When patient empowerment encounters professional autonomy: The conflict and negotiation process of inscribing an eHealth service

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Abstract

In Sweden, as in many other European countries, government and public agencies have promoted the expansion of eHealth in recent years, arguing that this development enhances patient participation, empowerment and cost efficiency. This article presents a study of the development of My medical record on the Internet, a civic service originally inspired by the home banking concept. The study illustrates how the technology is developed and inscribed with new technical norms, dictating access and use. These norms are in turn shaped by negotiations between social and legal norms as well as the values and beliefs of several different actors involved in the development process. Supported by the study, we conclude: 1) that the new technology challenges the medical professionals, thus causing resistance as the institutional boundaries are changed when patients are given digital access to their medical record; 2) that the technology changes or inscribes the law; 3) that a pilot project of this type is dependent on an enthusiast, seeing the project through until it becomes accepted on a larger scale; and 4) that increased patient participation requires improved access to information which differs from the NPM rhetoric advocating more service to customers.

Introduction

In Sweden, as in many other European countries, government and public agencies have promoted the expansion of eHealth over the last five years. Their aim is to enable patients increased access and influence over their health situation by emphasizing arguments such as "patient authorization", "patient transparency" and "patient empowerment". In Swedish healthcare, "eHealth services" have become a generic term for "healthcare using modern information and communication technologies" (Cehis, 2013, p. 5). The ongoing and planned deployment of eHealth services is described by key organizers in the field as a paradigm shift (Socialdepartementet, S2010.020; Cehis, 2013, p. 6) and is perceived as a pervasive reform of the communication and relationship between citizens and healthcare organizations.

This article focuses on the development of one such eHealth service, a pilot case entitled *My medical record on the Internet* governed by the intention to give patients better access to their healthcare information and for communication with caregivers (Eng & Torpe, 2008). The development process lasted for fifteen

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years (1997-2012) and illustrates how difficult it can be to develop a new technology that marks the institutional change that a paradigm shift brings with it. The technical features or norms that make it possible for patients or citizens to access their medical records turned out to provoke existing technical, legal and social norms, leading to conflicts, resistance and negotiations between different actors and norms.

Drawing on research from "the social shaping of technology" perspective (Williams & Edge, 1996), we describe and analyze these conflicts and negotiations and how they direct the process of setting the technical norms (Spicer, 2005; Constantinides & Barrett, 2006). Technical norms are set by "creating a fixed meaning and a set of uses associated with the technology" (Spicer, 2005, p. 869) or "technical inscriptions" (Joerges & Czarniawska, 1998) into the service or technology dictating who can access it and how it may be used. These norms are in turn shaped by the norms, values, ideologies and beliefs (or even hopes) of several different actors involved in the development of the service or technology (Bowker & Star, 1999).

The main questions we seek answers to in this article are: What actors are involved in the process that inscribes the technology behind the service (Pinch & Bijker, 1984)? What norms, values, ideologies and beliefs do they bring to the table in the process (Joerges & Czarniawska, 1998; Spicer, 2005)? And what happens when different actors' opinions and preferences on who can use the technology and how it should be used encounter each other leading to conflict and negotiation (Pinch & Bijker, 1984; Spicer, 2005; Constantinides & Barrett, 2006)? We are also interested in how the constraints and affordances (Leonardi & Barley, 2008) of the service are defined and inscribed into the technical norms of the service, and how the process seeks to direct the agency of the target user.

Originally, the idea of patient digital access to their medical records was neither launched by the Government nor by public agencies. Instead, an enthusiastic Information Technology (IT) strategist and his project team in Uppsala County Council (UCC), one of Sweden's 20 county councils, came up with the idea in the late 1990s. Over a fifteen-year period, they promoted and defended their idea, as well as dealt with several challenges, and in November 2012, *My medical record on the Internet* was launched as a pilot case in Sweden.

The time span for the development and acceptance of the service thus extends from the New Public Management (NPM) wave into the new era of "e-government" (Pollit & Bouckaert, 2011). NPM's decentralization as well as increased demands for different types of audits, both in quantity and extent, has increased the demand for information transfer, within and between different organizations. The digitalization of information thus became a prerequisite for NPM as well as a trigger for the development of IT systems in Swedish public organizations.

According to Leonardi & Barley (2008), there is a general agreement that information technology is constituted by the interplay between social and material phenomena. Most of the research and writing on IT from "the social shaping of technology" perspective (Williams & Edge, 1996) have reflected the interplay

between IT and its users in organizational settings. It has focused on different aspects of the social-material shaping of technology such as negotiation, human agency, personal interest, how organizing is affected by the interaction between people and machines, social or technical subsystems, and social and material practices (Leonardi & Barley, 2008).

Theoretical framework

Several researchers have studied the relationship between technology and organizational forms and functions from different theoretical perspectives. Examples of this are (new) institutional theory (Avgerou, 2000; Orlikowski & Barley, 2001), structuration theory (Giddens, 1984; Orlikowski & Robey, 1991; Jones & Karsten, 2003), social construction of technology (SCOT) (Pinch & Bijker, 1984) and action network theory (ANT) (Law, 1992; Law & Hassard, 1999; Hanseth, Aanestad & Berg, 2004). Some of the key issues in these perspectives have been how socio-material practices in organizations intertwine so that the social is inscribed into the technology as structures, and how human action "enacts emergent structures through recurrent interaction with the technology at hand" (Orlikowski, 2000, p. 407). As the focus in our case is on the development of the technology before it reaches the end user, the framing of how technology is shaped and reshaped by the users in an organization does not really fit our purposes.

We are thus inspired by Spicer's article "The political inscribing of a new technology". In our study as in Spicer's, the actors involved in the political process of inscribing the technology are not the end users and the process is also carried out in a public arena and not a specific organization. We also recognize the political process of defining or inscribing (Joerges & Czarniawska, 1998; Orlikowski, 2000; Spicer, 2005) the technology, and how this process is colored by various political wills and logics (Spicer writes of "discourses") through, amongst others, conflict and negotiation.

For a better understanding of the results of these conflicts and negotiations that are inscribed into the technology, we turn to the three-norm framework presented by Joerges & Czarniawska (1998). According to the authors, who define technology as a "particular mode of institution" (ibid. p. 372), there are three types of norms that are inscribed into a technology: 1) technical action norms, 2) norms for machine behavior, and 3) norms for the natural environment. The technical action norms "define human rights and duties" (ibid. p. 378), that is, the norms that indicate how the user should handle the technology. Norms for machine behavior prescribe both how a specific piece of technology should be constructed and how it functions regardless of human interaction. These technical norms cannot be altered by the "regular" user. Joerges and Czarniawska use a clock to illustrate what they mean by norms for machine behavior: "A clock in the Central Station obeys in its normal operation neither the expectations and interventions of passers-bys nor those of its producer or serviceman. It may be justified to say: the clock works by itself, and those who want to use it or

must use it inescapably have their time pre-structured by it" (ibid. p. 379). Some of the norms inscribed into a technology thus function independently from human interaction. Norms for the natural environment are general standards that regulate the tolerated effects of a technology on nature. Joerges and Czarniawska exemplify these norms with the allowed becquerel pollution per kg reindeer and the emission limits for SO2 air pollution (ibid, p. 379). These norms can neither be inscribed into actors nor into technical artifacts, but do affect the frame for how a certain technology may be designed and used.

The first two types of norms – technical action norms and norms for machine behavior – apply to our case of development of an eHealth service. Whereas, the third type – norms for the natural environment – are not really applicable as there are no prescriptions or discussions about if, and in such case how, the technology behind eHealth services affects the natural environment throughout the development process. Instead, we lack the types of norms that prescribe the effects a technology may have on environments that are not natural but man-made, such as homes, hospital units, restaurants, shops, and schools. We thus propose a fourth norm to be added to the three-norm framework: "norms for man-made environments". In the case of Internet access to medical records, norms for man-made environments could prescribe the tolerated impact of the technology on the healthcare professionals' work environment and/or the patients' home environment.

How the norms that are inscribed into a technology during the development process are formulated is, however, a process of negotiation between the different actors involved in the process. According to Pinch and Bijker (1984) different types of conflicts can arise during the process: between different social groups (actors) in terms of the technical requirements, between conflicting solutions to the same problem, and moral conflicts. They further point out that "(W)ithin this scheme, various solutions for these conflicts and problems are possible – not only technological, but also judicial, or even moral" (ibid, p. 416) and it may thus take a period of time to develop a technology. During that period, different actors negotiate which interpretations and preferences (i.e. norms) should prevail and be inscribed into the technology. The power relations of and between the participating actors will reveal themselves in such negotiations (Walsham, 2001; Constantinides & Barrett, 2006; Spicer, 2005). Spicer thus argues "there are potent processes of political contestation and resistance involved in technical inscriptions" (2005, p. 869). According to Constantinides and Barrett the relation between the context or the socio-political structure and the development process of ICTs "is key for understanding the impact of new ICT initiatives" (2006, p. 29). Eriksson-Zetterquist et al. (2009, p. 1151) point out that professional groups or communities may take an active role in negotiating how the new technology should be interpreted and used.

Walsham (2001) underpins that power relations also can refer to how different actors acquire advantage through information access. Contestation and resistance can, accordingly, both be demonstrated by actors withholding information from an IT system and by inscribing different restrictions for access into

an IT system. The other side of the coin is that power also can be directed to design technologies to offer affordance to the users (Leonardi & Barley, 2008) allowing them to do new things they were not able to do before.

Another possible issue for negotiation is how dynamic a technology should be. Pinch and Bijker (1984) describe how a technology becomes stabilized when some of its features become taken for granted over time. These inscribed features will then become generic to the technology and will structure the way it can be used, in Joerges and Czarniawska's terms, "norms for machine behavior" (1998, p. 378). The more dynamic parts of technology allow for continuous enactment (Orlikowski, 2000). This in turn affects the extent to which the actions of the users are routinized. Processes of appropriation can, according to Walsham (2001), point technology to support routinized as well as improvisational activities. The appropriation of a technology can thus be designed to constrain certain actions by the users. According to Czarniawska (2009) inscriptions may also allow for new actions that oppose the institutional norms: "My point is that artifacts are inscriptions of institutions in the matter, but they also offer a possibility of a revolt against an institution" (p. 62). Our perception is that many Internet services offer a possibility of a revolt against earlier norms and institutions. One example is how the Internet enables people to both shop and do bank errands any day of the week and any time of the day, from wherever they are. That is quite a revolt against the norms of opening hours in shops and banks and the traditional bank clerk being the only person with permission to register deposits or withdrawals in one's account.

The impact of the Internet on society in general is vast. According to Pollit and Bouckaert (2011), "e-government" is not a model for governance in itself though, as is the case for New Public Management (NPM). However the "e-wave" can in many aspects be seen as a successor of NPM and e-services will thus be introduced into practices where NPM's control and management ideals have materialized in different forms. The basic doctrines of NPM described by Hood (1995) and Vrangbæk (1999) can be recognized in the Swedish healthcare system. They include the use of management models from private industry, enhanced focus on efficiency and cost reduction, and a shift towards service/customer orientation.

Research method

This article derives from a study in the Swedish research project *Deployment of Online Medical Records and other eHealth Service*" (DOME). In the study we aimed to create an understanding of the development of the service *My medical record on the Internet* by mapping the development process and the views and opinions of key actors involved in it.

The empirical data was mainly derived from archival material such as documents, both formal and informal, provided by key actors in the development process. These included policy documents on eHealth from both the local and national levels as well as official legal documents and reports. As much of the

debate on the development process took place in the media, we also collected over 70 posts from newspapers and other printed media. The archival material was structured chronologically and coded into three main categories: "actors encountering/using/resisting the technology", "norms/values/beliefs encountering the technology" and "the outcome of the encounter such as agreement or collision". Important events such as "a large scale launching of the civic service" created situations where new norms were articulated in the actors' argumentation and these events constituted the end of one phase and the starting point of a new.

In addition to the archival material, we conducted 17 semi-structured, interviews (Silverman, 2005), carried out between June 2012 and December 2013. The 17 interviews, 7 at the national level and 10 from Uppsala County Council, were conducted either face to face or by telephone and lasted on average 40 minutes. The respondents were selected as representatives for different key organizers at the national level (public agencies) or at the local level in Uppsala:

- · The National Board of Health and Welfare (Socialstyrelsen)
- · The Swedish Association of Local Authorities and Regions (SKL)
- · The Swedish Data Inspection Board (Datainspektionen)
- · The National Board of IT in Healthcare (Cehis)
- · Swedish Medical Association (Läkarförbundet)
- · The Swedish Association of Health Professionals (Vårdförbundet)
- · County Council of Uppsala: Project members, politicians and representatives from the medical professionals.

The interview guide consisted of 16 questions and related sub-questions that asked for the respondent's opinions on the most important actors in eHealth development, for their opinions on the advantages and risks with eHealth, and for the possible impacts on relationships between different healthcare actors. The respondents were subsequently asked about their own opinions and their perceptions of the opinions of other actors or actor groups. At the end of the interview, the respondents were asked specifically about the development in UCC. The interviews were recorded and transcribed and the material was coded into the three main categories described above. These categories relate to the research questions posed in the introduction of the article and constitute the basis for the empirical story. In the discussion section, we return to the research questions and align them with the empirical material.

The development process of *My medical record on the Internet*

This section tells the story of the IT development process evolving a project called SUSTAINS, an acronym for *Support for USers To Access Information and Services.* The development process took place between 1997 and 2012. In practice, SUSTAINS encompassed several projects at different stages, SUSTAINS I, II and III.

The story primarily takes places in Uppsala County Council and illustrates the impact of actions and interactions of, and between, local, national and supranational actors in the development process. One person, a local enthusiast with a strong belief in the eHealth service, appears in different roles and functions throughout the story. We have chosen to call him Ted – an acronym for some of his most important roles in the story – **T**echnician, **E**ntrepreneur and **D**eveloper.

From bank account to health account (1997-2000)

In the autumn 1997 Ted, now the IT strategist at UCC, was contacted by a consultant representing a Swedish consulting firm concerning participation in an EU project called SUSTAINS. The project was funded by the European Union and included a number of European countries such as Greece and Italy. The aim of the project was to develop a number of "civic services" for patients with high information needs.

Technicians from both the UCC and the consulting firm formed a Swedish project team and were immediately inspired by the existing "home banking" technology – services that were developing rapidly in Sweden. The project team could see some distinct similarities between banking errands, such as handling your own bank account, and different administrative issues in the healthcare system. The developers argued that the citizens' role and position in relation to the bank had significant similarities with their corresponding role in relation to the healthcare organization. The balance of the health account was considered the property of the healthcare organization, meaning that the organization was in control of the documentation, while the citizens needed to be allowed access to the documentation without being able to modify it.

The basic idea of the health account was to create information access for the patients through the Internet. This caused some major difficulties for the southern European members of the EU project. According to Ted, who was the Swedish coordinator of the SUSTAINS project:

> That wasn't such a huge success in the Mediterranean. We explained to them that we wanted to copy the Internet based home banking concept and they did not understand what we were talking about. Internet was practically as unknown to them as it was to us in the 1980s.

The Swedish technicians were thus left with a health account system – a digital platform – that was not usable in southern Europe. Ted and the project team who wanted to find uses for the new technology in the Swedish healthcare system carried out a minor pilot test in Uppsala where 100 patients were given access to their own data in the hospital's patient administrative system for three months. The evaluation was positive and indicated that the patients requested different and more detailed information from the system – they wanted digital access to their actual medical records.

Norms for patient access encounter security norms (2000-2003)

SUSTAINS I was completed in the autumn 1999 and was followed by a second project, SUSTAINS II, funded by the UCC and the Knowledge Foundation, a Swedish research organization. The project team, managed by Ted, now comprised several technicians from different local organizations: the UCC, several consulting firms, and Uppsala University. Their technical solutions needed to be tested in practice. They established partnerships with three primary care clinics: two publicly owned health centers and one private practitioner in Uppsala.

The ambition was now to include the medical records in the health account information and a number of patients from the three health centers were thus offered digital access to their medical records through the health account. It soon became clear that the technology did not match the standards of the existing IT systems in the publicly owned health centers. The IT department in the county council insisted on such a high level of IT security that due to limited technical resources, it became impossible to put the new technology into practice. As put by Ted:

> But there [at the publicly owned primary care clinic], the technology was so new and so many people wanted some kind of say in the process. The decision-making process was excessively long and finally the system was so secure that it became nearly impossible for anyone to gain access to and actually use it. So it did not survive very long.

The private primary care clinic, on the other hand, was able to be much more flexible in developing and using personal health accounts.

According to the final project report for SUSTAINS II, presented in October 2001, the health account empowered the patients to gain influence over their own healthcare and enhanced quality and cost efficiency for the health centers. The report thus concluded that the development of the health accounts had to continue. The project was completed in the fall of 2001 and the preparation for an even larger launch of the health account commenced.

Norms for patient access encounter the law (2003-2004)

The ambition of the project team and the UCC politicians was to deploy the new technology on a larger scale throughout the entire county and on August 17, 2003, one of Sweden's largest morning papers, *Dagens Nyheter*, published an article about the larger scale deployment of health accounts. The article reported that every hospital patient, approximately 300,000 people, would be offered the service during 2004 and included an interview with Ted, the project manager and the IT strategist of the UCC. He stressed the importance of the project, not least, as the patients now would become a valuable resource to be utilized by the healthcare organizations:

> The patients will become their own coordinating resource in an increasingly complex healthcare system [..]. We will gain an army of

free controllers to keep track of things such as referrals and test re-
sults (*Dagens Nyheter*, August 17, 2003, authors' translation).

The article included an interview with a patient with experience of using the
health account. She confirmed that digital access had facilitated her situation and
her interactions with the primary care clinic in several ways. One of the main
advantages was gaining digital access to important information without calling
the doctor. Her reasoning included the parallel between home banking and health
accounts:

I use the Internet to pay my bills and my health account is just as se-
cure. And medical records printed on paper are no guarantee for secu-
rity and personal integrity (ibid.).

The article portrayed the SUSTAINS Project as innovative and entrepreneurial
and the essence of the article was that the use of health accounts including medi-
cal records constituted a win-win situation.

The article attracted a lot of attention. Among the interested readers was the
Swedish Data Inspection Board (DI), an authority with the explicit task to pro-
tect the individual's privacy in the information society. The DI acted immediate-
ly and only two days later a journal for healthcare professionals, *Dagens
Medicin*, and the newspaper, *Dagens Nyheter,* reported that the legality of the
project had to be reviewed as it might very well be against several laws. Two
months later, a formal decision by DI put an end to the ambitions to deploy
health accounts in Uppsala and the UCC immediately terminated the deployment
project.

The main argument in the DI's decision was that digital patient access was
in conflict with legislation concerning how to handle healthcare registers. To be
allowed digital access, the access had to be necessary for the person to carry out
his/her work. Thus, as the patient did not need the information as an employee,
digital access to the health account and medical records was considered illegal.

The DI's decision resulted in a number of strong reactions as well as reports
and articles in media. The criticism from the project team soon followed suit and
Ted made several media statements. He referred to the "lack of common sense"
and emphasized that the purpose of the law was not "to protect the patient from
himself". The UCC legal department, in collaboration with the project team,
appealed to the Administrative Court to overturn the DI's decision. The main
argument was that the Court had to consider the purpose of the law and that a
number of legislative changes were to be expected in the near future, all with the
overall aim to strengthen the patients' status.

In October 2004, the Court's decision confirmed that patient digital access
to healthcare information was illegal and that the UCC was not allowed to restart
the deployment project. However, the Court findings also referred to the fact that
SUSTAINS had attracted attention from the Swedish Government. On June 23,
2004, the Government decided to give supplementary instructions to the ongoing

Commission of Inquiry on Patient Data and Integrity (below referred to as the Commission). The instructions were that the legislation had to be reviewed and if relevant changed based on, among other things, the SUSTAINS' case. The project team was asked to collaborate with both the DI and the Ministry of Social Affairs, to assist the Commission.

Aligning the law and the technical norms (2004-2011)

Despite the content of the Court's decision, it constituted the beginning of a new and constructive phase in the development process. Digital access to health accounts was reintroduced at the private practitioner's primary care clinic, which was made possible by a creative turn from Ted and the rest of the project team. The development project was declared to be a research project, which constituted an exemption from the legislation. Towards academia, the project team now used the acronym *SPRIG – Shared Patient Records in General Practice* and Ted was referred to as the research project manager.

The research work was preceded by an application for ethical review in accordance with the Ethical Review Act (2003:460). The application emphasized the project's importance for the Commission's work and made it abundantly clear that the project's overall aim was to contribute to the change of an ineffective and inexpedient legislation by using a research approach (November 16, 2004):

> Without any doubt, some modern legislation involving data processing has been over hasty and decided without previous empirical studies.

The application focused on the patients' perspective, and the importance of patients' digital access to healthcare information. The project team also pointed out that the research results might be of interest for different healthcare organizations, enabling them to "draw conclusions concerning the effectiveness of the services." Once again, the UCC supported the project and the County Council Director signed an assurance that the UCC would provide the resources required to complete the research project. The work of the project team members, now defined as researchers, continued at the general practitioner's healthcare clinic. Questionnaires were distributed to patients using the health account but the actual reporting of the scientific findings was limited.

Meanwhile the process of changing the law continued and in the Commission's final official report, SOU 2006:82, some references were made to experiences in the two SUSTAINS Projects. The argumentation was easily recognized from the previous debates. The patients' digital access to health accounts gave them an opportunity to participate in and influence their own healthcare. Another quite familiar argument was the patients' roles as controllers and verifiers that the information they provided was correctly reproduced in their medical record. Finally, on July 1, 2008, the Patient Data Act came into force, which changed the patients' rights to healthcare information extensively. One of the changes

was that patient's digital access to their own healthcare information including medical records now became legal.

Formally, the research project continued until 2011 but in practice the project team (research team) changed focus and direction in 2008 due to the legal changes allowing a large-scale deployment of digital health accounts. From 2009 on, the project team focused on resolving security issues, confidentiality, integrity, traceability and availability. The project team also started to work on regulations for the digital access of medical records. Most of the technological issues concerned patients' access to their medical records and solutions were sought in cooperation with the software consultant *EVRY*. Some of the concerns evolved around the authentication mechanisms and that the information would be transferred from the medical records, stored in the healthcare IT system, to a platform wherefrom it was made accessible to patients through the health account.

Local politicians gradually became more involved in the deployment process and in 2009, members of the project team and three politicians approached the European Union concerning the possibility of creating a European consortium for "digital medical records and patient empowerment". From this point, the work continued both locally and on the European level. In October 2010, a European interest group was founded, involving representatives from almost every member state. At the beginning of 2011, the *ICT PSP Fifth Call* was released. The overall aim of the call was "empowering patients and supporting widespread deployment of telemedicine services" and the time for preparatory work was limited:

> Then we had three months to complete this [the application] and by that time we already had a pre-designed consortium. We were 16 organizations representing 11 countries [...] and after the holidays we were called to the first hearing (Ted, June 11, 2012).

The application from the recently formed consortium was approved by the EU Commission and November 2011 became the starting point for a three-year European deployment project, once again called SUSTAINS. The UCC became the principal and coordinator of the project and Ted its manager. SUSTAINS had thus reentered an international arena, now as a deployment project.

Patient empowerment encounters professional autonomy (2012)

The deployment project (SUSTAINS III) started with a kick off meeting in Uppsala in January 2012. The health account or digital platform was now called *My medical record on the Internet*. Although access to medical records was just one of twelve services, it was perceived as the most important. Again the project attracted media attention. The newspapers reported on an imminent development characterized by patient empowerment and patient participation but also about the UCC "taking on a leading role". The citizens in Uppsala would be the first to get digital access to their medical records. The news upset some members of the medical profession whose immediate response was to express perceived threats

and misgivings about the deployment. The project was considered rash as well as lacking the support of the medical profession. In the local radio news, *Upplandsnytt,* the chairperson of the local medical association described the project as "operated by politicians and IT geeks". The dispute between the medical profession and the deployment project was fundamental and apparent to the public.

The conflict with the local medical association deepened during the spring 2012 and in February, due to lack of cooperation with the employees' associations, the UCC was accused of violating the Employee Participation in Decision-Making Act (1976:580) and the Work Environment Act (1977:1160).

The deployment project focused on establishing local regulations concerning digital access to and the use of medical records. As described by Ted, the former IT strategist, project manager and now coordinator of the European SUSTAINS consortium, the process was anything but simple. In an interview with the *IT in Healthcare* (*IT i vården)* magazine, he concluded, "reaching consensus on this [the local regulations] is like mediating peace in the Middle East" (April 19, 2012). The relationship between the local medical association and the deployment project became increasingly strained.

The arguments posed by the medical professionals focused on two separate, but closely connected, sub-questions: patient security and the patients' ability to understand their medical records. The professionals felt that the terminology might be difficult for lay patients to understand and that the professional practice of including suspected diagnoses to be further investigated might be interpreted as "the final verdict". The medical profession's criticism stressed that professionals would become unwilling to use medical records as communication tools, which in the long run would increase the risk for malpractice and misunderstandings. Medical records were primarily viewed as working tools for the professionals; thus patient accessibility could endanger the records effectiveness and value.

Another prominent argument against patient access concerned the initial ambition to include non-verified and non-proofread entries in the medical records. The medical professionals heavily criticized this decision and strongly argued, that doctors had to have a two-week respite to proofread the records to avoid misunderstandings and errors. The professionals emphasized that there could be considerable health risks for patients if non-verified information were accessible.

The local debate in Uppsala resulted in a political decision to postpone patient access from the summer of 2012 to November 2012 when the actual deployment of *My health record on the Internet* took place.

In an attempt to explain the strong professional reaction, some of the respondents in the interview study argued that this could be caused by worries that the patients, due to enhanced transparency, would be able to monitor and control the professionals. The professionals regarded the patients' immediate access through the Internet as a means of control, more than a service to the patients.

As shown above the development and deployment of the civic service *My health record on the Internet*" in UCC was characterized by expectations and concerns from several different actors throughout the fifteen year long period. Our story ends in November 2012 when the service was made accessible on a broad scale in UCC. And by the end of May 2014, one and a half years later, more than 65,000 people had accessed their medical records through the service.

Discussion

In this section we return to the research questions posed in the introduction.

The actors involved in the development process

According to Pinch and Bijker it is important to identify "relevant social groups" or actors (1984, p. 414) that are concerned with the development of a technology (in their terms, "the artifact") as the development and implementation of a technology will be affected by the actors taking part in the process as they identify different problems and solutions throughout the process. Constantinides and Barrett (2006) point out that some of these actors are more important than others in terms of legitimizing the project and that IT implementation in healthcare is often unsuccessful as the implementers fail in building commitment amongst the different interest groups and individuals or key actors.

There were several different actors, both internal and external to the County Council, that were involved in or claimed the authority to be involved in the development of the eHealth service throughout the development process. The first and most important actor was, of course, Ted with his project team. In addition to running the project, the team formulated and presented the aims and arguments for the project to the outside supporting and opposing groups to gain legitimacy. The team also functioned as a procurer for the inscribers – the technicians active in the inscription process of the technical norms (cf. Czarniawska, 2009).

The role of the inscribers, members of the UCC project team, software consultancies and academia, was to find solutions to the requests and/or requirements handed to them by the project team, converting or translating them into technical norms.

The UCC also played a central role because its management and legal department were formally and legally responsible for the project and had an important role in supporting the project team, especially in confronting formal and legal obstacles. The UCC politicians, in turn, also supported the project but were most active in supporting and marketing the project to make it included in the EU call from 2009 on.

Initially, the UCC project team, the private practitioner and the patients were the most active actors pursuing the task of developing and testing the health account. However, the only patients active in the development process were those who happened to be enrolled with the private practitioner testing the technology. Apart from that, the patients as actors are remarkably absent from the

process. Instead, their interests were more or less taken over by all other actors (cf. Pinch & Bijker, 1984).

When the development project came in conflict with the law, the Government acted on behalf of the citizens or patients when it demanded the Commission of Inquiry on Patient Data and Integrity to cooperate with the development project in the revision of the law. This shows that in the development of a technology aimed at citizens authorities may direct the process by appointing a group of actors to find a common solution to a certain problem (cf. Pinch & Bijker, 1984). The solution, proposed by such a group, automatically gains legitimacy, as it is sanctioned by important actors, in the process (Constantinides & Barrett, 2006).

The local medical association's claim that its members, in part at least, contested patient access to medical records in order to protect patients from harm was, however, not given the same credibility. Thus, the medical profession was not really perceived as a legitimate actor in the development process.

Apart from the actors mentioned, the project team and UCC also cooperated with and/or committed deliverables to actors that were not trying to affect the inscription process as such, but who took an active stand for the development process, giving it legitimization and/or funding. Examples of these actors included the Knowledge Foundation, the Ministry of Social Affairs and the EU Commission.

The ideologies, values and technical norms

In the beginning, the parallel to the home banking or Internet banking was one of the most prevalent descriptions of and argumentation for the development of eHealth services in the UCC portion of the SUSTAINS project. Even calling it a health account was inspired by the banking system. This was similar to the rhetoric used in connection with many of the NPM reforms in Sweden: Ideas and technologies coming from the private sector are used as a role model for the public sector in general and healthcare in particular (Jonnergård & Erlingsdóttir, 2012).

In this phase it was primarily technical norms for machine behavior (Joerges & Czarniawska, 1998; Czarniawska, 2009) that were in focus as the technicians sought solutions for patient access to the IT system. The technology was not new, since it already existed in banking and the development process was thus more an adjustment to the context than a totally new technical solution (cf. Leonardi & Barley, 2008).

Gradually patient participation and empowerment through digital access to their medical information became the main argument for the eHealth service, emphasized by most of the key actors. However, most of the technological development was concerned with inscribing technical norms in the form of security configurations and restrictions for users. This illustrates the conflict between the aim of enhanced patient empowerment and the legal and ethical norms of technological security and integrity when handling sensitive information. Collste

(2011) points out that the digitalization of patient records increases the vulnerability of privacy protection. As security issues are not meant to be manipulated by the user, they are inscribed into the norms for machine behavior, which means that they can only be altered or enacted (Joerges & Czarniawska, 1998; Orlikowski, 2000) by technical experts with access to the system, not by the ultimate user.

Later in the process, it was time to formulate regulations about who should have access to their medical records through the Internet and what information should be accessible as well as when. These matters concerned both norms for machine behavior, since technical norms were inscribed into the IT system concerning who could access it, and technical action norms since the regulations also concerned how patients could access the system (Joerges & Czarniawska, 1998). According to Contini and Lanzara (2009), ICT technical standards and software codes can become regulative, supplementing legal norms and regulations. Formulating the regulations for Internet access was thus an important but also a delicate matter as the regulations could become a model for future deployment of the service, both on national and EU levels. The regulations also stabilized the technology in Pinch and Bijker's (1984) terms, as some of its features were defined and may, over time, be taken for granted.

Having only limited experiences from the private primary care clinic on how patients perceived the service, the project team had to base their work to a large extent on hypotheses about the best technological solutions. The technical norms inscribed into the technology were thus based on a combination of what was legally defendable, technically possible and justifiable from the patient empowerment perspective.

The arguments for patient participation and empowerment through eHealth services were that it would enhance patient safety. The medical profession, on the contrary, argued that patients' access to their medical records could be detrimental for patient safety and integrity as the information contained was not written for the patients but for storing and sharing with other medical professionals. Arguments put forth by the key organizers of healthcare about enhanced possibilities to access information from the IT system enabling financial measurements as well as measurements of quality and outcomes, were perceived as a possibility from both sides. However, as we show below, these were overshadowed by the dispute between the deployment project and the medical professionals.

Conflicts and negotiations

Spicer (2005) states that technology use is "shaped by a political process involving a variety of actors" (p. 686). In such a process different actors (or groups) will negotiate which norms are to be inscribed into the technology. These negotiations can reveal different preferences among the actors and conflicts may arise (Constantinides & Barrett, 2006; Spicer, 2005) that in turn will prolong the time span of the development of the technology (Pinch & Bijker, 1984).

The development of the eHealth service in the UCC could probably have been a rather fast process had it not encountered several contestations along the way. The first challenge can be seen as what Pinch and Bijker (1984) call a conflict between different technological requirements. This conflict emerged when the technical norms of data security in healthcare clashed with the aims of the development project. The conflict also shows that the seemingly homogeneous group of technicians at the UCC actually composed two groups: those participating in the development process in favor of swift solutions for patient access, and the IT security group focusing on security issues (cf. Pinch & Bijker, 1984). This may also indicate that the project team had not made enough effort to gain a commitment from the IT security group (Constantinides & Barett, 2006).

The next conflict arose when the developers wanted to implement the eHealth service on a broad front in UCC. Using a technology originally developed in another sector (banking) was a manifestation of innovativeness and entrepreneurship, but as the developing technology encountered the legal system, the development was temporarily terminated. According to the legislation at that time, this form of patient access was considered illegal. The technical action norms inscribed into home banking were legal in the banking context but not in the healthcare context (cf. Czarniawska, 2009).

It is not unusual that the legislation in an area is challenged by technological development (Lanzara, 2009) that in practice forces a revision of the law. In this case the legislation lagged behind as it dictated the inscription of technical norms into the IT system that did not take into account new uses and new users of healthcare information made possible by the Internet. By transforming the development and deployment project into a research project, and becoming a part of the governmental process to change the legislation, the developing technology along with the project team became part of the negotiation process in which new norms were inscribed into the legislation. The context or the arena for negotiation was also altered in a way that made it possible for the development project to both continue the development of the technology and to take part in the negotiation of the norms inscribed both into the technology and into the law, thus aligning the two sets of norms. A research project thus had more legitimacy than a development project in that situation (cf. Spicer, 2005; Constantinides & Barett, 2006).

The third conflict arose when the medical professionals became much more active actors by taking part in an increasingly public debate when SUSTAINS III entered the deployment phase and prepared for a full-scale deployment in UCC in 2012.

There were several parallel problems in the conflict between the deployment project and the medical professionals. The main standpoint of the local medical association was contesting patients' access to their medical records on the Internet all together. This can be interpreted as a fight between the deployment project and the medical association about who has the right to inscribe new technical norms into the IT system. The doctors viewed the medical records as their working instrument and did not want patients to have immediate and easy access

to them. They thus wanted to control both the technical action norms and the norms for machine behavior (cf. Joerges & Czarniawska, 1998) of the IT system so that it would be kept inaccessible for patients.

Another argument put forth by the local medical association was that patients would not understand the information in their medical records and could be harmed by alarming information they did not comprehend. The medical association claimed that this would harm the doctors' work environment as they could be inundated by questions from alarmed and/or inquisitive patients. The project team waved off these arguments as they were quite convinced that the eHealth service would not have any major consequences for the doctors' work process. Moreover, neither the project team nor their allies thought that the service concerned the doctors at all, as it, from their point of view did not require any new actions or altered work processes on the doctors' behalf.

According to Jeffcott and Johnson (2002), one of the main reasons for failure of IT deployment in healthcare can be traced to its damaging effect on work environments. The resistance from the doctors could thus be caused both by their disbelief in the technology as such and the effect they expected it to have on their work practices (Constantinides & Barrett, 2006). This may also be a reason why the medical profession got so upset when they did not control the interpretation of how the new technology would affect their existing practice (Eriksson-Zetterquist et. al., 2009). The medical association's actions can thus be understood as a desire to protect the doctors' work environment by obstructing the deployment process.

However, the local medical association was on a collision course with the opinion held by the key actors engaged in the deployment project. The project team, the UCC politicians, the Government and the EU Commission alike, were committed to the task of enhancing patient participation and empowerment by giving patients digital access to their medical information. As a pioneer project, SUSTAINS had been struggling for legitimacy, which it clearly gained both inside and outside the UCC by becoming the coordinator of the EU project in late 2011. This took place at the same time as the issues that the project team was working on were lifted to a new level. The project was not just a local event any more, but had become a pilot project for Europe giving the deployment project new status and power (Spicer, 2005; Constantinides & Barett, 2006).

Constraints and affordances

The inscriptions made into the technology evolved around directing the agency of the patient (Constantinides & Barrett, 2006; Leonardi & Barley, 2008), the affordance being the access to information and the constraints being the patients' inability to alter the information and restrictions on how and by whom the information could be accessed.

Doctors traditionally have had power over the medical records, which has given them a certain advantage in their relation with the patient. This can be interpreted as them acquiring an advantage through information access according to Walsham (2001). The deployment project together with the UCC politicians,

on the other hand, wanted to offer affordance to the patients by giving them access to their medical records, as Leonardi and Barleys (2008) put it, allowing them to do new things they were not able to do before. The power of the technicians and politicians were thus butting up against the power of the medical profession.

However, the power of the law is indisputable and the new law, in the form of the Patient Data Act, was in the deployment project's favor: Patient empowerment was prioritized over the autonomy and doubts of the medical professionals. The law thus set a standard for the possible inscription of the technology and the affordance that can be given to patients (Constantinides & Barrett, 2006; Leonardi & Barley, 2008).

Conclusions

The study offers insight into how the paradigm shift, brought about by eHealth, has materialized and how it encounters existing social, technical and legal norms. Institutional boundaries are challenged because *My medical record on the Internet* alters the balance between patient empowerment and the autonomy of the profession (cf. Freidson, 2001). The technical norms inscribed into the service enable a revolt against the institution (Czarniawska 2009, p. 62) that takes for granted that only medical professionals should be allowed to access and control medical records. The revolt is not to be found in the technology facing the medical profession per se – which does not change – but in the affordances that the new inscriptions offer to patients.

However, the medical association may be justified in its fears that patients' access to their medical records may have unintended side effects that can negatively affect the doctors' work environment. We thus suggest complementing Joerges and Czarniawska's (1998) three-norm framework with a fourth type of technical norms – norms for man-made environments. For this case this implies norms prescribing into the technology its effects on the doctors' work environment that can be tolerated.

Another conclusion is that legislation lags behind when new technological paradigms are introduced into society. The norms of patient participation and empowerment were in conflict with the current law when inscribed into the technology of the service. As the service and thus the technology matched the overall norms of society, the law had to be changed. The law was thus in part, inscribed by the new technology.

We also conclude that we must not underrate the importance of Ted – the local enthusiast – during the process in his several roles as the IT strategist, project manager, researcher as well as coordinator of the international consortium. His entrepreneurship and persistence in seeing the project through has probably had a vast impact on the development project. However, we also note that he and the project needed support of local politicians and the legitimacy of the EU consortium to prevail. This shows that new technologies just as other new ideas are dependent on the general "zeit geist" in society (Czarniawska & Joerges, 1996).

In fact, without the "zeit geist" in favor of patient participation and empowerment, the paradigm shift of eHealth would not be at all possible.

The NPM's introduction of the patient as a consumer in healthcare may well have paved the way for demands for increased patient participation. Still there are differences in the rhetoric for patient participation and the rhetoric for the patient as a customer. The connotation of "the customer" is linked to markets, freedom of choice and consumer rights (Nordgren, 2003). The argumentation for patient empowerment and participation is, on one hand, close to the customer concept: that the patient should have freedom of choice when it comes to health clinics, the right to medical records and so forth. On the other hand, increased participation is about patients taking a more active part in the healthcare process as a means to address future resource scarcity and an ageing population. Increased patient participation of this kind requires improved access to information. This aspect of the patient participation argument is different from the NPM's rhetoric that advocates more service to the costumer/patient (Nordgren, 2003). This indicates that public agencies no longer see efficiency of the healthcare sector as a sufficient solution to the resource problems; everyone will have to pitch in and eHealth may be one of the means to realize this aim.

Acknowledgement

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