating the values, preferences, needs and experiences of patients in, e.g., treatment plans are important for the practice of EBM and crucial for the engagement of the patient in the decision-making. EBM is also almost impossible to practice in the everyday clinical care, as healthcare practitioners typically do not have the time to carry out literature research while the patient is in the office as medical knowledge e.g., medical guidelines and systematic reviews, are not integrated within electronic healthcare records (EHR). Therefore, literature searches will necessarily take place offline (Lenz & Reichert, 2007). Those practitioners who search for medical knowledge during the patient encounter all too often find that existing knowledge may not necessarily correspond to the issue at hand (Clancy & Cronin, 2005). Some healthcare practitioners may even decide not to actively look for the required medical knowledge because textbooks, journals, and other existing information tools are not adequate for answering the questions that arise; textbooks are out of date, information in journals is too difficult, if impossible, to translate into daily work practice and current information systems (IS) solutions such as IT-based knowledge repositories are not widely used because they have not been developed to meet practitioners knowledge needs (Smith, 1996; Krasniqi & Persson, 2012).
The situation with absence of patient information and medical knowledge is untenable as the practice of EBM depends critically on the collection, seamless exchange, and utilization of information and knowledge within and across the organizational boundaries. Iroju et al., (2013) even argue that lack of interoperability amongst healthcare systems have resulted in increased healthcare cost and declining quality of patient care. Moreover, Lenz and Reichert (2007) and Iroju et al., (2013) argue that the treatment of the patient can be improved by selectively providing patient information and relevant medical knowledge according to the current context, and to support all of this in a way which seamlessly integrates with the practitioners work practice. However, current IS solutions are far away from this perspective. To achieve seamless and secure information transfer between care providers and access to relevant medical knowledge a more process-oriented approach, with supporting IT systems, must be considered. A process-oriented approach is an important foundation to achieve a system design that focuses on the care process from the patient's perspective and thereby sets the patient process in focus. This approach can streamline the flow of patient information and medical knowledge, and ensure that healthcare practitioners work according to EBM. Therefore, the aim of this paper is to present and illustrate how a prototype visualization of a process support system (PSS) can support the availability of relevant medical knowledge in a way which seamlessly integrates with healthcare practitioners work practice, and thereby enables healthcare practitioners to work in accordance with EBM. The PSS was originally developed during a research project named Future Healthcare Information Systems (FHIS) and illustrates the main features of a proposed process oriented approach for patient information distribution in future healthcare information systems. The key principles of the PSS have been presented in the paper by Åhlfeldt, Persson, Krasniqi and Wåhlander (2013), where the patient perspective is taken into account. However, since the original PSS only to a certain extent manages medical knowledge, the PSS, for the purpose of this paper, will be further modified to also visualize how such a system can improve the availability of relevant medical knowledge, and thereby support healthcare practitioners to work in accordance with EBM.

The remainder of this paper is organized as follows. In section 1.1 the theoretical background to the work is presented. Section 2 describes the research approach. In section 3 the architecture of the PSS is presented while section 4 presents the findings. The findings are discussed and concluded in section 5.

1.1 Theoretical Background

To achieve the goal of the paper, the research area of process orientation (PO) and knowledge management have been used.

As a response to increasing competition and more demanding customers several organizations have chosen to be more process-oriented. Process orientation (PO) means focusing on business processes ranging from customer to customer instead of placing emphasis on functional and hierarchical structures. PO emphasizes process as opposed to hierarchies with special focus on outcomes, particularly customer satisfaction (Kohlbacher, 2010, p. 135). The building block of PO is to focus on the core business process. In healthcare organizations, the patient process is considered as one of the most important processes. Therefore, in order to improve the quality and safety of care, healthcare organizations must place emphasis on organizational processes based on the patient perspective, instead of
placing 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, and thereby ensure that practitioners always have access to the right information when decisions must be made.

Knowledge is considered to be the most valuable and critical asset of the organization. With the entry into the “global knowledge society” where knowledge provides competitive advantage, many consider KM a useful tool for business transformation and a key factor in gaining and sustaining a competitive advantage (Wiig, 1994; Davenport & Prusak, 1998; Jennex, 2007). Although the term KM is widely used, there is no established definition. Instead, there are varying opinions on what it is and how it should be used, if used at all (Jennex, 2007; Jennex & Offman, 2002). However, a common denominator among the definitions of KM can be found. For example the majority of the researchers argues that KM is the process established to capture and use knowledge in an organization, for the purpose of improving organizational performance. They argue that KM involves distinct but interdependent processes of knowledge creation, knowledge storage and retrieval, knowledge transfer, and knowledge application (see e.g., Alavi & Leidner, 2001; Heisig, 2009). Within healthcare, the goal of KM is to promote and provide relevant and timely knowledge to healthcare practitioners where and when they need it to help them make high quality and well-informed patient care decisions. In practice, KM is pursuing this goal through the advancement of innovative knowledge-mediated solutions and their integration in organizational workflows (Abidi, 2008, p. 3). Only when this knowledge is made available to others and used by the members will it improve the quality and safety of care. Abidi (2008) emphasizes that the adoption of KM in healthcare advocates a healthcare delivery system that values medical knowledge as a vital resource to improve health outcomes. Abidi (2008) further stresses that each healthcare practitioner has unique and specific knowledge needs, depending on the clinical circumstance. Therefore, healthcare practitioners are not just asking for mechanisms to easily access knowledge, but rather the incorporation of current and relevant knowledge into daily work activities to support healthcare decisions (Abidi, 2008).

It is clear that healthcare organizations can profit from many advantages that KM provide, such as; improved patient care, safety and satisfaction, team-building across organizational boundaries and more informed decision-making by learning from others and building on individual experiences etc. (De Brün, 2007). The Swedish healthcare system, as the healthcare system in other countries, is facing significant challenges of delivering high-quality care, at lower costs. At the same time, there is growing recognition that healthcare organizations are knowledge-intensive and are suffering from information overload (Wickramasinghe, Gupta & Sharma, 2005; Chen, Liu & Hwang, 2011; Acharyulu, 2011). Therefore, the healthcare sector needs to embrace KM strategies, processes, IT-tools and techniques as it can support healthcare organizations to create greater value by delivering higher care quality more cost effectively (Wickramasinghe, Gupta & Sharma, 2005). In recent years, researchers have tried to resolve the gap between evidence and practice by introducing different solutions for how information systems can be used to support evidence-based medicine. Lenz et al., (2007) have in their research demonstrated how pathway compliance can be improved by the development of a successful IT-application that brings pathway recommendations to the point of care by reusing online routine documentation. The application is closely integrated into the electronic patient record system 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 clinical guidelines is to decrease errors and increase quality and
safety, validation and verification techniques are other topics of interest to many researchers (Peleg, 2013). Other researchers have focused on studying how clinical guidelines can be integrated into EHRs and organizational workflows. Peleg, Keren and Denekamp (2008) for example, have in their research studied how encodings of guidelines in a computer-interpretable format and integration of them with EHR can enable delivery of medical knowledge, in form of patient-specific recommendations, when and where needed. El-Gayar and Timsina (2014) have in their research 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. In Sweden several national projects have been initiated with the aim of developing IT-based knowledge repositories. The solutions are based on web-based services that help practitioners to access and use best practice. Some well-known project initiatives are “Kunskapsguiden” and “Vårdaktörsportalen”. These IT-based knowledge repositories aim to give healthcare practitioners easy access to medical knowledge such as medical guidelines. The information is made available in “document form”, containing a multitude of pages. Even though these knowledge repositories contain crucial 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 knowledge at the time when it is needed and related to the clinical situation is therefore difficult

Up until know, supporting evidence based decision making has primarily focused on reminders and integration of medical guidelines with the EHR. Computer based medical guidelines provide important summaries of good quality evidence, but they are usually limited in scope and topic coverage. Therefore, and as a complement to computer based medical guidelines, IT-based knowledge repositories solutions should be integrated with the current information system, such as with a process support system. As existing research has focused either on the integration of medical guidelines with EHR or on the development of IT-based knowledge repositories, this paper will demonstrate how these two solutions can be combined in order to improve the availability of current and relevant medical knowledge according to the patient process, and to support all of this in a way which seamlessly integrates with the healthcare practitioners work practice.

2. RESEARCH APPROACH

The research presented in this paper is based on two case studies.

2.1 Case Study One

In the first case study a prototype visualization of a PSS that demonstrates the requirements for future process-oriented information system support in healthcare was developed. The vision for PSS is that healthcare practitioners, from all levels of healthcare, and patients should have access to effective collaborative IS that supports a process-oriented care where the patient is a distinct and active collaborator. The PSS was developed in close collaboration between researchers and healthcare practitioners from a local hospital in the Region of Västra Götaland, Sweden. Since, addressing all the healthcare processes with related information systems seemed like an impossible task for the project, it was necessary to select an
appropriate delimitation. Therefore, the project selected a healthcare process that repeats throughout the healthcare system and that can demonstrate patient and healthcare communication; initiating, planning, carrying out and following up a patient’s visit to a healthcare provider. This process was termed “Patient meeting”. Before developing the PSS empirical data was collected regarding (1) how current IS support healthcare practitioners’ in their daily work practice with regard to availability of patient information, and to a small extent availability of medical knowledge (2) how patients’ experience the information exchange with healthcare organizations and (3) identify user requirement for future process-oriented IS support. For this purpose, different data collection activities were conducted:

1. **Current state analysis:** This activity was carried out in close cooperation with healthcare practitioners as well as patients from an orthopedic clinic. Eighteen semi-structured interviews and direct observations with healthcare practitioners (nursing assistant, nurses, doctors, and administrative staff) were conducted. In addition, seven direct observations and interviews with patients were conducted. All interviews were recorded and transcribed. Field notes were taken during the observations. The analysis of the transcribed interviews and the observation field notes have been conducted with inspiration from the Grounded Theory research method. Data obtained from the interviews and observations resulted in “As-Is” process models that described the patient meeting. The models were developed using the Visuera Business Process model tool method (Visuera, 2014). The models have helped in getting an overall picture of the business practice in the organization. They have helped to describe how things are done in the patient meeting and which information that is needed in order to perform various work activities. The models also helped in identifying user requirements for the PSS.

2. **Modeling the intended future state:** Based on the assessment of the current situation and “As-Is” process models, the work began by specifying the requirements of the proposed future state (To-Be models). Identification of requirements started with an “idea seminar” with the reference group of the project. 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 for the requirements. Based on these requirements, the future patient meeting processes were 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 process models. The information content was sketched in forms with the Visuera Business Process Modelling 2007 tool (Visuera, 2014). The following goals were identified for the future state; *Increased access to information both from practitioners’ and patients’ perspective, the need for increased coordination of both clinical and administrative information based on the patient process, the need for a holistic approach based on the patient’s perspective, increased patient involvement, and improved quality of care.*

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, an initial prototype was developed with several user interface screens. The prototype was developed in close collaboration with the healthcare practitioners. The prototype was evaluated through numerous channels, involving both healthcare professionals, patients and IS providers. Based on this feedback the prototype was refined. By using prototype development, the practitioners
got a better understanding of how the PSS can improve the availability of information in the patient process. The Visuera method (Visuera, 2014) was used to develop the prototype.

2.2 Case Study Two

This case study was conducted within the frame of a project called the “Knowledge repository project” 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 portal for different areas of knowledge bases in healthcare. Coherent, means that there is one entrance to the medical knowledge that the portal includes. Two studies were conducted within the frame of the project.

Study one: aimed at analyzing the characteristics and challenges of Swedish IT-based knowledge repositories containing medical knowledge. The results from this study are presented in the paper by Krasniqi and Persson (2012). Within the first study 15 IT-based knowledge repositories were included in the analysis. To collect the data two methods were used: (1) inspection of the repositories according to predefined questions. This inspection aimed at collecting a variety of repositories at national, local and regional level which would demonstrate the multitude of approaches to creating knowledge repositories. The second method was: (2) telephone interviews with managers of the repositories. This study did not only identify challenges that current knowledge repositories in Sweden are facing, but also the need for a comprehensive IT-based knowledge repository (Krasniqi & Persson, 2012). Based on these results, the project continued with the implementation of the second study.

Study two: aimed at exploring:
- How healthcare practitioners’ experience, availability of medical knowledge when and where they need it.
- What kind of medical knowledge is missing and/or is difficult to obtain at the point of care, as well as how they would like to access that information.
- Conditions for developing a coherent IT-based knowledge repository for different areas of knowledge bases in healthcare.

Within this study two interview guides were developed; one for managers and one for practitioners. The questions were based on the KM life cycle, which means that the following aspects were addressed:
- Processes for capturing and creating knowledge
- Processes for packaging, storing, sharing, applying and measuring knowledge.

In total, 62 semi-structured interviews were conducted with managers, nurses and nursing assistants from primary care, specialist care and municipality healthcare. All interviews were recorded and transcribed. The analysis of the transcribed interviews has been conducted with inspiration from the Grounded Theory research method. The study results confirmed that practitioners lack access to medical knowledge when preparing and conducting patient visits, as well as when making decisions about the care of the patient. Hence, they experience difficulties in the practice of EBM. One of the main reasons is that the participating organizations have failed to embed the KM process in everyday processes. In addition, the results confirmed that practitioners lack access to adequate IT-support for accessing and sharing knowledge. To simplify access and ensure application of knowledge that guides practitioners in delivering high quality care, practitioner expressed an urgent need to integrate medical guidelines and relevant knowledge sources such as IT-based knowledge repositories
with EHRs. Some also requested integration of reminders with EHRs. Practitioners also expressed a need for a comprehensive IT-based knowledge repository. There is also an urgent need for IT that supports sharing of tacit knowledge between practitioners within and outside the organization.

Based on the results from case study two the PSS has, for the aim of this paper, been further modified to also visualize how such a system can improve the availability of relevant medical knowledge, and thereby support healthcare practitioners to work in accordance with EBM. The modification of the PSS is seen as relevant for two reasons; (1) the original PSS deals with the access to medical knowledge to a small extent and therefore needs to be extended, and (2) healthcare practitioners, especially from case study two (and to some extend from case study one), have emphasized the need for information systems that; (1) include medical guidelines, and reminders, and (2) supports sharing of clinical experiences.

3. OVERALL ARCHITECTURE OF PROCESS SUPPORT SYSTEM

The vision for PSS is that healthcare practitioners and patients should have access to effective collaborative IS that supports a process-oriented care where the patient is a distinct and active collaborator. The words in bold are concepts that the FHIS project paid particular attention to, meaning that:

- Appropriate parts of the PSS are available for both patients and practitioners taking into account usability for different user groups.
- The involved roles/users interact through the PSS. The underlying approach is process oriented.
- Various relevant individual information systems interact with patients and practitioners through the PSS.

The PSS can be viewed as a layer of abstraction or user interface above the various individual IS, enabling enactment of the process and interaction between patients and healthcare practitioners through computers and mobile devices without accessing each individual IS (Perjons et al., 2005). The PSS drives the process forward, ensuring that it is carried out properly and hence, supports users in performing their work tasks. The PSS also provides a user interface to the various systems involved in performing a work activity. The principle is described in Figures 1 and 2.

![Figure 1. The principle of the PSS (Adapted from Perjons et al., 2005)](image-url)
Moreover, the architecture makes it possible, at least in theory, to replace individual IT systems without significant effect on the user. The PSS 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 integration of medical guidelines and an IT-based knowledge repository.

![Figure 2. Communication between the user, PSS and IS (Åhlfeldt, Persson, Krasniqi & Wåhlander, 2013)](image)

### 3.1 Key Design Principles for PSS

The key design principles for the PSS have been identified during case study one (Åhlfeldt, et al., 2013). To understand how a PSS can support the availability of relevant medical knowledge in a way which seamlessly integrates with healthcare practitioners work practice, one need to understand the design principles. Therefore, a brief description of the key design principles is given below:

**The patient process is in focus:** The PSS focus on the patient process through healthcare and on the patient information and medical knowledge that is needed by healthcare practitioners within the context of this process.

**The PSS is based on standardized information:** Having the right information when it is needed is a challenge in the healthcare context. To improve the availability of information, it is essential that the information is standardized and structured. To achieve this in the PSS, the information content of the national quality registers for selected diagnoses has been used. The types of information stored in quality registers have been transformed into checklists for each diagnosis. For example, when the physician plans for medical examinations for a patient with hip osteoarthritis the PSS provides support by showing what medical activities that should be prioritized and also conducted.

**Digital booking and coordination of patient treatments and examinations:** The process support enables electronic booking and coordination of the patients’ 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 meeting/visit, then this visit can be cancelled in advance. In this way one prevents the patient to come to an unnecessary meeting as test results have not yet been received.

**Electronic care request/referral:** The PSS enables the patient to submit an electronic referral through his/her user interface screen (see figure 3). A practitioner can also through his/her user interface send in an electronic referral to another healthcare provider.

The care request within the PSS is based on standardized checklists designed from national quality registers. In order to prevent incomplete referrals, the care request within the PSS is based on mandatory information that must be filled in by the doctor before it can be sent. The information in the referral is thus based on standardized checklists from predefined national medical pathways/care plans. The information displayed in the referral is in turn governed by the selected patient health issue or diagnosis.

**Efficient information flows:** By adopting a process-oriented approach the information flows can be more efficient. The PSS can ensure that the patient and the practitioner carry out the right activities during the different parts of the process. The challenge here, particularly in today’s decentralized healthcare, would be to determine which healthcare provider that should be responsible for performing which work activities and who should provide a specific type of information to the PSS. Furthermore, by structuring for example the referral, it is possible to ensure that all important information that is recorded in the referral follows the patient process. Moreover, a major advantage of a process-oriented approach and tools that supports the patient process is that the PSS drives the process forward. For example, when a work activity is completed, the PSS will present nearby activities that must be performed. For example, when a practitioner in secondary care has written and signed the final documentation for the patient record, the PSS automatically picks up the form “response to care request” that must be sent back to the referring physician from primary care.
4. RESULTS AND PRINT SCREEN EXAMPLES

To clarify the new function of the process support prototype related to the availability to medical knowledge, a hip osteoarthritis patient scenario will be used. The hip osteoarthritis scenario is about a 67-year-old man. The patient has previously been treated for chest pain and is taking medicine for high blood pressure. There are three general views in the PSS, representing the main roles in the patient meeting process. These are; the Patient View, the Care Planner View and the Patient Visit Leader View. Patient Visit Leader is defined as the healthcare practitioner (e.g., a physician or a nurse) who is responsible for the patient visit. Care Planner is defined as the healthcare practitioner (e.g., a physician or nurse) who prioritizes the care request and plans the upcoming visit. To visualize how relevant medical knowledge can be made available to healthcare practitioners the “care planer view” will be used in this paper.

The layout of the Care Planner View and Patient Visit Leader View is basically the same as the Patient View (see fig. 4). The credentials of the person who is logged into the system are presented in the upper left corner (see figure 4). In the left part of the view the Care Planer can access care requests that have been sent in by patients (inbox). In the middle of the view a notification box is presented.

![Care Planner View](image)

Figure 4. Overview of the Care Planner View (Åhlfeldt, Persson, Krasniqi & Wåhlander, 2013)

4.1 How a Process Support System can support the Practice of EBM

A PSS can significantly contribute to improving quality of care and enable practitioners to work from EBM, by providing timely access to up-to-date patient information - matched with relevant medical knowledge and with an IT-based knowledge repository (see figure 5). In the screen shot below (fig 5) the Care Planner (who in this scenario is a physician) has received an “own care request” (also called referral) from a patient regarding hip pain.

A patient with hip pain sends in a care request to a physician in primary care. When the patient fills in the symptom/disease, the patient is requested to fill in specific information related to hip pain depending on his/her health issues. When the patient has submitted the “own care request”, the role Care Planner, a doctor, receives the referral, checks the information and plans for further actions. In order to ensure that the physician works from the latest scientific medical knowledge, the PSS is based on national evidence-based medical
guidelines and on standardized checklists designed from 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 outcome.

To ensure that only relevant knowledge is made available to the physician within the patient process the knowledge-sharing solution is carried out in two stages. In stage 1; unique patient information is matched with relevant medical knowledge (in this case medical guidelines) within the PSS. Medical guidelines can thus be derived from previously entered patient data. For example, as the care request regards hip osteoarthritis, only medical guidelines and recommendation concerning this health issue will be shown to the healthcare practitioner. In this case the knowledge is more focused case-specific. Deviation from a medical guideline is possible but needs to be documented (see fig. 5). If a specific guideline cannot be followed because of the patient’s condition the PSS will generate a warning. For example, if the guidelines suggest that the patient should be prescribed drug X but the patient has an allergy to the drug, a warning will be generated. Moreover, to improve the safety and quality of care is not enough for the information a practitioner needs to be available someplace in the system application. Therefore, stage 2 provides a more holistic knowledge view related to the entered patient information via a comprehensive IT-based knowledge repository that is linked with the PSS. If the Care Planer needs more specific information related to a medical guideline or the patient’s condition (in this scenario hip osteoarthritis) a comprehensive IT-based knowledge repository is integrated within the PSS. When accessing the knowledge repository the medical information presented is automatically linked to the diagnosis and/or problem that the patient has applied for and to the specific part of the process that the physician is within. This implies that the practitioners do not need to explicitly search for the medical knowledge as this information is easy accessible from the PSS. Within the knowledge repository one can find different functionalities; (1) a search engine where practitioners easily can search for publications as articles, books, medical guidelines, video and audio, (2) EBM in practice. Here practitioners can learn more about EBM such as, how EBM can be used in decision making, how to find relevant evidence to support practice and how to implement EBM in practice. Here they can also find example databases that only provide evidence based knowledge, systematic reviews and summaries of primary research conducted at different hospitals in the country and at universities. The practitioner can narrow the search by entering a specific hospital or university. To ensure access to up-to-date and relevant medical knowledge practitioners can create an (3) individual profile, where they can get news and updates as they are published, including RSS feeds from selected research area/subject e.g., hip osteoarthritis and selected sources such as MEDLINE. Through the profile they can also get example of mobile apps which allow them to access healthcare information from the smartphone. Learning materials (4) as requested from healthcare practitioners in case study two are also available. They are presented according to topics. However, for this to work people must be willing to share their materials.
Figure 5. A snapshot of the patient’s digital "care request" in the Care Planner View, showing how medical knowledge is integrated with the PSS.

Additionally, to support healthcare practitioners to practice 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, (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 one-way retrieval of information to a two-way system that provides collaborative and exchange futures that support transfer, exchange and capture of knowledge. Some researchers such as Quinn et al. (2014) argue that portals have evolved from being an efficient web tool for retrieval and transfer of information to a platform for collaboration. However, collaborative futures in IT-based knowledge repositories are limited within the Swedish healthcare, although they are highly requested by healthcare practitioners, as shown in case study two. In contrast to Quinn et al., (2014) researchers as Jetha et al. (2008) and Peirson, et al. (2013) argue that current knowledge portals could be improved by enhancing collaborative features. Therefore, while in the knowledge repository practitioners can share tacit knowledge through informal online discussion forums, knowledge cafés and community of practice (CoP). Within the forums, but especially within the CoP, practitioners with common problems and interests of getting together can share knowledge. In this case technology can be a very effective enabler of creating a collaborative learning environment for experience mediated knowledge sharing. According to Abidi (2007) online discussions forums where healthcare practitioners are bound by a common objective of interest provide a virtual meeting space to engage in problem-specific decisions that leads to the explication and sharing of knowledge. Sharing
knowledge through discussion forums and/or CoP can have a problem-solving and a learning aspect where practitioners can explore ways of working in order to solve a specific clinical problem and identify new solutions. Although the knowledge that is shared in not evidence based, it may have high trust value as it originates from colleges (Abidi, 2007). The knowledge that is created from the e.g., online discussion forums can be captured (if relevant) to explicit knowledge which then can be packaged, stored and shared through the knowledge repository or be integrated as a guideline in the process support system. Another way of supporting practitioners in different clinical situations is through so called Peer Assists methodology. Likewise, technology can be a very effective enabler by making it possible to bring together a group of peers from the organization to elicit feedback on a clinical problem. Different professional roles from different departments and organizations can be brought together.

5. DISCUSSION AND FUTURE WORK

This paper has presented a prototype that visualizes how availability of medical knowledge can be improved through a PSS. The healthcare sector is a highly knowledge intensive environment where both tacit (e.g., clinical expertise) and explicit (e.g., medical guidelines) knowledge is recognized as being critical for EBM and therefore crucial for the quality and delivery of patient care (Abidi et al. 2005). A challenge in the increasingly knowledge-intensive healthcare is not only to offer current knowledge, but to only offer relevant knowledge according to the current context, and to support all of this in a way which seamlessly integrates with the healthcare practitioners work practice (Lenz and Reichert, 2007). A key solution to the problem presented in the visualization of the PSS is to view medical knowledge and patient information as interconnected such that they continually impact on the other. This solution is based on the assumptions that relevant medical knowledge such as medical guidelines can be derived from previously entered patient data. In this manner we can ensure that healthcare practitioners always have access to relevant and the best scientific explicit knowledge, when and where they need it. Subsequently, since EBM also includes clinical expertise, the PSS can facilitate the flow of tacit knowledge. For example, discussion forums and/or CoP can help practitioners to capture and share expertise, know-how, ideas, problems, innovations, talents, and experiences. Since, tacit knowledge is the most valuable source of practitioners “experiential know-how” acquired in critical situations (Abidi et al. 2005), it is vital to facilitate sharing of this knowledge type among clinical teams, particularly when they are not always physically co-located but must exchange their critical experiential knowledge (Abidi et al. 2005). Before we try to support EBM by means of process oriented information systems 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 level contradictions between the guidelines exist. Hence, based on empirical results a crucial challenge will be to agree on which medical guidelines that should be implemented within the PSS and within an organization. Without an agreement it will be difficult to motivate practitioners to adopt the recommendations that are given by medical guidelines. Likewise, if the patient process is to be improved there also needs to be a consensus among different healthcare providers regarding common practices, (see e.g., Lenz & Reichert, 2007). In addition, an IT-based knowledge repository that is integrated within the PSS can facilitate the sharing, creation and capture of knowledge. However, IT alone is insufficient. To ensure good practice and an efficient use and transfer of knowledge that makes a difference on the quality of care, one must connect people who are willing to share
the deep tacit knowledge they have. Once people start sharing and this becomes a natural part of the organizational culture, enablers like an IT-based knowledge repository can be provided (O’Dell, Grayson & Essaides, 1998).

In conclusion, the results of this research have shown that a process support as the one described in this paper can reshape the practice of EBM, by making current and relevant medical knowledge available to those who need it and where they need it. The research findings would immensely help the healthcare IT managers and knowledge based system developers to understand the healthcare practitioners’ requirements for future IS. Nevertheless, further research is clearly needed, particularly addressing the responsibility for process support systems that cross healthcare organizational boundary. Above all the challenges lie in who would be responsible for the ownership and the quality of the medical knowledge within the PSS and within the IT-based knowledge repository. Moreover, since collaboration between healthcare practitioners and the patient is essential in ensuring proper delivery care, future research should also consider how patients’ values, preferences, needs and experiences can be captured through a process support system, so that this information can easily be made available to healthcare practitioners in connection to decision-making.

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Information Systems for the Practice of Evidence-Based Medicine and Shared Decision Making

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Abstract: Evidence-based medicine (EBM) and shared decision making (SDM) are essential for the quality of healthcare. Using information systems to support EBM and SDM has been proposed as one of the important initiatives to significantly improve quality of care. They play a crucial role by allowing healthcare practitioners to access information and clinical evidence while formulating their patient care strategies. They can also create new opportunities for patients to participate actively in their care. However, current information systems solutions are far from this perspective for various reasons. The aim of this paper is to present and illustrate how a prototype visualization of a process support system can enhance the communication and collaboration among healthcare providers and patients by improving the access to patient information and medical knowledge, in so doing support the practice EBM and SDM. An important conclusion from this research is that a process support as the one described in this paper can reshape the practice of EBM and SDM.

Keywords: Process support systems, patient empowerment, evidence-based medicine, shared decision making

1. Introduction

Evidence-based medicine (EBM) and shared decision making (SDM) are both essential for the quality of healthcare, yet the interdependence between these approaches is not generally appreciated (Hoffmann, Montori, & Del Mar, 2014). SDM is an approach towards seeing the patient as having a central role in decision making about their own clinical care (Barratt, 2008, p. 408). It is a process in which healthcare practitioners and patients work together to make decisions, select medical tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values. The aim of SDM is to empower patients to express their values and preferences, to ask questions and to participate actively in decisions about their care (Barratt, 2008). EBM is defined by Sackett, Rosenberg, Gray, Haynes, and Richardson (1996), as the conscientious and judicious use of current best medical evidence in conjunction with clinical expertise as well as patient values and preferences to guide healthcare decisions. Following the principles of EBM, practitioners are required to formulate clinical questions based on the understanding of the patient’s clinical condition (El-Gayar & Timsina, 2014). After the patient’s condition has been identified and synthesized into clinical questions, the practitioner proceeds with the search of the literature for answers, evaluates the evidence for its validity and usefulness, and finally applies the information to patients (Lenz & Reichert, 2007). The degree to which practitioners can practice EBM is dependent upon the availability of information about the patient (such as diagnostic tests) and medical knowledge (such as medical guidelines). Patient information is thus a precondition for medical decisions and it is evidence based medical knowledge, clinical expertise as well as patient values and preferences that guide these decisions (figure 1).

![Figure 1: Challenges with EBM (Rexhepi, 2015a)](image-url)
Moreover, practicing EBM and SDM requires skills, such as the asking of well-built clinical questions, knowing how to find and evaluate the evidence and how to engage patients in medical decision making. Likewise, the practice of EBM and SDM is dependent on practitioners (1) having access to up-to-date patient information and high-quality evidence, preferably already synthesized, (2) capturing and understanding the patient’s values and preferences and (3) patients receiving clear and unbiased information that describes their condition. Fanjiang et al. (2005) even argue that patients must have access to the same information streams—in “patient-accessible” form—as their physician(s) and care team in order for them to communicate values, preferences and participate effectively in decision making.

Using information systems to support EBM and SDM have been proposed as one of the important initiatives to significantly improve quality of care. They play a crucial role by allowing practitioners to access information and clinical evidence while formulating their patient care strategies. They can also create new opportunities for patients to participate actively in their care, manage their medical problems and improve communication with their healthcare providers. Information systems can also enable healthcare providers to partner with their patients in a bold effort to optimize quality of care, improve health outcomes and transform the healthcare system on the macro-level (Lee, Grando, Rozenblum, & Bates, 2015). However, current information systems solutions are far from this perspective. According to the Swedish Ministry of Health and Social Affairs (2006) patients themselves cannot easily access evidence based medical knowledge or information about their clinical care which makes it difficult for them to become active partners. Electronic booking of examinations and communication with healthcare practitioners is also limited. Furthermore, due to interoperability issues existing information systems do not support a seamless flow of patient information along the patient process. Likewise, healthcare practitioners cannot easily access up-to-date patient information due to interoperability issues. Many implemented information systems, such as electronic medical records, have tended to be local, proprietary and insular. Therefore, numerous systems in use are not designed to communicate with others (whether inside or outside individual health provider organizations) (Iroju, Soriyan, Gambo & Olaleke, 2013). In some cases, they support single organizations very well, but overall they have trouble exchanging information between care providers and the community at large, e.g., social insurance offices, resulting in poor inter-organizational communication and collaboration (Ministry of Health and Social Affairs, 2006). Nor, do they support easy access to medical knowledge at the point of care. One of the main issues is that clinician practicing EBM have to search for the latest evidence, analyse it in context and implement it in practice because medical knowledge e.g., medical guidelines and systematic reviews, are not easily assessable. Since there is a multitude of research information available the search process becomes time consuming. In certain situations the found information can be difficult to translate into clinical practice (Rexhepi, 2015b). On this basis EBM and SDM are nearly impossible to practice in everyday clinical care.

Providing effective, efficient, and high quality healthcare is thus affected by how much information is shared within and between healthcare providers and patients, and how well that information is integrated within each clinical setting’s system and processes (Nicolette et al., 2015; Rexhepi, 2015b; Cardoso, et al., 2014). Therefore, for EBM and SDM to serve its purpose, patients and healthcare practitioners need information systems that give them quick and trouble-free access to all-round information. They also need information systems that can influence the patient and doctor relationships, such that they easily can work together in pursuing shared goals in healthcare, with attention to both illness and personal experience. Therefore, the aim of this paper is to present and illustrate how a prototype visualization of a process support system (PSS) can enhance the communication and collaboration among healthcare providers and patients by improving the access to patient information and medical knowledge, in so doing support the practice EBM and SDM. The key principles of the PSS have been presented in the paper by Åhlfeldt, Persson, Rexhepi and Wåhlander (2015) where either the patient or healthcare practitioner perspective has been presented. For the purpose of this paper, a holistic perspective of the patient process and the collaboration between healthcare providers and patients related to EBM and SDM will be presented through illustrations.

The remainder of this paper is organized as follows. In section 1.1 the theoretical background to the work is presented. Section 2 describes the research approach. In section 3 the architecture and the key design principles of the process support system are presented. The findings are discussed and concluded in section 4.

2. Theoretical Background

EBM should begin and end with the patient. Incorporating patient values and preferences is according to
Hoffmann et al. (2014) the most difficult and poorly mapped step – yet it receives the least attention. This has led to a common criticism that EBM ignores the patients’ perspective in the decision making (Hoffmann et al., 2014). Patient preferences refer to patient perspectives, beliefs, expectations, and goals for health and life, and to the processes that individuals use in considering the potential benefits and harms of care options in relation to one another (Montori, Brito & Murad, 2013). This means that practitioners and patients need to discuss medical options, and decide what treatments are best for them based on the patient’s clinical situation, available treatment options, scientific evidence, circumstances, beliefs, and preferences (Elwyn et al., 2014; Freedman & Martin, 2012; Stiggelbout, Pieterse, & De Haes, 2015). EBM and SDM have for the most part evolved in parallel, yet neither can achieve its aim without the other (Hoffmann et al., 2014). “Without SDM, authentic EBM cannot occur. Without SDM, “evidence may be poorly translated into practice and improved outcomes” (Hoffmann et al., 2014, p. 1295). Likewise, without attention to the principles of EBM, SDM becomes limited because decisions about the care of the patient must as far as possible be based on evidence rather than on clinical skills and experience alone. Evidence-based medicine and shared decision making have thus three important common features. These are (1) the involvement of the patient in decision making, (2) the requirement of having access to patient information and (3) evidence based medical knowledge. There is an increasing consensus among healthcare experts that when practitioners and patients have access to up-to-date and timely patient information and medical knowledge, and when patients participate more actively in their care process, we can create a new healthcare system with high quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients (Ferguson, 2007; Fichman, Kohli, & Krishnan, 2011; Koch, 2012). Numerous studies have demonstrated positive effects when using information systems in healthcare. In particular, information systems have great potential to significantly reduce the rate of adverse events and improve healthcare quality, by selectively giving (1) healthcare practitioners timely and up-to-date access to patient information and relevant medical knowledge at the point of care, (2) by providing patients with timely and easy access to their healthcare information and (3) by supporting the electronic communication between patients and healthcare practitioners. Yet, there is a discrepancy between the potential and the actual support of information systems in healthcare. Information system constraints are just some of the many issues preventing the practice of EBM and patients being actively involved in decisions about their care. Healthcare practitioners also need skills, such as the asking of well-built clinical questions, knowing how to find and evaluate the evidence and how to engage patients in medical decision making (see figure 2). However, without supportive technologies that improve information sharing between patients and their healthcare providers 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.

Figure 2: The interdependence of EBM and SDM and the need of both to improve quality of care.

3. Research approach

3.1 Case study
The prototype presented in this paper is a result of a case study named “Future Healthcare Information Systems” (FHIS). The case study aimed to develop a prototype visualization of a PSS that demonstrates the
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requirements for future process-oriented information system support in healthcare. The vision for the PSS is that practitioners, from all levels of healthcare, and patients should have access to effective collaborative information systems that supports process-oriented care in which the patient is a distinct and active collaborator. The PSS was developed in close collaboration between researchers at the University of Skövde, a local hospital in the Västra Götaland region, and healthcare organizations in the said region of Sweden.

The overall healthcare process is extremely complex. Trying to tackle it all within one project was clearly not feasible. Therefore, one of the first tasks of the project was to select a suitable sub-process for the work to focus on. The project selected the process of initiating, planning, carrying out and following up a patient’s visit to a healthcare provider. This process was termed “Patient Visit” and was limited to involve only ambulatory care. The selected process is frequently occurring, it exists both in primary and secondary care and demonstrates that communication between these healthcare providers. Hence, it involves the desired element of complexity. Several professional groups are also involved in this process and the patient is expected to play an active role. The chosen process is also suitable as it can demonstrate the intricacies of the communication between a patient and healthcare providers. In order to make the demonstrator concrete and illustrative, two scenarios of the “Patient Visit” process were chosen for implementation (Åhlfeldt, Persson, Rexhepi & Wåhlander, 2015).

3.1.1 Data collection techniques

A current state analysis: The objective of this activity was to; (1) explore and create a comprehensive picture of how current information systems support healthcare practitioners’ and patients’ information needs and (2) identify requirements for future process oriented information system support. For this purpose, interviews and direct observations were seen as adequate techniques for data collection. Eighteen semi structured interviews (approximately two hours each) and direct observations of healthcare practitioners were conducted. The observations of the healthcare practitioners lasted between 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). The consultations and conversations that took place between the patient and the physician during the patient meeting were also observed. In total, seven direct observations that lasted between 10 - 20 minutes were conducted. Each observation was complemented with a semi-structured interview. All interviews with patients and healthcare practitioners were taped, transcribed and analysed with inspiration from the Grounded Theory research method. Data obtained from interviews and observations resulted in “As-Is” process models that described the current patient meeting. These models helped to gain an overall picture of the business practice in the organization. They also simplified the description of how tasks were carried out during the patient meeting and what information was needed to perform various work activities. Finally, the models also facilitated the identification of user requirements for the future process support system. The method used for modelling of the chosen process and for prototype development was the “Visuera method” (see paper by Åhlfeldt, Persson, Rexhepi & Wåhlander, 2015).

Modeling of the intended future state: Based on the collected empirical data from the current state analysis and the “As-Is” process models, requirements for the proposed future state were specified through the development of “To-Be” process models.

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. There are three general views in the PSS, representing the main roles in the patient visit process. These are; the Patient View, the Care Planner View and the Patient Visit Leader View. Patient Visit Leader is defined as the healthcare practitioner (e.g., a physician or a nurse) who is responsible for the patient visit. Care Planner is defined as the healthcare practitioner (e.g., a physician or nurse) who prioritizes the care request and plans the upcoming visit. The resulting prototype was evaluated in relation to the identified user requirements, workshops and interviews. In addition to this, identified user needs were also evaluated in relation to the Swedish national strategy for e-health and during seminars involving healthcare practitioners, patients and information system providers. Based on this evaluation, the prototype was refined.
4. Research results

4.1 Architecture of the process support system

The vision for the process support system is that healthcare practitioners and patients should have access to effective collaborative information systems that support a process-oriented care where the patient is an active and important collaborator. The words in bold are concepts that the FHIS project paid particular attention to, meaning that:

- Appropriate parts of the PSS are available for both patients and practitioners taking into account usability for different user groups.
- The involved users interact through the PSS. The underlying approach is process oriented.
- Various relevant individual information systems interact with patients and practitioners through the PSS.

The involved users interact through the PSS. The underlying approach is process oriented. Various relevant individual information systems interact with patients and practitioners through the PSS.

The PSS can be viewed as a layer of abstraction or user interface above the various individual information systems, enabling enactment of the process and interaction between patients and healthcare practitioners through computers and mobile devices without accessing each individual system (Perjons et al., 2005). The PSS drives the process forward, ensuring that it is carried out properly and hence, supports users in performing their work tasks. The PSS also provides a user interface to the various systems involved in performing a work activity. The principle is described in figure 3.

![Figure 3: The principle of the PSS (Perjons et al., 2005)](image)

4.2 Key design principles for the Process Support System

Efficient information flows and the patient process in focus: One of the challenges identified in the “current state analysis” is inadequate information flows meaning that:

- Critical patient information and medical knowledge when needed to influence prescribing decisions is not available.
- Timely and reliable communication of critical test results is limited.
- Coordination of medical examinations, treatments and medication orders at points of the interface or transfer of care is limited.

Efficient information flows between different providers as well as within on provider area in healthcare is crucial for the quality of care. Often, necessary information does not follow the patient when he or she is transferred to another service or is discharged from one component or organization to another, which hampers the practice of EBM and SDM. To tackle these issues the PSS has been designed to follow and focus on the whole patient process through healthcare. By mapping and analysing the actual patient journey across a spectrum of healthcare it has been possible to identify the actual patient information and medical knowledge that is needed by practitioners and patients within the context of this process. Therefore, the PSS follows the idea that patient information and medical knowledge needed by practitioners when preparing for and carrying out a patient visit should be available when it is needed.

During “the current state analysis” it was shown that one of the most common sources of patient dissatisfaction is not feeling properly informed about (and involved in) their care process. Moreover, lack of easy access to information about their own care made it even more difficult for patients to participate in decision making or express opinions about different treatment methods. Therefore, the patients emphasized...
that they want more information than they are routinely given by healthcare practitioners, and many would like a greater share in the process of making decisions about how they will be treated. In order for the patient to play a distinct role in their healthcare and be part of decision making they need information. Access to information can thus improve a patient’s knowledge and understanding of their condition and their level of involvement in medical decisions (Coulter et al., 2008). Therefore, the PSS is designed to increase patient engagement by letting them (1) electronically submit care requests to primary and secondary care, book appointments with doctors and/or nurses, and (2) access information regarding their own healthcare such as their medical records and “patient visit summaries” (see figure 4).

Since the underlying approach of the PSS is process-oriented, the process support is designed to drive the process forward by presenting nearby activities that must be performed. For example, when a practitioner in secondary care has written and signed the final documentation for the patient record, the PSS automatically picks up the form “response to care request” that must be sent back to the referring physician from primary care. In this manner we can improve the flow of information and ensure that right activities are carried out at the right time within the patient process. The process approach also minimizes duplication of documentation, as already registered information follows the process and therefore does not need to be registered again.

**Digital booking, electronic care request/referral and coordination of patient treatments and examinations:** Overall, the role of the patient has changed from a passive recipient of care to a more active participant in care delivery (Fanjiang et al., 2005), and healthcare information systems must keep up with this change. Another challenge identified in “the current state analysis” is that patients are limited in playing an active role in their care. To help patients in playing this new role effectively, the PSS is designed to meet the requirement for electronic booking and coordination of treatments and examinations. Patients can thus electronically make appointments with their physician and submit care request. A clinician at primary care can also electronically schedule a patient visit at secondary care and vice versa. Moreover, to help both patients and practitioners to get an overall view of planned and completed activities, it is possible to follow the status of these through the PSS (figure 4). If some activities, such as e.g. laboratory tests, are not completed before the scheduled patient visit, then this visit can be cancelled in advance. In this way one prevents the patient to come to an unnecessary meeting.

**Figure 4:** The patients view. From this view the patient can (1) create a new care request, (2) see past and future visits (activities in the patient process) and (3) read their medical record

**Shared goals for the patient visit:** SDM, where patients are involved as active partners with the clinician in treatment decisions requires that the patient is given the opportunity to not only access information regarding their care, but also to express their values, preferences and expectations ahead of an upcoming patient visit. As this is a precondition for EBM and SDM, the PSS helps patients to capture and share information about his or her expectations of an upcoming patient visit, values, preferences and other expressed needs (figure 5). In this matter we can, to a certain extent, ensure that patient values guide all clinical decisions.
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Figure 5: Patient view. The patient fills in a care request with questions related to their condition, they can also fill in values, preferences and/or other expectations prior to a doctor’s visit.

Standardized information: Physicians and nurses that are involved in the care of a patient need to share and access both information and medical knowledge to ensure that patients are getting the proper treatment and medications, and that none of those treatments conflict. However, having access to the right information when it is needed is a challenge in today’s healthcare context, thereby the work towards an evidence-based practice and shared decision making is hampered. To improve the availability of both patient information and medical knowledge, it is essential that the information is standardized and structured. Firstly, to ensure that practitioners have access to current patient information, the referral that the patient and/or the physician submit through the PSS is standardized and structured. Here, the information content of the national quality registers for selected diagnoses have been used and converted into checklists. This means that, if a patient submits a referral regarding hip pain he/she is requested to answer a number of questions related to the condition he/she is seeking care for. These questions are taken from the Swedish national quality registers. By structuring the referral, it is possible to ensure that the information that is recorded in the referral follows the patients’ journey through healthcare. If the doctor needs further information in addition to that recorded in the referral then he/she can, through the PSS, access the National Patient Summary (NPO), a system that allows caregivers to share essential patient information across organisational boundaries such as examination results and pharmaceuticals prescribed by different care providers. Moreover, in order to ensure the healthcare practitioners consults scientific medical knowledge, the PSS is based on national evidence-based medical guidelines and on standardized checklists designed from Swedish 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 outcome. To ensure that only relevant medical knowledge is made available to the physician unique patient information is matched with relevant medical knowledge (in this case medical guidelines) within the PSS. Medical guidelines can thus be derived from previously entered patient data. For example, as the care request regards hip osteoarthritis, only medical guidelines and recommendation concerning this health issue will be shown to the practitioner. In this case the knowledge is focused thus case-specific. Moreover, if additional medical knowledge is needed, a comprehensive IT-based knowledge repository is linked with the PSS (figure 6).
5. Discussion and Conclusion

Many medical decisions are not clear cut. Patients and practitioners need to discuss the options using the best available medical evidence and make informed joint decisions that take account of the patients’ clinical condition, values, and preferences (Agoritsas et al., 2015). But implementing EBM and SDM is not easy. In addition to skills, practitioners need access to up-to-date patient information and the best medical evidence. Patients need information and support. Our study 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 practitioners, and many would like a greater share in the process of making decisions about how they will be treated. Shared decision making, with supporting information systems where patients are involved as active partners with their healthcare practitioners 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. One of the biggest challenges is to adopt a process-oriented approach with supporting information systems. This approach is an important foundation for achieving a system design that focuses on the patient process from the patient’s perspective and thereby sets the patients and their healthcare journey in the center of care. The key design principles of the PSS presented in this paper are important contributions to present research as they provide ideas for how future healthcare information systems can support patients and practitioners in the decision making by integrating patient information and scientific evidence (EBM) with patients’ values and preferences (SDM). However, numerous challenges still exist which must be carefully understood and which require basic research before we can come to a complete solution approach. We believe that the implementation of a process-oriented information system as the one described in this paper will be a major challenge for the healthcare organizations. The challenges identified in this study are both organizational and technical. For example, the question of who is responsible for the entire patient process must be resolved before appropriate information technology support can be discussed. To determine the ownership and responsibility of a process support system that crosses organizational boundaries and that supports a patient-centered care is another challenge to be solved. Moreover, for patients to communicate their needs and preferences, participate effectively in decision making, they must have access to the same information as their physician(s) and care team (Fanjiang et al., 2005). While not all patients want to play an active role in choosing treatments most still want practitioners to inform them and take their preferences into account. Therefore, future healthcare information systems must be designed so they are more inclusive in the...
way they enable patients to take control of their healthcare and thereby also empower them. It is, however, important to stress that technology can only support practitioners in practicing EBM and SDM. Healthcare practitioners must consider patients and their families as “partners” and they must want to incorporate their values and wishes into the decision making. Without this perspective the information system support – even if it is a killer application – will fail.

References


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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.