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# **eHealth services, patient empowerment and professional accountability –**

## **An empirical study on the changing patient-doctor relationship in the digital world.**

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*First draft – please do not quote*

In Sweden, as in many other European countries, government and public agencies have promoted the expansion of eHealth over the past years, arguing that this development enhances patient participation, empowerment and cost efficiency. The development is part of a more comprehensive movement, emphasizing patient's rights including options to make far reaching decisions concerning the patient's own care and treatment. This study focuses on the deployment of one such eHealth service – the patients' digital access to their own medical records over the Internet. The use of electronic patient records (EPRs) is reported as being one of the most important services within the development of eHealth services and constitute a prominent part of the movement towards computerization in healthcare overall. In November 2012, the eHealth service "My medical record on the internet" was introduced in Uppsala County Council and the same civic service was introduced in another Swedish county council, Region Skåne, in March 2014. Both launches have caused resistance and, in some cases, strong negative reactions among many of the medical professionals. Simultaneously, the

actions of the medical professionals have been discussed as well as criticized by other actors participating in the development process.

A prominent part of the medical profession's critique towards the introduction of EPR pivots around a more or less pronounced resistance against the transformed and enhanced transparency initiated by the technological development – that is the computerization (Freidson, 1985). As the medical professionals' work becomes more transparent, the opportunities to request explanations and justifications concerning decisions and actions is enhanced (Sinclair, 1995). The computerization transforms the professionals' accountability in relation to different actor groups, patients as well as managers, politicians and auditors (Freidson, 1985; Wintereik et al, 2007). Among the opinions expressed in the public debate caused by the launches, a common fear among the professionals is that the autonomy of the medical profession is expected to change and decrease. The autonomy of particularly the medical profession in relation to organisational governing and control systems has been frequently discussed in research literature (Abbott, 1988; Abernathy & Stoelwinder, 1995; Abernathy et al, 2007; Kurunmäki, 2004; Kurunmäki & Miller, 2006). Less attention has been drawn towards professional transparency versus autonomy in relation to the patients.

The aim of this paper is to contribute to the academic debate on professional accountability by increasing our knowledge concerning the medical professions in a situation characterised by increased transparency in the patient-doctor relationship. Our focus will be on two separate but related questions:

- How the medical profession act and react as the patients get direct digital access to their medical records?
- How other actors involved in, or with interests in, the deployment process perceive the actions and reactions of the medical profession?

## **Accountability, transparency and professions – some theoretical considerations**

### **Accountability and transparency**

During the past decades, calls for increased transparency and accountability have been frequent both in the academic and in the public debate (Messner, 2009; Roberts, 2009). The two concepts are closely connected and are sometimes considered as synonyms and

sometimes as interdependent – transparency is a prerequisite for accountability. According to Roberts (2009) the concepts relate to each other as follows:

This is precisely the promise of transparency as a mechanism of accountability, to cast light upon what would otherwise remain obscure or invisible and to do so in order to provide the basis for confidence for distant others.

The transformation of transparency, and therefore the conditions for accountability, constitute important means to govern and control organizations (Roberts & Scapens, 1985; Munro & Mouritsen, 1996; Messner, 2009; Roberts, 2009). The managerial level may change the behaviour of an actor by changing the way the actor's work becomes transparent to others. This is particularly the case in highly professionalised contexts characterised by high complexity and multidimensional goals (Kraus & Lindholm, 2010). On the other hand, the disadvantage of such powerful means to govern and control is that the actors' reactions to the changed transparency might be unexpected and initiate undesirable behaviour (Roberts, 1991).

Research within the field of business studies and accounting have showed that ambitions to change accountability within public sector organizations have guided the New Public Management movement (Hood, 1991; Hood, 1995). The development has been characterised by implementation of management accounting models aiming towards increased cost efficiency and output control. By making professional actors, such as medical doctors, accountable for making profits and fulfilling financial goals, the professionals' accountability has changed towards an increase in managerial accountability (Hood, 1995; Sinclair, 1995; Olson et al, 2001). Frequently this development has caused resistance among the professionals who claim that the increased awareness of financial considerations has been induced at the expense of professional accountability such as professional quality and ethical considerations (Kurunmäki, 2004).

In parallel, the professionals' work has been visualized by the increased use of performance measurement systems, emphasising and assessing quality indicators (Jonnergård & Erlingsdottir, 2012). Such indicators are compiled into comparisons both on national and international level and published in joint reports in order to rank healthcare organizations (Blomgren & Waks, 2011). Accordingly, the demands on the medical profession to explain and justify conduct are constantly changing and increasing. Therefore, in their daily conduct, the medical professionals encounter a web of sometimes conflicting and incompatible accountabilities (Sinclair, 1995).

Research on accountability shows efforts to develop and differentiate the basic definition of accountability – to explain and justify reasons for daily conduct (Roberts & Scapens, 1985; Roberts, 1991, Sinclair, 1995) – in order to enhance the understanding as well as the potential of the concept. Boland and Schulze (1996) define accountability by using two separate dimensions: the actors' willingness and the actors' capacity to explain and justify. Thus, accountability involves both how the actors perceive different obligations as well as the ways and methods used to explain conduct with a story understood and accepted by other actors. This distinction is particularly relevant when analysing how actors perceive changing accountability due to technological changes.

#### *Actors' willingness to explain and justify*

An actor's decision to explain or justify reasons for conduct is to a large extent decided by the actor's desire to control how, one is perceived, by other actors within a social system. Accountability is constructed within processes where actors continuously interact and over time create images – identities – in the minds of other actors (Willmott, 1996). The occurrence of interactions and relationships are pivotal to the concept of accountability - to be accountable requires an audience (Checkland et al, 2004). Within organizations, accountability is often, though not exclusively, related to the distribution of power and control. Actors are, on formal grounds, accountable to the management or executive level, for example by giving accounts produced within the management accounting system. Such hierarchical accountability is defined as a form of accountability associated with alienation, feelings of uncertainty as well as triggering the creation of strategies to prevent accusations of shortcomings and mistakes (Roberts, 1991, Roberts, 1996).

Another situation where the construction of accountability is characterised by uncertainty and an urge to avoid accusations and public disapproval, is the common publishing of media articles and reports indicating that someone's lack of accountability has meant drastic consequences to other people (An & Gower, 2009). The impact of such media reports is substantial, as they demand explanations and justifications concerning topics of great importance to the public such as bank crisis or healthcare scandals (Roberts, 2009). These situations have some common traits. They are highly emotional and the accountable actors, such as politicians responsible for the maltreatment of the frail elderly, face disapproval and strong reactions from an indignant public.

Lately, research on accountability has focussed on the risks connected with calls for accountability, particularly in the public debate. The increasing demands for explanations and

justifications have caused actors to first and foremost protect oneself from disregard (Roberts, 2009; Messner, 2009; Joannides, 2012; McKernan, 2012). In opposition to the public debate, this research concludes that not all transparency is constructive, particularly not complete transparency, which is described as 'an alluring but also terrifying idea(l)' (Robert, 2009). Using the financial markets and the credit crisis as examples, researchers request limitations and a more intelligent accountability, characterised by humility and ethical considerations. Understanding the construction of accountability in practice also requires an understanding of actors' counter strategies – of some researchers called accountertability – to resist accountability (Kamuf, 2007; Joannides, 2012).

### *Actors' capacity to explain and justify*

The second part of the definition of accountability pivots around different means available to explain and justify reasons for conduct. Previous research has focussed on the distinction between numerical and narrative accounts, where numerical accounts such as statistics and accounting numbers have been proved to be particularly convincing to the accountability audience. Being able to explain by using numerical accounts - transparency through measurement (McSweeney, 1996) – creates a particular trustworthiness in a society more and more obsessed with statistics (Munro, 1996). On the other hand, it is important to notice that numerical accounts in isolation are unable to create understanding and context. Numerical accounts must be combined with narrative accounts to create a story believable to other actors – to explain and justify reasons for conduct (Boland & Schulze, 1996).

A central theme in the academic debate on accountability in highly professionalised contexts has been the perceived problems to measure and assess complexities, for example in the work performed by the medical profession (Kurunmäki, 2004; Kurunmäki & Miller, 2006). The value of decisions and actions guided by professional ethics are considered extremely difficult to measure and compare. Such arguments have been considered particularly relevant in discussions concerning New Public Management when subtle values have to compete with established financial measures such as cost efficiency. Critical voices have emphasised that accounting numbers and measurements has created a distorted transparency, governing healthcare towards behaviour in conflict with values created within the medical profession (Abernathy et al, 2007; Sinclair, 1995). Actors' capacity to give accounts is also affected by technology and technological development, such as computerization. Digital access to information over the Internet changes and enhances the conditions for transparency drastically (Freidson, 1985; Checkland et al, 2004).

### **Professions, professional accountability and computerization**

Within highly professionalised contexts, such as hospitals, decisions and actions are based on established codes of patient-centred ethics and conduct as well as professional cultures (Abbott, 1988). According to previous studies on professions, a person with a high professional orientation is one who primarily identifies with his/hers professional group, is committed to developing and retaining the power and prestige of the profession, develops an abstract knowledge system and looks to professional colleagues both within and outside the organisation for support (Abbott, 1988; Freidson, 1986). Decisions and actions are governed by professional knowledge, which, where ongoing controls are concerned, makes the professional actor autonomous to some degree in relation to organisational rules and regulations. The degree of this autonomy is dependent upon the strength of the profession. Being regarded as trustworthy and knowledgeable is of vital importance to the medical profession, both in relation to the patients and to the actors governing and controlling the healthcare organizations. The profession's degree of autonomy depends to a large extent on its capability to create positive images of the profession and the profession's willingness to accept and handle accountability issues. Sinclair (1995) defines professional accountability as follows:

Professional accountability invokes the sense of duty that one has as a member of a professional or expert group, which in turn occupies a privileged and knowledgeable position in society.

From the medical professionals' point of view, explanations and justifications of conduct create visibility and opportunities to be regarded as knowledgeable and responsible experts. Related to the computerization movement and the development of electronic patient records, a vital question concerns the accountability audience. Who are the primary receivers of the digital accounts given within the medical records?

### ***The patient as the primary receiver of digital accounts***

The medical profession, as well as professions such as lawyers and accountants, are characterized by a strong patient/client orientation. At the same time, the status of a profession is dependent on a substantial knowledge gap between the professional and the patients. Such knowledge gap creates, maybe paradoxically, trust in the relationship as the patients lacks sufficient knowledge to demand explanations and justifications from the professional (Freidson, 1985). As the patients become more knowledgeable, the professions

privileged position changes and decreases. The erosion of the knowledge gap decreases the trust within the patient-doctor relationship, initiating a process of deprofessionalization (ibid).

As early as in 1985, Freidson argued that computerization may contribute to the decreasing of the knowledge gap as more and more information become easily accessible. Still it is important to question whether the computerization of new knowledge increases the capacity of lay people to use or understand such information. According to Freidson, the key question is whether laymen are able to mobilise sufficient motivation to become knowledgeable to the extent that they will be able to challenge the professional actors. Checkland et al (2004) argue, somewhat in opposition to Freidson, that the former adage “trust me, I am a professional” is obsolete in today’s society. They emphasise that direct access to information over the Internet may contribute to enhanced trust in the patient-doctor relationship as the patient becomes knowledgeable and enlightened.

#### *Politicians and auditors as the primary receivers of digital accounts*

From a governmental point of view, the enhanced transparency increases the opportunities to govern and control the professional actors, for example by implementing performance measurement systems and/or explicit quality requests. This is also the case when it comes to electronic patient records as the computerization of such data increases the opportunities to compile large amounts of data in order to assess and compare professional performance. Previous research has shown that medical professionals (general practitioners) did welcome the implementation and development of electronic patient records as an opportunity to visualize the outcome of their work to the management level in the healthcare organization (Wintereik et al, 2007). This form of accountability, connected to audit and auditors, was expected to increase the autonomy of the medical profession.

### **Research method**

The empirical material in this paper derives from three main sources:

- 1) Interviews with “key organizers” on both national and regional levels – primarily politicians, civil servants and technicians.
- 2) The open answers from a questionnaire sent to 1600 medical doctors in Uppsala County Council (400 respondents). The survey in UCC was conducted in June 2013 i. e. six months after the introduction of the service.
- 3) Interviews with medical doctors in Region Skåne.



The empirical material from the national and county council level derives from personal, qualitative, semi-structured, interviews (Silverman, 2005) carried out in the autumn of 2012 and spring of 2013. The 20 interviews, 6 from key organizers, 8 from Uppsala County Council, and 6 from Region Skåne, 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 two the county councils. The key organizers and the county councils that were approached were:

- The National Board of Health and Welfare (Socialstyrelsen)
- The Swedish Association of Local Authorities and Regions (SKL)
- The Center for eHealth in interaction (Centrum för eHälsa i samverkan, CeHis)
- The Swedish Data Inspection Board (Datainspektionen)
- Swedish Medical Association (Läkarförbundet)
- The Swedish Association of Health Professionals (Vårdförbundet)
- County Councils of Uppsala and Region Skåne.

The interview guide consisted of 13 questions and some sub-questions. All the interviews were recorded and transcribed. On the national level the interviews were conducted during Autumn 2012, that is, before the service “My medical record on the internet” was launched in Uppsala County Council and Region Skåne. The interviews in Region Skåne, on the County Council level were conducted prior to the implementation of the service in Region Skåne. In Uppsala County Council the interviews were conducted after the deployment process there. The main reason for this is that the situation was too tensed before the launch of the service due to strong negative reactions on behalf of the local branch of the Medical Association (the doctors’ union).

*In the survey in Uppsala* the questionnaire was constructed from suitable questions through a pilot study made by a medical student to a group of primary health care doctors assembled for a medical meeting in Uppsala, in February 14<sup>th</sup>, 2013. The questions were tested for reliability (Cronbachs’ $\alpha$ ) and validity (content-validity and face validity) with sufficient outcome (Hamne 2013). The questionnaire consisted of 24 statements where the magnitudes of agreement were given by help of a five-graded Likert scale. In the end there was an open question where the doctors could write their experiences or opinion of the patient’s direct access. The 144 statements in the questionnaire were related to how the deployment of the service had influenced the doctor’s workload, way of writing notes, patients’ interference etc.

as well as the doctors general opinion of the reform. The questionnaire was sent to all doctors in Uppsala (1600) in Uppsala County Council (400 respondents). It was distributed electronically in June 2013 i. e. six months after the introduction of the service. A reminder was sent out two weeks after the ordinary dispatch and 400 responses were collected of which 144 contained posts on the free answer space where the doctors could write their own comments.

*The interviews with the nine doctors in Region Skåne* was carried out during late summer and Autumn 2013 in form of personal, qualitative, semi-structured, interviews. The interview guide comprised 13 questions with some sub-questions. All interviews were conducted face to face on the doctors' workplaces and lasted on average 40 minutes. The interviews were all recorded and transcribed.

The aim was to get an idea of doctors' perception and experience of eHealth services in general and direct patient access to their medical record in particular. In addition, we asked about their knowledge about development and implementation of eHealth services both nationally and regionally. They were also asked question about patient participation in healthcare and were asked to define and/or give examples of what eHealth services might mean. The questions in the interview guide resembled the questions in the interview guide for the "key actors" with some adjustment for the profession. The interviews were carried out primarily during the autumn in 2013 i. e. prior to the implementation of the reform in Region Skåne. Five of the doctors worked in hospital wards in a university hospital in South Sweden and four of them in primary care (different clinics) in the same area.

## **Backdrop**

In Swedish healthcare, "eHealth services" has become a generic term for "healthcare using modern information and communication technologies" (Cehis, 2013, p. 5) where eHealth and eHealth services are used more or less as synonyms by public agencies.

The National Board of IT in Healthcare was established in 2005 by the Ministry of Social Affairs after an agreement between the government and the Swedish Association of Local Authorities and Regions on establishing close cooperation concerning development of IT in the healthcare sector. In 2006 the Board launched a national IT strategy for healthcare. The strategy's purpose was to function as support for local and regional work and to lay a foundation for intensified national cooperation. The strategy was directed towards five action areas: 1) harmonizing laws and regulations for extended use of IT, 2) creating a common

infrastructure, 3) creating a common technological structure, 4) enabling access to information across organization borders, 5) making information and services easily accessible to citizens.

The Center for eHealth in interaction (Centrum för eHälsa i samverkan, CeHis) was established in conjunction with the national strategy. CeHis's assignment is to coordinate the county councils concerning the common development of eHealth services, technical infrastructure and rules and regulations. CeHis has published a strategy for 2013-2018 in which eHealth is described as a paradigm shift in healthcare, changing established ways of thinking and requiring comprehensive transformation investments. The core issue is to increase the individual's possibilities to participate in his or her healthcare and to support citizens' engagement in their health. This is seen as a response to an ageing population and increasing pressure on healthcare. Even though the necessity of cooperation, and a common development of core services is stressed in the strategy, it is clearly stated that the responsibility and the decision are in the hands of the county councils/regions and the municipalities.

### **Implementing the service in Uppsala and Region Skåne**

The two county councils of Uppsala and Skåne represent quite different approaches to eHealth. All citizens in Uppsala County have had access to their medical record on the Internet site "My Healthcare Contacts" since November 2012. Uppsala County Council launched the EPRs as a part of the first step of the EU deployment project, SUSTAINS, where 12 different eHealth services were made accessible to citizens. The EPRs were made accessible together with other services such as booking online, choice of health centre, paying online. Even though the EPR is just one of twelve accessible services, it has been the most debated and criticized of them all. The most critical group is the medical profession and the local doctors' union. They expressed their disbelief in the service and have even tried to obstruct the project. However, the project on making electronic medical records accessible to patients has a longer history in Uppsala County Council than the deployment project or the national strategy.

In Region Skåne there is a political interest for the deployment of eHealth services and the rhetoric in Skåne is more about patient empowerment and participation but also about creating a prosperous climate for the development of eHealth businesses in the region, which can lead to expansion into international markets.

## Empirical findings

In the empirical section we first present the medical professionals reactions to the deployment of the service. This section includes the voices of the doctors, actively working in health care and presents data from the free answers to the questionnaire to all doctors in Uppsala County. The data from Region Skåne derives from interviews with nine doctors.

The next section presents the key organizers' expectations concerning patient digital access to their medical record. These actors are both on the national and county council level and can be civil servants, politicians and some even have their background in a medical profession but are then either representatives for a union or have a managerial position of some kind.

### Some voices from the medical profession

As the material from Uppsala County Council and from Region Skåne derives from two different types of data collection and were collected after respectively prior to the implementation of the service, we choose to present them separately.

#### *The questionnaire in Uppsala County Council*

Amongst the 144 free answers some themes emerged as the most common. Except for general comments on the reform, the themes are:

1. The medical record as the doctors' working tool
  - a. The contents of the medical record
  - b. Unsigned medical records
  - c. Transparency
  - d. Risks

#### General comments about the reform

Some of the respondents expressed very negative opinions on the reform as well as emotional answers like "Send the IT-morons to the dump", "Useless reform", "Totally unnecessary and unacceptable" and "...it even runs against the medical ethics: to never inflict damage" indicate that many respondents are upset by the deployment of patient digital access. There are also several comments on the aim of the reform i. e. enhanced patient participation and empowerment:

*Patients should be involved in their own care, but to introduce a general access to the medical record without a prior ethics review and acceptance amongst the professionals is not the right way to go!*

*I do not understand why “the record on the internet” is considered a means to increase participation in care. What facts is this based on?*

*Unfortunately I do not believe that this will contribute to the equality within healthcare at all.*

Some doctors point out that they have too little experience of the reform to have an opinion indicating that the questionnaire was sent out too soon:

*This survey is sent out too soon. The medical record on the Internet has not yet been established enough and most people do not know of it. Not even all of us doctors. More negative effects will come.*

One of the most common comments about the reform is that it might not be a bad idea in itself, but that the implementation was poorly performed. Primarily, the doctors criticize what they perceive as a lack of anchoring the reform amongst the professionals as well as insufficient preparation. Thus, the medical doctors protest against the fact that technicians and politicians have cooperated in a decision highly relevant to the medical profession and without sufficient professional collaboration. Still, there are some voices among the doctors emphasising that the development are in line with the requests for enhanced patient empowerment and participation.

*This is, in essence, a positive reform as the medical record belongs to the patients and is used as a tool by the healthcare system. Caregivers have no right to censor the records or to not provide them.*

This opinion is in line with the notion that the patients have right to access all information in the medical record and that the patient is the owner of the medical record. This interpretation is in contrast to the primary argument against patient access - the medical record as the doctors' working tool.

#### The medical record as the doctors' working tool

The most common comment of all is that the medical record is the medical professionals' working tool. The respondents stress that this tool will be affected by direct patient access as the doctors will change their writing style and censor the information put into the records. A general fear is that this, in turn, will dilute the information in the medical records and lead to increased patient risks. This argument derives from the fact that patients are transferred within and between different health care organizations and that the medical record contains information about the patient and his/her condition vital for the receiving doctor.

*Who owns the medical record? Is it the working tool of the healthcare professionals or the patients? What brings the greatest benefits; maximal information to the patients or maximal help? When you can't write everything you are thinking it becomes a conflict of interests and a risk that the patient does not get the best care.*

Another, but connected, argument is that the patients may oppose to the information written in the medical records and how it is expressed:

*In my opinion the medical record is primarily a working tool for doctors and other healthcare professionals. I see clear risks that you do not "dare" to express yourself, as one would have done otherwise, in fear of the patient taking offense.*

A major stumbling block for many medical doctors is that the patients are laymen without sufficient medical training and understanding:

*The records are working tools; the information in them is aimed for health care professionals. As most patients lack medical knowledge they may misunderstand things and that might harm them.*

The fact that patients can choose to read their medical records before they have been verified and proofread also upsets many of the doctors:

*I find it completely unethical that test results can be read before they are verified and proofread. People have had crisis reactions from this. Even worse is that the patient can access my notes before I've had a chance to correct any inaccuracies that occur time and again caused by indistinct dictating or because the secretary mishears or misunderstands. It is legally unsafe!*

The fear of being scrutinized as a doctor also seems to be interlaced in their reaction to digital patient access to medical records:

*I have to use a large part of my working hours to write "correct" records and formulations – I avoid important medical information in fear of patients reading and scrutinizing the comments. I avoid verifying the records until later when I know what to say to the patient. I fear entering the medical records as the logging is visible for the patient. It takes a lot of time to explain to patients what you mean etc. the patient googles information on possible hypothesis, and investigations and become unnecessarily concerned. My work as a doctor is affected in a strongly negative way, it takes more time, gives patients more worries, I do withhold important information automatically as I do not want to create unnecessary concern. I can't have a discussion through the medical record with my colleagues in a patient-safe way. FOR ME AS A DOCTOR THE WEBB-BASED MEDICAL RECORD IS PURELY NEGATIVE, I REFUSE TO WORK IN SUCH A CARE SYSTEM!*

Another comment:

*The experience is that the reasoning behind the reform is that transparency is of larger importance than good care.*

The doctors also express fear that patients and patient security can be at stake in a more concrete way:

*I'm also concerned that for instance abused women and immigrant women in risk of 'family honor violence' can be forced to show their medical record to their family members/spouse etc. via the internet and may be harmed as a result from this. I have heard concerns about this from patients and have been asked to lie/leave out information from the medical record so that their relatives will not be able to read about their doctor appointment.*

### ***The interviews with doctors in Region Skåne***

When the nine medical doctors were asked to name some eHealth services that they knew of, most of them were quite vague in their answers. Almost all wondered how one should define eHealth services and were asked to come up with a definition of their own. Several respondents referred to the digital prescription of medication and some to the digital transfer of radiographs but claimed that they hardly had any experience of civic services in form of eHealth. All the doctors knew about the service "My medical record on the internet" and most had learned about the service through the media debate concerning the deployment in Uppsala.

### ***The medical record as the doctors' working tool***

When asked what they thought of the service the answers became quite similar to the comments from the doctors in Uppsala. We can mainly detect two groups though amongst the doctors in Region Skåne: The first one claims to basically be positive towards patient direct access to their medical record but point out that the medical record is primarily a working tool for the doctors and that this may lead to conflicting interests as the service may affect the way that doctors handle information in the records. The problems they foresee was linked to all the themes we detected in the free answers from Uppsala: The medical record as the doctors' working tool, the risk of the contents of it being diluted, problems that might arise as a consequence of increased transparency of the doctors' work and the risks that the service could pose to patients:

*Principally I'm positive towards patients reading their medical records but I'm also aware of that it is problematic as the record is also a working tool for the care giver and one has to have the opportunity to write ones thoughts about a case or a diagnostic problem, and this one does long before one has found the right diagnosis or the right decision and a person without medical education who reads this can get quite concerned and worried if one*

*speculates about different diseases before one reaches the diagnoses. And maybe one also writes about social and economical conditions, drugs abuse, earlier diseases and hereditary diseases that also may concern the patient....And it will result in that one now is forced to become much more restrictive about what one writes in the medical record and then you will lose information and what is especially negative these days is that we have such a lack of continuity between patient and doctor, I mean that if I had a better continuity and relation to my patients it would have been easier to handle, but now I have to write things taking in to consideration that another doctor will meet them next time and that is where it becomes problematic.*

The other group was negative all together to the idea of eHealth and patient direct access to their medical record. Interestingly enough all the GPs were ranging between rather negative to extremely negative. Responding to the question what eHealth meant to him, one of the GPs responded “problems!”. When asked if he could think of possible positive effects of eHealth he answered “no!”. Another interesting thing about the GPs was that they had asked the other doctors at their Clinique how they felt about eHealth and patient direct access to their medical record, prior to the interviews, and thus more or less spoke for all of their colleagues. In one of the clinic the GP told us that “we are 10 doctors here and nine of us are strongly against the service (referring to “My medical record on the Internet”, our comment)”. Their fears of the service was basically the same as the doctors’ in the Uppsala survey but they were also more concerned about the affects it might have on their contact with the patient and seemed more convinced that the face to face relation between doctors and patients could and should not be replaced by different IT services:

*One can't attend to health over the telephone or the Internet, you have to see it, you have to be able to touch or listen...if the patient tries to describe a rash, it's hopeless. It may take me less than a second to recognize, I just see it and then I see that it is shingles. The patients can describe it for half an hour without me getting any wiser. It's a great difference when you meet face to face...*

*I'm quite skeptical towards these eHealth services and these apps that are coming....I think it is much better to find other ways to healthiness than these eHealth services.*

On the question about what they thought of patient participation in their own care, all doctors responded that they thought that it was important but also that they thought that patients already are involved in their own care. Still it was obvious that their interpretation of patient participation was patient participating when interacting with the doctor and not through the Internet:



*I feel that my patients could not be more involved than they already are. I think I already do everything I can to explain and let them choose what there is to choose between.*

*For me it (patient participation, our remark) means that patients participate in decisions about themselves. So in some situation instead of me taking the decision I do it in consensus with the patient.*

### **Discussion**

The respondents' reaction to the implementation of patient digital access to medical records show that they strongly disapprove of the development and that this disapproval pivots around the change in transparency in the patient-doctor relationship. The increased transparency will transform the professionals' accountability – according to the respondents' expectations in a dramatic way. The change of accountability audience appears to be the most prominent motive for professional resistance. The argument is that medical records are working tools for the medical professionals and that increased transparency, which follows from patient digital access, threatens that function and purpose of the record. Knowing that comments and remarks are transparent to the patient and not exclusively to other medical professionals appears as a major limitation. The respondents also refer to the knowledge gap between the patient and the doctor and emphasize that the patient is unable to understand the content of the medical record. The increased transparency, including the laymen patient, increases the risk of becoming accountable to situations over which they lack control and influence.

Another argument is that the patients' opportunities to read their own medical record will create situations where the patient feel a need to pose follow up questions – demand explanations and justifications - and therefore consume more and more of a scarce resource – the medical professionals' time. Explaining and justifying notes and entries in the medical records will become an additional work task for the medical professionals, one which is considered unnecessary to many of the respondents.

The empirical data indicate a connection between the two dimensions of accountability – willingness and capacity. The technological development – the computerization – has substantially changed and enhanced the professionals' means, that is capacity, to explain and justify reasons for conduct. The immediate response to that change is a reduction in the professionals' willingness to produce such accounts transparent to the patients. The traditional patient-doctor relationship is characterized by the knowledge gap, according to which the patient need to trust instead of question the doctor.

### Some voices from the key organizers

As one of the first questions in the interview the respondents were asked what they thought would be the most important impact of the introduction of eHealth services in general and patient access to their medical record in particular. The answers were quite unanimous and on a general level. The enhanced digitalization and access to information through eHealth services is presumed to lead to increased transparency of healthcare information and thus to enhanced possibility of control and quality. The most important reasons to implement patient access to their medical records is however claimed to be enhanced patient rights, empowerment and patient participation in their own care as well as to give patients better service. The representative for the The Swedish Association of Health Professionals expressed this as follows:

*...patients' opportunities to manage their own health, to take control over their own health situation, so to speak.*

And one of the politicians at a county level as:

*Well the major benefits are the easy way of communicating, that the patients get an opportunity to see what happens in their care, make appointments, read referrals and read their medical record, things like that. There will be a totally different level of communication between patients and caregivers. In that way the power relation between patient and caregivers will be evened, and I believe that is extremely important.*

This in turn is seen as a means to enhance patient security:

*The main motivation for developing eHealth services is that there are large gains to be made in patient security as patients can participate more in their own care (key organizer, SALAR).*

And efficiency in health care:

*...that it (eHealth out remark) provides an opportunity to ensure that the care and care chains become more efficient (One of the board members in CeHis).*

*Civic servants in higher management positions within healthcare in Sweden and politicians put an almost ridiculous trust in that eHealth and the IT-wave will save us from the bad that comes with an older population and an disability to increase the tax income so that the cost explosion will be met by some sort of "taking care of yourself at home" (IT-manager)*

Other than above, the respondents also mentioned that patients can check their data and correct misunderstandings and other flaws in the data. Patients are also expected to be better prepared for their appointments with doctors. Many of the respondents mention patients with chronic diseases as one of the most important groups for digital access to the medical record.

The respondents were also asked the question “Do you perceive different attitudes towards eHealth services between different healthcare professionals?” Many of the respondents answered that they perceived the healthcare professionals and foremost the doctors as conservative and negative towards eHealth services in general and patient direct access to medical records in particular:

*...the majority of the health care professionals are rather conservative towards this type of services. Not that they really have a particularly strong point of view but there is this culture of strong traditionalism within the work force...if we speak of patient access to their medical record they all claim that” this is our working tool and they are owned by us and exist for us and they concern nobody else”. And these eHealth services can come in conflict with a perspective like that. (Manager at UCC Hospital)*

Several of the respondents also pointed out that eHealth services means a paradigm shift for the doctors and that in it self creates concerns amongst them. One of the respondents, a representative for the Swedish Medical Association claimed that:

*...the paradigm shift leads to an enhanced audit...personally I have no problems with that but I understand that many that feel insecure from the beginning will perceive this (eHealth, our comment) as extremely problematic.*

In the same line of reasoning an IT manager in Region Skåne pointed out that the “paradigm shift”:

*... puts heavy demands on the profession to express themselves properly and more intelligible than they do today. So I think there is some kind of mixed emotions towards this as it will put a new type of demands on the profession in the future, which they are not at all familiar with today.*

Still some of the respondents are more nuanced and stress that one ought not to judge a whole profession by, what they perceive as, the reactions of some individuals amongst the profession. Or as one respondent from the national level puts it:

*One has to respect the fact that these are times of transition to new methods and that the changes have to be made with certain consideration. I do not know of any general resistance amongst healthcare professionals but there are single people and single groups and sometimes it is about habituation and even misunderstanding.*

## **Discussion**

The key organizers emphasize that the development constitutes a paradigm shift in the patient-doctor relationship. The respondents also stress that the professional resistance can be explained by the fact that the medical profession are conservative and unwilling to make

changes, particularly in the direction of increasing transparency and accountability. The key organizers first and foremost define the development as part of the more comprehensive movement towards enhancing patients' rights and participation. The service is not directed towards the medical profession even though it affects the professional actors.

Another argument presented by the key organizers is that patient digital access increases cost efficiency as well as professional discipline as the patient becomes "a voluntary and unpaid controller" in the health care system. From an accountability perspective, this part of the development is expected to enhance the possibilities to govern and control the medical profession by assistance from the patients.

### Concluding remarks

The study indicates that the recently launched eHealth service "My medical record on the internet" has the potential to change the medical professions accountability in the patient-doctor relationship. Direct digital access enhances patient empowerment as well as transparency which make the patient an active and participating actor instead of a passive patient in need of protection. The medical professionals to a larger extent may need to explain and justify their actions and decisions to an enlightened as well as controlling patient. This erosion of the knowledge-, as well as information-, gap triggers a changed and enhanced professional accountability. The traditional status of the medical professions partly depends on the professionals' decisions and actions being a mystery to the patient.

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