A THIRD PERSON IN THE ROOM: A CASE STUDY OF THE SWEDISH RHEUMATOID REGISTER

Christina Keller
Jönköping University, Jönköping, Sweden, christina.keller@ju.se

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Research paper

Keller, Christina, Jönköping University, Jönköping, Sweden, christina.keller@ju.se

Abstract

The purpose of this paper is to examine how a quality register in rheumatoid arthritis care was adopted in the Swedish medical community of rheumatologists and what helped and hindered this. A mixed methods case study was carried out to collect data covering the development and adoption of the quality register. By performing 17 key informant interviews and document analysis, significant themes focusing on the context, content, process and outcomes of the innovation was sought for. The innovation process proceeded from idea generation, development phase, and consolidation phase to a phase of shared decision-making. Resistance from physicians, perceived threats to the medical consultation, organisational change climate and lack of integration with other health care IT-systems were perceived as barriers to the adoption of the quality register. Access to longitudinal patient and treatment data, change champions, transformational leadership, changes in the physician-patient dialogue and increased control of treatment quality and costs were identified as drivers of innovation spread. These factors can be categorised as belonging to the construct of perceived usefulness.

Key words: Information systems in Healthcare, Innovation, Adoption, Strategic Change, Sweden

1 Introduction

Arthritis was once a painful condition with few effective treatments. In the beginning of the 1990s, early care for initial onset arthritis allowed more effective interventions. In 1999, new “biologic” drug treatments made possible the relief and management of a number of arthritis-related diagnoses. In Sweden, these developments were accompanied and accelerated by an arthritis database, one of a number of Swedish “quality registers”. New information technology and new thinking about shared decision-making and how to organise outpatient clinics have also led to improvements.

This paper reports research into an innovation in arthritis care involving these elements. The objective is to report findings about how the register was developed and spread, and to present and assess evidence about what helped and hindered this. The aim is to identify implications for others in how to develop and spread quality improvement innovations for other diseases and patient groups.

Although most national quality registers are recent, such registers have existed in Sweden since the 1970s, the first register being the Register for Knee Arthroplasty, which began as a research project in 1975 (Garpenby and Carlsson, 1994). The development of national quality registers has been decentralized in its nature, accomplished by professional communities. Practitioners having the greatest use of the data also have been responsible for developing the registers and their content, and the registers are nationally spread among clinical departments. In 2016, 100 quality registers were established in Sweden, categorised into 15 groups: cancer, circulatory system, dental care, elderly palliative care, emergency, anaesthesia and intensive care, endocrine organs, eyes, infection, lung diseases, musculoskeletal system, nervous system, pediatrics, obstetrics and gynaecology, psychiatry, stomach and intestines, and other areas (Sveriges Kommuner och Landsting, 2016). The rheumatology register belongs to the category of musculo-skeletal systems.

Research studies about quality registers from an implementation perspective are few, and seldom consider factors driving or hindering the innovation. Previous research on diffusion of innovation and in-
tentional spread of innovation shows factors which may also apply to quality registers if these are considered as an innovation. A review of 213 empirical and 282 non-empirical studies, found the diffusion and/or the intentional spread of innovations depended on the characteristics of the innovation, adoption by individuals, as well as organisational antecedents and readiness for innovations. Other important factors were characteristics of the implementation process, such as decision-making, internal communication and external collaboration, and the outer context of the innovation, consisting of socio-political climate, incentives and mandates, inter-organisational norm-setting and networks and the degree of environmental stability (Greenhalgh et al., 2004). Acceptance and adoption of information systems in healthcare by professionals has also been investigated from the perspective of technology acceptance. The acceptance of telemedicine, which is one of the earliest applications of information technology in healthcare, among physicians was examined by the technology acceptance model as early as 1999 by Hu et al. Perceived usefulness was found to be a significant determinant of telemedicine use while perceived ease of use was not. Yi et al. (2006) performed a study with 222 US physicians as respondents, where the influence of personal innovativeness in IT, results demonstrability, image, subjective norm, perceived behavioural control, perceived ease of use and perceived usefulness on acceptance of information technology was tested. Perceived behavioural control was found to influence behavioural intention to use information technology indirectly through perceived ease of use and perceived usefulness. To perceive results demonstrability was a significant determinant of both perceived ease of use and perceived usefulness. Also, personal innovativeness in IT had a strong influence on the behavioural intention to use information technology. Furthermore, an Australian study of an unsuccessful implementation of an information system in an emergency department pinpoints how physicians can be accustomed to autonomy of their own work practice and are disinclined to engage in activities which they see as interfering with patient interaction (Lederman et al., 2015).

In Sweden, Garpenby and Carlsson (1994) described the development of what was then called “national quality registers”. In a later study, the dependencies between Swedish quality registers, which were developed within closed professional networks, and the state were described (Garpenby, 1999). Another Swedish study describes the arthritis quality register from the perspective of the organisation of early arthritis clinics, underlines its role in changing drug prescription patterns, but also anticipates the role of the register for evaluation of new biologic therapies (Klareskog et al., 2001). Other studies of arthritis quality registers have included studies of physicians’ prescriptions and perceptions of the rheumatoid arthritis health status index (DAS28) (Carli, 2008), a study of the register as a “feed-forward system” for patient participation and provider support (Hvitfeldt et al., 2009), and from a design theory and realist evaluation perspective (Keller et al., 2009a), as well as an example of knowledge management and innovation (Keller et al., 2009b; Edenius et al., 2010). Organisation and management of twelve cases of innovations in Swedish health care, of which the quality register focused in this study is one, showed that clinical leaders played a more important role than managers in innovation implementation as did internal organisational context factors. Strategies for change implementation were found to differ per the type of innovation (Ovretveit et al., 2012). The Swedish rheumatology register is also described in a study with the purpose of describing how clinical registers were designed and used to serve multiple purposes in three health systems, in order to contribute practical experience for building learning healthcare systems (Ovretveit et al, 2016). However, none of these studies have explored the actual development and spread of use of the register from the perspective of strategic change management (Pettigrew and Whipp, 1992).

2 Method

A mixed methods case study was carried out in 2008-2009 to collect data about the development and implementation of the quality register and a new model of care between 1993 and 2009.

The aim was to be able to describe and explain the changes which took place over time in a way which was useful to implementers, and could contribute to scientific empirical and theoretical knowledge.
key feature of the research design was a data gathering framework to guide data gathering, which was informed by previous research into changes in health care strategic change model (Pettigrew and Whipp, 1992). This model was developed and specified to guide data gathering about the content and process of the changes (the “intervention”), the context, and intermediate and final outcomes. Defined as essential dimension and questions related to the strategic change model of Pettigrew and Whipp (1992), “content” is the answer to the question “what” was changed by the intervention. “Process” is defined as the answer to the question of “how” the intervention was introduced, implemented and spread. “Context” is the answer to the question of “why” the intervention is accepted and spread or not (Stetler et al., 2007; 2009). “Outcomes” was defined as the quantitative spread of the register as well as changes brought by the intervention in qualitative terms. Moreover, within the data categories of content, process, context and outcome, drivers and barriers of the innovation was sought for. Data was gathered at different times, and about different time periods in the history of the innovation. The framework focused data collection on these subjects, but the details of what was collected and from whom were continually adjusted so as to check findings from one source against other sources, follow up discoveries or test emerging hypotheses.

Data about the innovation was gathered during 2008-2009, from documents, semi-structured interviews and local service statistics. Seventeen semi-structured interviews based on critical incidents technique (Gremler, 2004) were conducted. In total, there where fourteen interviewees, among them ten active rheumatologists. The other four interviewees had key roles in the implementation of the register as decision-makers on national and local levels. No patients were interviewed. The characteristics of the interviewees and the number of interviewees are summarised in table 1. The register manager, which was also the champion implementer, was interviewed at three occasions, while the other interviewees were interviewed once. This means that seventeen interviews were performed in the study. Interviewees among physicians, researchers and significant individuals of register development and implementation were chosen on recommendation by the register manager and national quality coordinator. Documents collected and analysed included agreements, articles, meeting minutes, and presentations materials and was used in order to create the phase model presented in the paper. Service statistics collected and analysed included annual reports from the Swedish Rheumatology Quality Register, Swedish Associations for Local Authorities and Regions and The National Board of Health and Welfare.

<table>
<thead>
<tr>
<th>Characteristics of interviewees</th>
<th>Number of interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Register manager (and rheumatologists)</td>
<td>1</td>
</tr>
<tr>
<td>Rheumatologists</td>
<td>5</td>
</tr>
<tr>
<td>Rheumatologists acting as clinical managers</td>
<td>4</td>
</tr>
<tr>
<td>Decision-makers in register implementation</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>14</strong></td>
</tr>
</tbody>
</table>

*Table 1. Characteristics and number of interviewees.*

This method involved a “snowball” investigation approach, which included a degree of analysis while conducting the data gathering: findings from one interview or document were not only noted, but also used to decide which other data might be needed to check the findings and to plan further data gathering, or to formulate new hypotheses for investigation in subsequent interviews or document analyses. The researchers carried out regular internal summaries of the data collected and emerging themes noted and adjustments made to the data collection plan.

Interviews were recorded and transcribed verbatim. The interviews were analysed by content analysis, identifying significant data, and categorising the data into themes (Miles and Huberman, 1994; Robson, 2002). The analysis of the interview texts was interpretative (Neuendorf, 2002) in order to find conceptual categories. The date was first categorised into four groups, representing the concepts of the
framework by Pettigrew and Whipp (1992): content, process, context and outcome. Second, themes from the data, were identified within each main category. Documents were listed in summary forms and categorized into themes by means of content analysis (Miles and Huberman, 1994). Data triangulation was used to compare and combine data from different sources and from different methods to establish patterns and differences (Yin, 2003). Data from interviews were compared to data from the document analysis and statistics to find if these data supported or disconfirmed the interview data (cross-data validation). The analytic method applied to the data was inductive hypothesis or theory-generation, based on detecting common themes or patterns noticed in the data from the case study (Eisenhardt, 1989).

3 Findings

The findings first present a case overview and then report the themes which the analyses discovered in the data, categorised into the concepts of context, content, process and outcomes (Pettigrew and Whipp, 1992).

3.1 Case overview

The register includes data on which treatments prescribed, assessment of health status by the rheumatologist and the patient, and evidence-based and internationally valuated measurements.

In the end of the 1980s, new effective treatment strategies of drug combination therapy against rheumatoid arthritis had been introduced along with the insight that rheumatoid arthritis should be treated in the very early stages of the disease (Klareskog et al., 2001). Before the introduction of new treatment, the treatment policy of rheumatologists had been one of wait and see. Arthritis is an insidious illness, something that also contributes in making diagnoses late. Sometimes patients are reluctant to report slighter, initial symptoms because they think that it is not serious enough to bother the doctor with (register manager).

With the introduction of new treatment opportunities, a growing interest was discerned among rheumatologists in evaluating treatment outcomes. Discussion of a quality register in rheumatoid arthritis started in 1993 in the professional community of Swedish rheumatologists. An assigned group of rheumatologists were given the task to develop a prototype for a national monitoring system. At the start in 1995, the register had seven participating clinics including a total of 144 patients. The first rheumatology clinics to attend the register were Karolinska (Solna), Umeå and Sahlgrenska (Gothenburg), Spenshult Rheumatology Hospital and the clinics of Malmö, Kalmar and Kristianstad. Before the medical consultation, the patients were asked to fill in paper-based forms of patient and treatment data. The patient and treatment data was then registered in the quality register after the consultation by a physician, a nurse or an administrator. The discussion of the rationale behind the register and what data to include was lively during the first years of the register:

*And there were a lot of discussion about why we had to do this, and – above all – why everyone should spend so much time on filling out forms, which is something you must do to create a register (register manager).*

Other physicians wanted to measure as many indicators of the disease as possible, and entered too much data in the register. At the same time, other physicians thought that the paper-based forms were too extensive and tried to come up with reasons for not including patients into the register. Resistance towards the use of the register also took on other forms as physicians were afraid of being exposed and not agreed on the assumption that quality could be measured. Initially, there were also resistance towards the register from researchers as researchers did not want to share their data with other researchers:
And research is an incredibly strong force, because research is a means of qualifications and career. Everyone looks after one’s own interests in that respect. Of course, you want to attend the register, but more so if you are able to use data for research, that is, in benefit of your own career (register manager).

As a result, the initial impact of research on the development and implementation of the register was negative. With time, the resistance towards the quality registers from researchers decreased, with the realization that the register contributed to research by providing large amounts of clinical data.

The register received funding in a combined call from the ministry of health and the federation of Swedish county councils from 1996. The main criterion of national support was sufficient quantitative coverage in the national use of the register. The main aim of the Swedish Rheumatology Quality Register was to improve health of Swedish rheumatoid arthritis patients, which was a qualitative goal. The register was one of the first disease-oriented quality registers, focusing on the diagnosis of the patient and recording all relevant treatment. The first national quality registers, introduced in the late 1970s, were method-oriented, recording surgical procedures. Therefore, the purposes and functions of method-oriented quality registers were widely known and accepted, while disease-oriented registers, such as the quality register of rheumatoid arthritis, were considered untried and different.

During this time, we were questioned by the decision committee for national quality registers. They were the pioneers of supporting quality registers, and it is the pioneers who shape the views and ways of thinking. They were familiar with surgical procedures when the patient only occurs once in the register. And that we had many procedures per patient hard for them to realize (register manager).

He [the register manager] had difficulties with the committee because he couldn’t show increasing coverage [of rheumatology clinics] in a persuasive way (former member of the decision committee of national quality registers).

During the spread of the register, the register manager used formal contracts as a means of formalising and stabilising the relationship with register stakeholders, such as rheumatology clinics, professional associations and other rheumatology registers. Formal agreements were considered important as a register manager is not a clinical manager of register users, and has no other formal means of power. There was also an informal and influential side to the agreement of using the register as the strategy of the register manager was to find win-win situations, which at the same time developed the register and brought added value to register users.

Until 1999, when biologic drugs were introduced, the focus of register use was registration of treatment of early arthritis. From 1999, a further focus was added; the registration of treatment with biologic drugs and their side-effects. In 2001, a web-based user interface was introduced, which provided opportunities of entry of data by the patient before the consultation and by the physician and patient together during the medical consultation. In 2006, the web-based user interface had been refined and began to spread among Swedish rheumatology clinics. In 2009, eighteen rheumatology clinics used the web-based user interface for patients at the clinic. In the county council of Dalarna, patients were able to register their disease activity from a web-based user interface independent of place e.g. from their home or workplace. All other patients of the clinics adopting the web-based interface registered their data on assigned computers placed in the waiting-room of the rheumatology clinic. With the introduction of the web-based user interface, the focus of register use changed into management and follow-up of the treatment of individual patients.

The patient data entered into the register includes treatment, findings of laboratory tests, self-assessed patient evaluations of general pain, global health, daily function, as well as swelling and tenderness of 28 index joints. Based on the data, a patient health status index, labelled as DAS28 (Disease Activity
Score of 28 joints, is created. The DAS28 index serves as a point of reference from which treatment outcomes are evaluated. When the patient has entered data, an overview of disease activity is created by the register. The patient prints the overview and brings it to the medical consultation. As soon as data is entered by the patient, the same data is visible on the physician’s screen. The overview gives a comprehensive summary of disease activity and treatment over time. Together with the physical examination of the patient by the physician, the disease activity overview will form the basis of a shared decision on further treatment.

The patient registers data, which I process and we reach a shared decision which is shown in a summary showing both hard and soft data (clinical manager).

You get an overview of the disease [by means of the register], and that is difficult to achieve by only unstructured, longitudinal notes. You get structured and quantified data, which makes it easier to evaluate the actual health status of the patient (researcher).

At the launch of the register in 1995, seven rheumatology clinics were included. In 2015, the register was used by 57 rheumatology clinics, which is 100% of all Swedish clinics, and included 70,000 patients (Svensk Reumatologis Kvalitetsregister, 2016). Drawing on the qualitative and quantitative data of the case study, four phases of the innovation process can be discerned; the idea phase, the development phase, the consolidation phase, and the final phase labelled as the shared decision-making phase. The idea phase, during which the foundation of the register was laid and a register prototype developed, lasted from 1993 to 1994 and produced the initial version of the register. During the development phase 1995-1998, which was focused on the registration of treatment of early arthritis, the number of attending clinics increased rapidly. During the consolidation phase 1999-2005, which was focused on the registration of treatment effects of biologic drugs, the number of attending clinics was constant or slowly increasing, while more patients were included in the register. The increase in spread of the register to clinics was triggered by the treatment of early rheumatoid arthritis, while the increase of patients was triggered by the introduction of biologic drugs. During the last observed phase, starting in 2006, the quality register evolved into a web-based tool for shared decision-making between physician and patient, focusing on quality assurance of the treatment of individual patients. The four phases of the innovation process are presented in table 2.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Idea</th>
<th>Development</th>
<th>Consolidation</th>
<th>Shared decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus</td>
<td>Preparation and prototyping</td>
<td>Early arthritis identification</td>
<td>Biologic drugs introduction and uptake</td>
<td>Individual patient treatment management and follow-up</td>
</tr>
<tr>
<td>Number of clinics and patients</td>
<td>1995: 7 clinics, 144 patients</td>
<td>1999: 40 clinics, 3,091 patients</td>
<td>2005: 44 clinics, 16,131 patients</td>
<td>2006: 45 clinics, 19,918 patients</td>
</tr>
</tbody>
</table>

Table 2. Phases of the innovation process.

According to Rogers (2003), the innovation process in organisations consists of two broad activities: *initiation*, defined as the entire information gathering, conceptualizing and planning for the adoption of an innovation, and *implementation*, all of the events, actions and decisions involved in putting an innovation into use. Initiation is divided into two stages, *agenda-setting* and *matching*, while implementation comprises the three stages of *redefining/restructuring*, *clarifying*, and *routinizing*. Agenda-setting occurs in the innovation process when a general organisational problem that may create a need for an innovation is defined. During this stage a *performance gap*, a discrepancy between an organisation’s expectations and actual performance, is defined. During the matching stage, the innovation is tailored to solve the organisational problem and fill the performance gap. The first stage of the imple-
mentation is redefining/restructuring, when the innovation is re-invented to accommodate the organisational needs more closely. Clarifying occurs as the innovation is put to a more widespread use and the meaning of the innovation becomes clear to the organisation’s members. Routinizing marks the end of the innovation process, as the innovation becomes an incorporated part of the organisation and ceases to be an innovation. The innovation process according to Rogers (2003) is depicted in table 3.

<table>
<thead>
<tr>
<th>I. Initiation</th>
<th>II. Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Agenda-setting</td>
<td>2. Matching</td>
</tr>
<tr>
<td>3. Redefining/restructuring</td>
<td>4. Clarifying</td>
</tr>
<tr>
<td>5. Routinizing</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. The innovation process in organisations (Rogers, 2003).

When comparing the identified phases of the innovation process described in table 2 with the innovation process described by Rogers (2003), the idea phase 1993-1994 is interpreted as the initiation, including the agenda-setting and matching. The development phase 1995-1998 corresponds to the redefining/restructuring phase as a new organisational need (early arthritis identification) is emerging. An additional organisational need is identified in the consolidation phase where the use of biological drugs need to be registered. Finally, the consolidation phase, starting from 2006 means that the innovation of the rheumatology quality register is starting to be a routine, as all Swedish clinics use the register.

3.2 Themes in the data

The analysis of the interviews and documents identified common themes under the categories of context, content, process and outcome in the model of strategic change by Pettigrew and Whipp (1992). The themes are presented and illustrated by quotations from the empirical material in table 4.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Illustration of theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Context theme 1 (why): Resistance from physicians</td>
<td>“And there were a lot of discussion about why we had to do this, and – above all – why everyone should spend so much time on filling out forms, which is something you have to do to create a register.” (register manager).</td>
</tr>
<tr>
<td>Context theme 2 (why): Clinical research</td>
<td>“And research is an incredibly strong force, because research is a means of qualifications and career. Everyone looks after one’s interests in that respect. Of course, you want to attend the register, but more so if you are able to use data for research, that is, in benefit of your own career.” (register manager).</td>
</tr>
<tr>
<td>Context theme 3 (why): Perceived threats to the medical consultation</td>
<td>“And the more processes and information systems that are imposed on us by someone else, who thinks that this is really great, the more time is lost in close contact with patients, to examine their joints, to treat them properly.” (clinical manager).</td>
</tr>
<tr>
<td>Context theme 4 (why): Organisational change climate</td>
<td>“This clinic is probably quite change avert – at least it has been – I have tried to change it. It is hard to introduce ideas that have to do with increasing the order and structure of physicians’ work. It is time-consuming to change this attitude among colleagues.” (clinical manager). “It’s nearly always the same people who suggest and drive change. But it is also important how you are received by others when you want to change something. If they say “no”, or “it’s impossible” or “I’m not interested”, then a lot of your will and ability to drive change disappears… Management is very important. If management does not take responsibility to lead change, the inertia will be enormous”. (rheumatologist).</td>
</tr>
</tbody>
</table>

Table 4. Themes of context, content, process and outcome in the development and spread of the innovation.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Illustration of theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content theme 1 (what): Access to longitudinal patient and treatment data</td>
<td>“You get an overview of the disease [by means of the register], and that is difficult to achieve by only unstructured, longitudinal notes. You get structured and quantified data, which makes it easier to evaluate the actual health status of the patient.” (researcher).</td>
</tr>
<tr>
<td>Content theme 2 (what): Lack of integration with other health care IT systems</td>
<td>“There is no data from the quality register, that I couldn’t find in the electronic medical record. Preferably, the two information systems should be interacting.” (clinical manager).</td>
</tr>
<tr>
<td>Process theme 1 (how): Change champions</td>
<td>“You have to be diplomatic and in some way or the other be a friend of most or your colleagues. You cannot force colleagues to accept and drive change. You have to listen to them, and then, with the respect that you command, present the reasons – and above all – the added value that the innovation can bring to the individual.” (register manager).</td>
</tr>
<tr>
<td>Process theme 2 (how): Transformational leadership</td>
<td>“He [the register manager] has a vision for the quality register, and constantly strive to inspire us.” (clinical manager). “The register manager has shown great enthusiasm... He has shown us how to use the web-based patient interface from stage at one of our conferences, to set an example to follow.” (former member of the decision committee of national quality registers).</td>
</tr>
<tr>
<td>Outcome theme 1: Changes in the physician-patient dialogue</td>
<td>“It is like having a third person in the room... But it feels secure and comfortable, as the computer presents facts and not guesses or beliefs... The patient tells me that he or she doesn’t feel very well. Then I look at the results from the laboratory tests or the [DAS28] index, and I can confirm that the patient’s health status has deteriorated. It is a fact and not just a vague perception or whimpering.” (rheumatologist). “With the register, some patients really dare to tell me that they only take four pills each day instead of eight, which I prescribed. I think that this brings a clarity and an honesty [to the medical consultation], and finally perhaps compliance will increase because the patients feel involved ... Treatment will be more equal as all patients have the opportunity to measure disease activity – and then you will discover the patients that really have a high disease activity. And that might not be those patients who complain a lot or make many telephone calls.” (clinical manager).</td>
</tr>
<tr>
<td>Outcome theme 2: Increased control of treatment quality and costs</td>
<td>“By means of the register we can tell politicians that a certain number of patients need biologic drugs. Without the register, we wouldn’t have stood a chance.” (rheumatologist). “To read the health status overview before the medical consultation saves ten minutes, which I can use to examine the patient, instead of trying to scroll through e.g. 750 pages of written medical records.” (clinical manager).</td>
</tr>
</tbody>
</table>

*Table 4, continued. Themes of context, content, process and outcome in the development and spread of the innovation.*

Barriers to the spread of the innovation revealed by the interview data were: resistance from physicians (context theme 1); perceived threats to the medical consultation (context theme 3); organisational change climate (context theme 4) and lack of integration with other health care IT-systems (content theme 2). There is evidence that drivers of innovation spread included: access to longitudinal patient and treatment data (content theme 1), change champions (process theme 1), transformational leadership (process theme 2), changes in the physician-patient dialogue (outcome theme 1) and increased control of treatment quality and costs (outcome theme 2). Clinical research (context theme 2) was a barrier initially, but became a driver of the innovation with time.
4 Discussion

4.1 Initial outcome: The spread of the quality register

During phase II of the innovation from 1995 until 1998, the number of clinics participating in the register rose from seven to forty. According to the interviewees, the significant increase in register use was due to earlier intensive discussions, negotiations and “marketing efforts” from 1993 to 1994 (in phase I). During the expansion of register users in phase II, the focus of attention was treatment of early arthritis. With the introduction of the new “biologic” drugs in 1999, the number of participating clinics did not rise, as most rheumatology clinics already was included in the register during phase I. Yet the number of patients included rose from 3 091 in 1999 to 16 131 in 2005. One plausible interpretation is that treatment of early rheumatoid arthritis was a reason for clinics participating in the register, while the new use of biologic drugs was a motivation for including more patients. What may have explained the subsequent addition of clinics to 100% participation from 2006 and onward was the spread of the web-based patient interface.

4.2 Context: Why was the quality register not spread to all rheumatologists?

The spread of the quality register evoked resistance among some physicians. Research into information systems innovations in health care has shown that these can be perceived by health care staff to threaten the quality of medical processes (Lapointe and Rivard, 2005; Øvretveit et al., 2007). The innovation is perceived to take time from the medical consultation, more than adding value to it. This is in accordance with the findings of Lederman et al. (2015), who found that physicians where reluctant to engage in activities that took time from patient interaction. According to the physician interviews, the lack of integration between the quality register and electronic medical records complicated and made the work routines of physicians more time-consuming. This reaction could also be explained by the limited capacity of humans to handle complexity and pay attention to non-routine issues:

...because people and their organisations are largely designed to focus on, harvest and protect existing practices rather than pay attention to developing new ideas (Van de Ven, 1986 p. 591).

From the interviews, an organisational change climate characterised by change-aversion and inertia was identified as a barrier to innovation spread. One possible explanation of this could be the organisational characteristic of “complexity” (Rogers, 2003). Complexity is the degree to which an organisation’s members possess a relatively high degree of knowledge and expertise, measured by their degree of professionalism and formal training. Drawing on this definition, rheumatology clinics can be considered as having a high degree of complexity. Complexity has been found to encourage organisational members to conceive and propose innovations, but simultaneously making it difficult to achieve consensus about implementing them. Another explanation might be lack of compatibility (Rogers, 2003) between the values and beliefs behind the development of the quality register and the values and beliefs of individual physicians regarding their professional role:

Physicians were afraid of being exposed. This is due to the old notion that “it is only the patient and me”, and no one else should give a damn. I have not encountered this in any other organisation, besides health care. There was an endless discussion about what might happen: There were fear of losing integrity, fear of too much work, and most of all, fear of exposing patient treatment outcomes. There were also methodological questions: It is impossible to measure health! (former member of the decision committee of national quality registers).
This quotation suggests the values and beliefs behind the quality register were not compatible with the values and beliefs of individual physicians. The quality register is founded on the belief that quality can be improved by measuring and exposing treatment data. The professional values and beliefs of some physicians are, per the interviewees of the study, still that the patient-physician relationship is a closed entity and that quality and health cannot be measured. This interpretation corresponds to the findings of a previous study where quality registers and the information they contain illustrated the ongoing conflict between openness in health care and professional autonomy (Garpenby & Carlsson, 1994).

4.3 Content: What are the contents of the innovation?

The two significant themes of the content category were; (1) increased access to patient and treatment data, and (2) lack of integration with existing health care information systems, e.g. electronic health records. Both circumstances influenced rheumatologists’ work routines significantly. Increased access to patient and treatment data changes the interaction between rheumatologist and patient, as it is no longer necessary to start the medical consultation by repeating basic patient data. Instead, the consultation could be focused on issues of importance for the chronically ill patient. This circumstance also creates a foundation for a new model of shared decision-making in rheumatology care (see below, section “Final outcome: A new model of shared decision-making”), and as such acts as a driver of the innovation. The affordances brought by the quality register can be categorised as perceived usefulness according to the technology acceptance model and the studies performed by Hu et al. (1999) as well as Yi et al. (2006).

In contrast, the lack of integration between the quality register and other information systems in health care acts as a barrier to further spread of the innovation. Due to lack of integration, patient and treatment data need to be registered in multiple information systems. This is time-consuming and regarded as a patient safety hazard, as the risk of errors increases with the number of times the same data must be registered. Systems requiring extra time and work to operate for clinical work have been found to be a factor hindering implementation (Ovretveit et al., 2007).

4.4 Process: How was the register implemented and spread?

“Change champions” were reported by the interviewees as a significant driver of the development and spread of the register. This observation is frequently made in other innovation research. Champions are individuals which...

...identify with the idea as their own, and with its promotion as a cause, to a degree that goes far beyond the requirement of their job (Schön, 1963, p. 84).

Schön (1963) proposes that such champions are necessary for radical innovation. In this case the primary change champion, the register manager, was observed to use “transformational leadership” (Burns, 1978) in spreading the innovation. “Transformational leadership” refers to the leader moving the follower beyond self-interest through charisma, inspiration, intellectual stimulation, or individualised consideration (Bass, 1999). Furthermore, this type of leadership has, in previous research, been identified as a significant factor for innovation success in health care and hospital contexts (Bass, 1999).

Idealized influence and inspirational leadership are displayed when the leader envisions a desirable future, articulates how it can be reached, sets an example to be followed, sets high standards of performance, and shows determination and confidence. Followers want to identify with such leadership (Bass, 1999, p. 11).
4.5 Final outcome: A new model of shared decision-making

During the last phase of the innovation process, beginning in 2006, the quality register evolved into a new care model of shared decision-making. Shared medical decision-making is a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on agreement (Frosch et al., 1999). Charles et al. (1997) suggests four key characteristics of shared decision-making in the medical encounter: that at least two participants – physician and patient – are involved, that both parties share information, that both parties take steps to build a consensus about the preferred treatment, and that an agreement is reached on the treatment to implement. Shared decision-making is closely related to concepts such as patient-centred care, and patient empowerment (Whitney et al., 2004). To allow patients to register data in the quality register before the medical consultation brings new qualities to the physician-patient relationship. The patient is more prepared for the medical consultation. During registration, the patient is reminded on what issues to bring up in the consultation. There was also evidence from the interviews of tacit knowledge (Nonaka, 1994) of patients and physicians being confirmed or made explicit by the register (see also Hvitfeldt et al., 2009; Keller et al., 2009), as e.g. a vague perception of decreasing health status of the patient could be confirmed as an increase of disease activity measured by the quality register:

The patient tells me that he or she doesn’t feel very well. Then I look at the results from the laboratory tests or the [DAS28] index, and I can confirm that the patient’s health status has deteriorated. It is a fact and not just a vague perception or whimpering. (rheumatologist).

According to the interviewees, the quality register gives a good foundation for shared decision-making, as it not only provides a longitudinal overview of patients’ health status, but also portrays the treatment options that are reasonably available to the patient. As stated by Elwyn et al. (2000), this is one of the key competences in shared decision-making.

4.6 Implications for practice and research

Based on the findings from this research, we suggest that managers and implementers should consider the following in developing similar healthcare innovations:

- Choose change champions carefully, and encourage their work during all phases of the development and spread of the innovation.
- Consider the values and beliefs of professionals in the health care organisation and their compatibility with the innovation assumptions. In this research, physicians were found to be focused only on their work with their patient. This focus acted as a barrier to innovation spread, as the openness of treatment data brought by the use of the register was opposed by physicians and it was only by showing the value in enhancing the physicians work with their patient which advanced the registers use.
- Pay attention to the attitude towards organisational change, as resistance might block people from seeing the advantage of an innovation.
- Strive for integration between clinical computerised information systems, such as e.g. quality registers and electronic medical records. Integration will reduce data redundancy and the time that physicians spend on entering data. If the workload of entering the same data many times is released, the quality register might no longer be regarded as a threat to the quality of the medical consultation.
- Make the positive outcomes of innovations, in this case e.g. the changes in the physician-patient dialogue, and increased knowledge about treatment outcomes and costs, observable in the health
care organization. These added values can also be categorised as perceived usefulness of the quality register, and is the strongest driver of behavioural intention to use an information system.

4.7 Limitations and suggestions for further research

As the study is a single-case study, generalisations of conclusions to other registers or other types of innovations, and to other countries should be made with caution. Many data are from interviews and reconstruct events over sixteen years. Another limitation of the study is that the perspectives of other interviewees than physicians are not captured. Furthermore, the sampling of the interviewees was performed by snowballing, which is not a randomized sampling technique. The sampling targeted physicians who used the register on a regular basis. Although all Swedish rheumatology clinics use the register, there might still by occasional rheumatologists who do not, and these were not included in the study. However, there are consistent patterns in the data and some valid conclusions can be drawn from the study about what helps and hinders the development and use of this type of innovation in health care.

Rheumatology patients were not focused in the case study. Future research is needed to explore their views about the rheumatology quality register. The quality register is a disease-oriented register focused on a chronic disease. The implementation strategy of the quality register was characterised by clinical champions. Future research is needed for other implementation strategies and for method-oriented quality registers and registers of other diagnoses.

References


