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### **Patients' Perceptions of their Medical Records from Different Subject Positions**

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## Abstract

Better knowledge of habits and preferences of patients helps to understand why and how they might need or want to access their medical records and other health and e-health services online and offline. Such knowledge provides a basis for designing new digital systems and mechanisms for providing complementary health information. The aim of this article is hence to report and discuss how patients' conceptualizations of their health information related preferences, motivations and needs are linked to the perceived role of medical records as an informational artifact and a source of different types of health related information. We identified seven subject positions: (P1) *Hypothetically positive to e-Health services generally*, (P2) *Positive to reading medical records due to implications*, (P3) *Positive to all internet use including medical records online* (P4) *Distrustful and wants to be in control of health treatment*, (P5) *Worried about health*, (P6) *Does not understand their medical record*, and (P7) *Wants communication with health care professionals*. The analysis shows how these subject positions can explain the mixed evidence of worry and enthusiasm documented in earlier literature. The diversity of subject positions implies that medical record and healthcare information services should be planned with different subject positions in mind rather than a simple demographic group. Special attention needs to be given to finding flexible solutions that address the opportunities and worries of the identified subject positions.

## 1 Introduction

Contemporary health care emphasizes giving patients a more active role in their care. A key factor in the empowering of patients is the provision of online access to health information and medical documentation of their condition, as well as previous and planned treatments and visits to healthcare providers (Munir & Boaden, 2001; Joubert et al., 2007; Hoerbst et al., 2010; Ammenwerth et al., 2012). In many countries patients have had the right to access their own medical records for a long time, but even if the number of studies is increasing, there is relatively little research on how and why patients use this facility (Fowles et al., 2004; Woods et al. 2013; Nazi et al. 2013). The upsurge of initiatives around the world to open online access to personal medical and health records (Pagliari et al., 2007) underlines the need for a better understanding of the needs and preferences of the actual users of these currently mostly non-digital services. Although it

may be speculated that the digital services are prone to attract new users, patients who are already accessing their medical records are likely to continue to do so using new digital tools. Therefore, a better understanding of the habits and preferences of the patients who already use medical records on paper helps to understand why and how they might need or want to access their medical records and other health and e-health services online and offline. Such an understanding provides a basis for designing new digital systems and mechanisms for providing complementary health information.

The aim of this article is to report and discuss how patients' conceptualizations of their health information related preferences, motivations and needs are linked to the perceived role of medical record as an informational artifact and a source of different types of health related information. The study uses the notion of interpretative repertoires (repertoires of premises to think about things in particular ways) from the discourse analysis of Potter and Wetherell (1988) to describe the factors identified using exploratory factor analysis (EFA) and their relation to the medical records. This exploratory study is based on the hypothesis that there are different practiced (i.e. activities rather than merely attitude based) interpretational repertoires that function as frames for how patients interpret their own medical records as informational artifacts. The analysis is based on results of a survey study (N=354, 35.4% response rate) of patients, residing in a Swedish county, who have ordered a copy of their medical record from the regional health care authority. The analysis revealed seven factors that underlie the preferences of patients consulting their medical records. These findings are useful for developing new tools for opening medical records for patients. Moreover, they provide new evidence on how and why patients are using their medical record and how the reading of medical records links to the use of other forms of health information.

## **2 Literature Review**

The development of e-Health services and the provision for giving patients access to their personal medical records are motivated by several diverse arguments. The contemporary policy climate is a cocktail of the ideals of commercialism, empowerment, (market) libertarian freedom, consumerism, technological utopianism and individual responsibility (e.g., Mager, 2012; Robertson & Vatrapu, 2010). In the context of

healthcare, consumerist ideals have translated into a desire to give patients more rights and responsibilities to take charge of their health and medical care (Huber & Gillaspay, 2011). It has been argued that giving patients an active role reduces errors (Institute of Medicine, 2001), decrease health care budgets (Bernabeo & Holmboe, 2013; Carman et al., 2013), give patients a better understanding of their condition (Ferreira et al., 2007), improve the quality of care, and the compliance of the patients (Sittig, 2002; Detmer et al., 2008). Another observation is that similar practical measures are advocated as a means to demedicalize healthcare (i.e. to broaden its focus from medical treatments to comprehensive care of health) and improve the rapport between medical doctors and their patients (Evans, 2007).

There is empirical evidence that active patients have better experiences and health outcomes (Hibbard & Greene, 2013). The study of Hibbard and Greene (2013) also suggests that it is possible to influence patients to become more active. In contrast to active patients, less active patients are associated with higher costs of health care (Hibbard et al., 2013). Many of the proponents of increasing the amount of personal responsibility taken by patients see the patient access to their medical records as a significant precondition of the anticipated healthcare revolution (e.g., Munir & Boaden, 2001; Sittig, 2002; Joubert et al., 2007; Gaunt, 2009; Hoerbst et al., 2010; Ammenwerth et al., 2012). At the same time, however, evidence of the causal correlation between providing access and/or accessing medical records and “patient activation” (Ross & Lin, 2003) or other positive outcomes is not conclusive (Ammenwerth et al., 2012).

Earlier surveys of patients and healthcare professionals show polarised attitudes. The management of medical records is a complex informational problem (Galvao & Ricarte, 2011). Medical knowledge is messy and consists of a blend of propositional, professional craft and personal knowledges (Robinson, 2010). Medical records have multiple functions and they are used by different groups of professionals for various purposes (Reddy & Bradner, 2005). The medical records must contain complex information on patients’ clinical history, but have to be flexible enough for a number of different purposes (Currie et al., 2009). Winman and Rystedt (2012) show how health care professionals use medical records as translatory rather than directly informative devices. When these types of professional knowledge are brought together with patients’ ways of knowing, a certain level of friction between the two types of knowledges is unavoidable.

A summary of issues related to making medical records available to patients was provided by Beard et al. (2012) and underlined the fact that many challenges revolve around the tenure of the records. It also anticipated both negative and positive outcomes of breaking established boundaries of professions and expertise. Even if there is a clear tendency to polarize these issues, in general, the breaking or maintenance of any boundaries tends to have both a positive and negative impact that goes beyond individual groups of stakeholders (e.g. Fennell et al. 1987; Denis et al., 1999; Desombre et al. 2006; Finn et al., 2010; Chreim et al., 2013). The eradication of the professional authority of clinicians can have a very real negative impact on health care. This does not mean that the professional authority needs to be based on the non-disclosure of information, but at the same time, there is a growing body of evidence that in general, the mere availability of information is not sufficient to address the information needs of non-professionals (Blandford & Attfield, 2010, p. 21).

It has been known for several decades (Michael & Bordley, 1982) that a large majority (up to 90% of the patients) tend to be positive towards the introduction of an access to the medical records (Ball et al., 2007) and that patients expect to access their records if the information were easily accessible on the internet (Ekendahl, 2011). In a slightly earlier study, Fowles et al. (2004) found that 36 % of the respondents (survey N=4500, response rate 81%) stated that they were very interested in reading their medical record. Interest correlated with active health information seeking, subscribing to a health newsletter, and the use of a health resource book in the month prior to the survey. The interested respondents were also likely to be very concerned about errors in care and lacked trust in their clinician. Health status, use of health care services, education, or income did not explain the interest. The most common reasons for patients wanting to consult their medical record were to see what their clinician had written about them.

Fowles et al. (2004) also found that the clinical characteristics of the patients were not as important as their consumption behavior (i.e. how and what types of services and information the patients were using) as an explanatory factor of their interest in reading their medical record. Gender was related to the interest, as the authors expected (men were less interested), whereas education and income were not. In 2001, Munir and Boaden (2001) concluded that the majority of the respondents of their study in the UK were in favor of being given access to records, but also that a majority still would not be interested in reading their record. They

also concluded that a majority of those who would read, would like to consult their records on paper rather than online. The findings of Ross et al. (2005) confirm this trend and underline the fact that some patients have strong feelings against accessing medical records online. Even if the higher age of the patients tends to correlate with lower interest in consulting online health information sources (Manafó & Wong, 2012; Pálsdóttir, 2005), it does not seem to be related to the interest in reading medical records.

Patients with poor health (Bhavnani et al., 2011) or chronic illness, frequent health care users and individuals caring for their close relatives are shown to have the greatest interest in medical records (Ball et al., 2007, see also Østerlund et al., 2010; Guy et al., 2012; Earnest, 2004). There are, however, studies showing that the interest in seeing medical records does not necessarily correlate with an actual behaviour. It has not been uncommon for only a small minority of patients to have ordered a copy of their medical records (Michael & Bordley, 1982; Ross & Lin, 2003).

The opinions of health care professionals regarding patient access to medical records are more split. Frequent users of health care services are often acknowledged as a fruitful audience for participatory care (e.g., Langel, 2013), but at the same time health care professionals have expressed concerns about the possibility of patients over-interpreting documented symptoms and thus becoming depressed at uncertain early diagnoses (Delbanco et al., 2010). The proponents of online access to medical records report more efficient use of time while the sceptics tend to be concerned with the opposite (Delbanco et al., 2010; Davies, 2012). The opening of medical records has also been conjectured to enhance patient participation in treatment, increase patients' knowledge and self-management, improve patient-provider interaction, increase patient safety, and to improve communication (Vaart van der et al., 2012). Health care professionals have raised concerns about the possible consequences of opening medical records (e.g., Ross & Lin, 2003; Allvin, 2011; Hackl et al., 2011) and have reservations accepting information patients themselves have sought on their condition (Henwood et al., 2003). Professionals have anticipated problems with extra workload, changes in visits and consultations, negative influences in the patient-provider interaction (Vaart van der et al., 2012) and physical security problems with, for instance, psychiatric patients (Brakoulis, 2013).

Patients are often worried about the confidentiality of the records (Delbanco et al., 2012; Ball et al., 2007;

Åhlfeldt and Söderström, 2010), even if only a minority tends to be aware of specific incidents (Ball et al., 2007). A related aspect of confidentiality is that a patient can violate the privacy of others (e.g., family members and healthcare professionals) by disclosing their own personal information (Chaytor et al., 2006). Patients with chronic conditions tend to be those most concerned with privacy issues, while at the same time those most willing to share information with their care providers (Ball et al., 2007). In a national US survey in 2005, only half of the respondents saw medical records of their 'own' information (Ball et al., 2007). In contrast, many health care professionals have a tendency to claim that they 'own' patients' medical records or parts of them either directly or indirectly (e.g., Vaart van der et al., 2012).

It has been argued that the observed challenges associated with opening patients' medical records relate to insufficient health information literacy of the patients, suboptimal clarity of medical records (Rudd et al., 1999) and the problems and availability of practical and reliable technologies and approaches for providing the access. Some of the systems have also been difficult to use for the patients, or have been developed for the provider (Davies, 2012) or physician (Archer et al., 2011) rather than with a user perspective, and this has limited their popularity and is suggested to have had a negative impact on the acceptance of future systems. Furthermore, it has been shown that the will and capability to use and master health related information resources have a significant correlation with self-appreciated social status, health and (in terms of the theory of Antonovsky, 1987) sense of coherence (Ek & Widén-Wulff, 2008).

Worries about the incomprehensibility of the language in the medical reports have been expressed both by professionals (Vaart van der et al., 2012; Ball et al., 2007) and patients (Ferreira et al., 2007; Ball et al., 2007) as a significant issue. Doctors fear that medical records may contain expressions that are embarrassing for both themselves and for the patients (Delbanco et al., 2010). Writing more mundane records is feared to lead to imprecise documentation (Delbanco et al., 2010). Both healthcare professionals (e.g., Allvin, 2011; Wilce, 2009) and researchers within the profession have underlined the importance of specialized language to enable and ensure reliable communication within professional communities and shaping and maintaining professional identities. The language needs to be commonly understood within a professional community and be specific enough in the area of its specialization. A specialized language also helps to create an aura of authority for the work and, for example, medical diagnoses and procedures (Ogden et al., 2003). At the same



time, allowing patients to read their medical records can foster the development of both health information literacy (Moreno et al., 2009) and a common language, a factor which, according to Gadamer (1996), is essential for patients and professionals to understand each other. Research shows that many patients are interested in participating in their care and do not see major problems in understanding their medical records (e.g., Pyper et al., 2004). Ball et al. (2007) note that a patient can understand the general meaning of a specific medical term even if they are unable to comprehend all its specific details. At the same time, however, analyses of record-keeping practices show that medical records are highly heterogeneous (e.g. Baldacchino et al., 2010; Bilston & Brown, 2008; Mann & Williams, 2003; Runyan et al., 1992). In spite of the use of specific terms, the natural language varies between individual writers and the records contain typographical errors, duplicates, ambiguities and non-standard abbreviations (Bursa et al., 2012), all of which require specific competence of the reader.

In contrast to the large body of literature on the anticipated impact of giving patients a direct access to their medical records, there are only a relatively small number of empirical studies on the same topic. In a systematic review of controlled trials between 1990 and 2009, Zhou et al. (2007) report significant changes in the behavior of the portal access group in comparison with the control group for the following issues: quicker decrease in visit rates and slower increase in the number of telephone contacts, increase in the number of messages sent, changes in medication, and better adherence to treatment. Woods et al. (2013) report similarly positive response from patients and indications of empowerment, even if their findings are not conclusive on the actual clinical impact of medical record access. Other studies provide contradictory evidence of both increase (e.g., Palen et al., 2012) and decrease in the number of visits to and time spent with physicians (e.g., Delbanco et al., 2012; Pagliari et al., 2012; Ålander et al., 2004). Surveyed self-reported benefits experienced by patients include positive impact on following medication and lifestyle advice (Bhavnani et al., 2011) and improved health (Nazi et al., 2013). In one Norwegian study, interviewed patients described reading medical records as a means of obtaining a more complete account of the course of their condition, taking responsibility for the flow of correct information and verifying the accuracy of the record. At the same time, some informants described experiences of feeling underestimated and misjudged by the health care professionals when the recorded information did not correspond with patients' view of the communication (Wibe et al., 2011). Similar findings have emerged from other studies.

In contrast to negative experience, it has been suggested that access can help to prepare patients for visits, compensate for communication problems during visits and to provide patients with a comprehensive view of their health and a feeling of greater engagement in their personal health care (Fisher et al., 2009). A study by Asan and Montague (2013) shows that using different strategies of sharing electronic medical records during the visit can also facilitate information sharing between clinicians and patients. The study by Østerlund et al. (2010) describe another strategy used by the mothers of minors with chronic conditions in which they kept home-based records, often organized as timelines.

Trends and changes of particular quantitative indicators can be expected to hide a plethora of individual behaviours. The extent of research and the number of tested viable theoretical models of health information access give indications of the complexity of the phenomenon of health information seeking and use (Marton & Choo, 2012). Pálsdóttir (2005) has extensively studied Icelandic populations and their health information behavior. She reported considerable differences between active, moderately active, and passive health information seekers. In contrast to predominant assumptions and the findings of an array of empirical studies, Henwood et al. (2003) have shown that many patients are content with being relatively passive and are not interested in assuming a more active role in healthcare. Moreover, record access has been shown to have a small impact on health behavior intentions (Fisher et al., 2009). By the same token, even if many patients indicate that they are interested in reading their medical records, a long line of research shows that few do so in practice (e.g., Michael & Bordley, 1982; Munir & Boaden, 2001; Ross & Lin, 2003; Delbanco et al., 2010).

Controlled trials have shown that patients with access to their medical records tend to have lower interest in reading their medical records than members of control groups who are prone to be over-optimistic about their potential interest. Similarly, physicians who have experience of patients accessing their medical records tend to be more positive towards allowing patients' to access their records than their colleagues in the control groups. The same applies to post (patients less interested, physicians more positive) versus pre-implementation studies (e.g., Ammenwerth et al., 2012; Walker et al., 2011; Ålander et al., 2004). One explanation of the prevalence of contradictory findings and the existence of conflicting views might relate to

people struggling to maintain a balance between 'appropriate' and 'inappropriate' behaviors. In his study of heart patients and their relatives, Tuominen (Tuominen, 2001; Tuominen et al., 2003) found that the informants reflected upon their personal positions by referring to four partially conflicting "interpretative repertoires". *Experience repertoire* represents personal, experiential, subjective and emotional way of speaking about a medical condition. *Expert repertoire* is largely opposite formally mediated, diagnosed and objective version of discussing about health. *Virtue* and *anxiety* repertoires represent another conflicting system of meaning: optimism and rationality versus emotionality, negative feelings and anxiety. All of these four repertoires were related to the occurrence of different information behaviors. The experience repertoire emphasized subjective experience whereas the expert repertoire emphasizes objective medical information. In the virtue repertoire, information seeking was seen as part of the healing process whereas the anxiety repertoire tended to focus on information avoidance.

In summary, the attitudes and experiences of health care professionals and patients concerning the provision of access and reading of medical records show considerable variation. Most patients and professionals tend to be at least somewhat affirmative of the patients' right to consult their own medical records, but in practice there are divided opinions about the perceived benefits and drawbacks and whether the access could or should be unlimited and provided online.

### **3 Theoretical background**

This study is based on the theoretical assumption that patterns of how people perceive the relevance, opportunities and obstacles of accessing their medical records and e-Health services are related to particular interpretative repertoires and *subject positions*. Instead of being determined by rigid roles or group membership, we hypothesize on the basis of the social constructivist positioning theory of Harré (van Langenhove & Harré, 1998) that the different ways of seeing medical records and e-health are related to positions assumed by and imposed on people. According to Davies and Harré (1990, p. 46), "a subject position incorporates both a conceptual repertoire and a location for persons within the structure of rights for those that use that repertoire." A particular subject position gives a person an identity and a position in a

specific structure. Individuals see the world from the vantage point of particular subject positions after assuming them as their own. An individual can take a particular position as granted or reflect upon it, occasionally even change the position (Fairclough, 1992).

In Potter's and Wetherell's discourse analysis, subject positions are complemented, and in later versions replaced by the notion of interpretative repertoires. Tuominen (2001) uses the combination of subject positions and interpretative repertoires to analyze how heart patients and their relatives articulate their lives. Tuominen argues for the persuasive power of interpretative repertoires. The repertoires do not determine how people think about things or how they behave, but provide a stock of possible and 'preferred' ways of interpreting the world. Even if the repertoires are not prescriptive, their 'offering' of particular identities almost forces individuals to relate their actions to the repertoire. As offerings of interpretative repertoires, the subject positions are not predetermined or static. Similar to ideologies, meanings and discourses, they can be paradoxical (Tuominen, 2001). In its original context, as a critique of cognitivist social psychology (where action results from processes operating within the heads of individuals) in Potter and Wetherell's (Potter, 1996; Wetherell, 1998) discourse analysis, the interpretative repertoires are primarily perceived as "language units". They are different culturally possible versions of speech or text (McKenzie, 2005). In more general terms, the search for both subject positions and interpretative repertoires can be seen as a process of abstraction (Talja, 1998). Instead of being a strictly linguistic issue, we argue that this process of abstraction can also occur by other means of expression as actions, practices and choices. In traditional discourse analysis, the abstraction is done using qualitative analysis of textual and oral discourses. We suggest that the expression of interpretative repertoires and subject positions can be captured by using certain quantitative and statistical methods. We propose exploratory factor analysis of survey data in which individual respondents have articulated their points of view by answering questions using a Likert-like scale, as one possible method for collecting and categorizing data, which can be explained in terms of subject positions and interpretative repertoires. Principal component analysis approach to exploratory factor analysis (EFA) converts individual observations (in our case, responses in Likert-like scale) into linearly uncorrelated variables (i.e. principal components). The variables are orthogonal (uncorrelated) and defined in the order of largest possible variance (Jolliffe, 2002).

Technically, our approach is not significantly different from the traditional interpretation of analytical clusters as categories of opinions (or positions in a somewhat more colloquial sense). The proposed approach has, however, two advantages in comparison to traditional interpretation of categories. The positioning theory helps to articulate the overlap between different categories and explain why different categories do not need to be mutually exclusive in order to have explanatory power. Even if qualitative data gathering provides means to capture richer data compared to a multiple choice questionnaire, on a fundamental level, both approaches are based on an analysis of the differences of how individuals articulate different views, either in words or by checking boxes in a questionnaire. Nevertheless, the two approaches for pinpointing interpretative repertoires and their related subject positions are methodologically very different and the resulting repertoires and positions are supported by very different types of evidence. In discourse analysis the categories are qualitative, relative to language use and its interpretation according to methodological and theoretical principles discourse analysis In the statistics-based approach, the categories are quantitative and relative to mathematical transformations. The similarities and differences of the methods can be expected to imply that both approaches can expose similar and related subject positions and interpretative repertoires, but in spite of their similarities, the categories revealed by quantitative (EFA) and qualitative analyses (discourse analysis) are only indirectly comparable to each other.

#### **4 Methods and Material**

The aim of the study was to map the preferences and motivations of patients ordering a copy of their medical record. Contextual data was gathered on their self-perceived health, health information behavior and demography. The survey instrument consisted of 39 questions. Eight of them were analyzed in the present study (Table 1). These eight questions consisted of 53 statements on a 5-point Likert-like scale (Table 2). The survey questionnaire was constructed on the basis of earlier questionnaires (Ekendahl, 2011; Fowles et al., 2004) and complemented with additional questions developed by the researchers on the basis of their expertise and the specific research questions of this study.

Table 1: Statements (V1-V52).

V#	Statements
	<b>I ordered a copy of my medical record because of</b>
V1	To get an overview of my health/condition
V2	To check/verify some details
V3	Because I was unsure whether I received correct treatment
V4	To follow-up what was said during my last visit
V5	Involve my family members in my care.
	<b>Contents of the medical record</b>
V6	I understood most of the contents of the medical record.
V7	I understood the parts of the medical record I was interested.
	<b>What would you do if you did not understand something in the record text</b>
V8	Ask online the health care professionals I usually contact (e.g. by secure email)
V9	Ask a family member or a friend
V10	Ask a healthcare professional I know personally, either in my family or among my friends.
V11	Seek information by myself e.g. in the Internet.
V12	Ask someone to help me to translate the record from Swedish to my own language.
V13	Ask healthcare staff using telephone.
V14	Ask healthcare staff during my next visit.
V15	Ask a person with knowledge of healthcare, e.g. using 24/7 telephone counselling service.
V16	Use social media e.g. discussion forum or Facebook to get help.
	<b>What it means to you to be able to read you own medical record</b>
V17	It improves communication between me and the healthcare professionals
V18	It leads to the improvement of the care I receive.
V19	I will better understand my health/condition.
V20	I will take better care of my health.
V21	It is necessary for me to actively participate in my healthcare.
V22	I will keep the medical record for my own record.
V23	I am distrustful of the healthcare.
	<b>General questions of an online access service to own medical records</b>
V24	It is a very good idea to be able to read medical record online (similarly to that how I can manage my bank accounts online).
V25	I am generally worried of the security of the service.
V26	I am worried that the medical records are not managed securely enough in the healthcare information systems if they can be read online.
V27	I am worried that the service will too difficult to use.
V28	I am not so interested in my medical record that I would read it online.
V29	I do not want to read my medical record online, only personally discuss with healthcare professionals.
	<b>It would be useful to have an access to following information services based on the information found in your medical record:</b>
V30	Letters of referral (contents and how they are processed by the care providers)
V31	List of all my medications
V32	Overview of my vaccinations
V33	Test results directly after tests have been conducted
V34	Overview of all contacts with healthcare together with a possibility to read the entire medical record
V35	Possibility to manage and order medical certificates
V36	Possibility to report errors in my medical record.
V37	Possibility to write own comments in the text of the record.
V38	Possibility to provide information of my own health (e.g. to submit a health declaration [obligatory in Sweden] before each visit).
V39	Possibility to provide information e.g. by reporting self-test results taken at home.
V40	Possibility to contact healthcare online and to ask questions of the contents of my medical record.
V41	Possibility to block parts of my medical record from other healthcare staff (who have not written them).
V42	Possibility to see, which healthcare units and categories of staff have read and written in my medical record.
V43	Possibility to manage services for my children (e.g. letters of referral, vaccinations and medication lists).
V44	Possibility to manage services for elderly family members (e.g. letters of referral, vaccinations and medication lists).
V45	Possibility to manage services for other persons (e.g. letters of referral, vaccinations and medication lists).
	<b>Questions about health</b>
V46	I am very worried about my health.
V47	I often think my health.
V48	My health condition is very good.
	<b>Health information behaviour</b>
V49	I like to communicate with medical doctors using email.
V50	Internet is a very important source of health information for me.
V51	I use a lot of social media services on health information matters (e.g., discussion forum, Facebook, Twitter).

Table 2: Contextual variables.

#	Contextual variables	Alternatives
1	How did you order a copy of your medical record?	1) Called county council telephone exchange, 2) Called medical records unit, 4) Visited county council website or 1177.se, 5) Ordered using email, 6) Other.
2	Have you ordered a copy of medical record earlier?	1) No 2) Once 3) Multiple times.
3	How long time you think it is acceptable to wait before being able to read you medical record online?	1) Access should be immediate, 2) A day, 3) A few days, 4) Two weeks, 5) A month, 6) Longer time, 7) Can't say.
4	If you would be able to read your medical record online, would you like to be able to read possibly worrying information, e.g. a suspicion of a serious condition?	1) I would like to read everything at once, 2) Yes, but only if there is someone I can contact right away, 3) No, I would like to hear such information only personally.
5	I have a cronical condition	Yes/No
6	How long time do you use a computer daily?	1) Not at all, 2) Less than one hour, 3) 1-3 hours, 4) More than three hours.
7	Employment	1) Employed, 2) Entrepreneur, 3) Unemployed, 4) On parental leave, 5) Pensioner, 6) On medical leave, 7) Student, 8) Other.
8	Education	1) Elementary, 2) Secondary, less than 3 years, 3) Secondary, 3 years or more, 4) Tertiary, less than 3 years, 5) Tertiary, 3 years or more, 6) Post-graduate.
9	Have you got Internet access at home?	Yes/No
10	Were you born in Sweden?	Yes/No
11	Does someone in your family or among friends work in healthcare sector?	Yes/No
12	Do you work or have you worked in healthcare sector?	Yes/No
13	Gender	Male/Female/Other
14	Are you a member in a patient association?	Yes/No
15	Have your physician ever recommended you to seek health information on the Internet?	Yes/No
16	Have you used the Internet to seek health information during last week?	Yes/No
17	Have you read a medical book during the last year?	Yes/No
18	Are you subscribing to one or more health magazines?	Yes/No

The survey was sent to 1000 patients that ordered a paper copy of their medical record from a Swedish county council in June-August 2012. Response rate was 35,4% (N=354). An invitation to participate in the study and a survey form was mailed to the respondents in the same envelope as a copy of their record. Respondents were also offered the possibility to fill in the survey online. The mailing of the survey forms and the online survey were administered by the county council. All responses were completely anonymous. No identifying personal data was collected.

It is apparent that the sampling and data collection methods have implications on the findings of this study. In the studied Swedish county approximately 11 000 patients (of the population of approximately 300 000), 3,6%, have ordered a copy of their medical record annually in the 2000s (Leif Lyttkens, personal communication, August 15, 2013), which corresponds rather well with the rates documented in the literature (e.g., Michael & Bordley, 1982; Ross & Lin, 2003). In the county where the present survey was conducted, in August 2013 nine months after the introduction of a web based access system approximately 6% of the registered patients had consulted their medical record online (Benny Eklund, personal communication, November 16, 2013).

74% (233/343) of the respondents were female and 26% (90/343) male. 89% (309/349) of them were born in Sweden. 37% (131/350) were employed, 7% (23/350) entrepreneurs, 4% (13/350) unemployed, 10% (35/350) on parental leave, 9% (30/350) on medical leave, 0.6% (2/350) on part-time medical leave, 4% (13/350) fulltime students and 27% (96/350) were retired. 84% (286/342) had at least secondary or upper secondary level education. 3% (10/342) had no formal education. 66% (219/334) used internet at least one hour every day. 9% (31/334) were non-users of internet. 92% (310/338) had internet access at home.

The data differed somewhat from the general population of the county (Statistics Sweden, [www.scb.se](http://www.scb.se)) where in 2012, 50% of the population were females and 86% of the population were born in Sweden. In 2011, 84% had secondary or upper secondary level education (Statistics Sweden, 2012). The same year 84% of Swedes had internet access at home and 74% had used internet at least a few times a week (Weibull et al., 2012).



It is clear that the sample represents a particular group within the entire population of the county. All of the respondents took the effort to order a copy of a record and a comprehensive survey, which is a sign of a particular interest in medical records. Therefore, the results cannot be generalized to all patients and it is necessary to take into account that the sample contains both a known and an unknown bias. Considering the aims of the study to investigate the preferences and views of the patients who read their medical records, the limitations of the sample should be considered to be acceptable. It is unlikely that the medical records would play a significant direct role in the health information related practices of patients who have not read their records, or that these patients would have specific medical records related information practices, preferences or views at the present.

The data were analyzed using SPSS 21.0 using descriptive statistics and exploratory factor analysis (EFA), using principal component analysis as the method of extraction. The data fulfill the commonly accepted criteria of EFA:  $N=354$ , Kaiser-Meyer-Olkin Test of Sampling Accuracy (KMO) .694 and Sig. .000 Bartlett's Test. For EFA, a 7 factor solution was selected on the basis of the analysis of the Scree plot (Fig. 1) and the (non-)triviality of the factors. The solution fulfills Hatcher's (1994) recommendation of 5:1 subject variable ratio. These measures are common indicators that the analyzed data satisfy the technical requirements of EFA, and that consequently, the extracted categories (factors) have analytical validity that corresponds to the trustworthiness and quality of the outcomes of qualitative explication of corresponding categories.

The communality of the statements (32) is relatively low, which has been taken into account in the interpretation of the factors. The statements with low communality values were retained on the basis of a literature based theoretical assumption of the potential significance of the aspects and a consequent interest in analyzing how they load in different factors together with other statements. Considering the exploratory and indicative rather than confirmatory nature of the study, the level of statistical reliability of the resulting set of factors (i.e. categorizations) was considered acceptable. In a qualitative study, the reliability (i.e. credibility and soundness) of the same categorizations could have been assessed by using such methods as reflection, negative case analysis or theoretical thinking. The variation of the factors and the contextual variables (Table 3) was tested using one-way ANOVA, Welch (with Tamehane and Games-Howell post-hoc

tests), and logistical regression analysis. This procedure corresponds with a qualitative analysis of categories and how they are related to context, for instance, how different interpretative repertoires are articulated by men and women or by members and non-members of patient associations.

Table 3: Results of the Exploratory Factor Analysis. C: Communalities, P1-7 Factors representing interpretative repertoires.

Statements	Rotated Component Matrix (a)							
	P1	P2	P3	P4	P5	P6	P7	C
V1	.142	<b>.386</b>	.091	<b>.414</b>	-.047	-.152	.207	.417
V2	-.021	.284	.012	<b>.674</b>	.214	.007	.042	.584
V3	.080	.194	-.037	<b>.671</b>	.263	.020	-.269	.638
V4	-.066	.203	-.071	<b>.650</b>	.113	.131	.193	.540
V5	.086	.159	-.122	.207	<b>.346</b>	.329	.022	.318
V6	-.011	.172	.020	-.118	.034	<b>-.766</b>	-.104	.642
V7	-.057	.161	.019	-.179	-.009	<b>-.793</b>	-.163	.718
V8	.142	.160	.220	.171	-.202	.227	<b>.515</b>	.481
V9	.034	.220	.120	-.249	-.192	<b>.479</b>	-.241	.450
V10	.012	<b>.452</b>	.049	-.119	-.201	.324	-.158	.391
V11	.075	<b>.521</b>	.321	.252	-.064	-.025	-.240	.506
V12	.035	.068	.059	-.063	.197	<b>.639</b>	.015	.461
V13	.045	.176	-.054	-.083	.017	-.001	<b>.596</b>	.399
V14	.075	.078	-.008	-.051	.271	.005	<b>.595</b>	.442
V15	-.094	.259	-.003	-.060	-.266	.089	<b>.498</b>	.406
V16	.091	.190	<b>.404</b>	-.052	-.112	.161	.047	.251
V17	.169	<b>.720</b>	-.008	.175	.212	-.117	.169	.665
V18	.175	<b>.649</b>	.006	.186	.126	-.060	.132	.523
V19	.062	<b>.768</b>	.026	.050	.077	-.002	.211	.648
V20	.168	<b>.688</b>	.062	.003	.273	.048	.056	.586
V21	.076	<b>.742</b>	.055	.305	.105	.047	.132	.683
V22	.058	<b>.430</b>	.050	.209	-.276	-.067	.057	.318
V23	.047	.180	.009	<b>.675</b>	.216	.083	-.332	.653
V24	<b>.345</b>	-.073	<b>.726</b>	.050	.178	.059	.069	.694
V25	-.001	-.060	<b>-.761</b>	.176	-.165	-.084	.133	.666
V26	.080	-.037	<b>-.787</b>	.158	-.181	-.062	.081	.694
V27	-.147	.059	<b>-.403</b>	-.029	.253	.199	-.080	.298
V28	-.328	.052	<b>-.542</b>	-.184	-.149	-.026	<b>-.374</b>	.601
V29	-.224	.161	<b>-.725</b>	-.214	.157	.078	-.186	.713
V30	<b>.776</b>	.048	.078	-.028	.100	-.023	.140	.641
V31	<b>.727</b>	.208	.149	-.119	.059	.080	.135	.637
V32	<b>.732</b>	.053	.041	-.225	-.006	.036	.141	.612
V33	<b>.632</b>	.106	.160	-.066	<b>.342</b>	-.120	.071	.577
V34	<b>.758</b>	-.023	.302	.012	.226	-.098	.052	.730
V35	<b>.771</b>	-.036	.176	-.030	.039	-.007	.009	.630
V36	<b>.756</b>	.026	.026	.246	.102	-.047	.072	.652
V37	<b>.643</b>	.111	.133	.330	-.053	.000	-.258	.622
V38	<b>.645</b>	.175	.213	.173	-.275	.073	-.046	.605
V39	<b>.659</b>	.135	.106	.164	-.285	.014	-.018	.573
V40	<b>.802</b>	.157	.239	.063	-.055	-.027	.185	.767
V41	<b>.673</b>	-.049	-.125	.265	-.265	-.027	.145	.634
V42	<b>.542</b>	-.046	-.030	<b>.396</b>	-.207	.041	-.061	.502
V43	<b>.605</b>	.077	.081	-.241	-.322	.201	-.169	.610
V44	<b>.686</b>	.159	.012	-.077	-.232	.171	-.172	.614
V45	<b>.569</b>	.193	-.075	-.209	-.111	.116	-.260	.504
V46	-.109	.228	-.091	.305	<b>.696</b>	.053	.078	.658
V47	-.093	.169	-.007	.104	<b>.632</b>	.041	-.017	.450
V48	.087	.033	-.089	<b>-.401</b>	<b>-.648</b>	.033	-.006	.599
V49	.184	.171	<b>.447</b>	.206	-.292	-.065	.133	.412
V50	.236	.180	<b>.505</b>	.271	-.156	-.222	-.195	.528
V51	.084	.215	<b>.473</b>	-.161	-.153	.014	-.127	.343

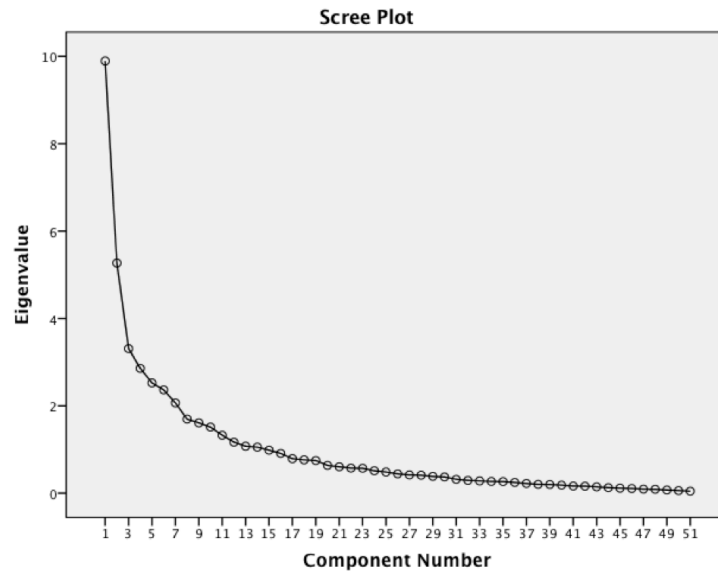


Figure 1: Scree-plot of the exploratory factor analysis.

## 5 Analysis

Exploratory factor analysis (EFA) with principal component analysis (PCA) as the method of extraction was used to reduce the dimensions of the data and to identify behavior and preference related patterns. An analysis of variation (one-way ANOVA) and binary logistic regression of the components was conducted to identify relations between factors and contextual variables (V1-V51 in Table 3), for instance, whether gender or education was related to a specific factor.

We interpreted the factors as seven subject positions with associated interpretative repertoires related to medical records and health services. The following interpretive repertoires were found using the method. Each interpretive repertoire has been given an identifying name that conveys the characteristics of the principal component. The characteristics described without explicit statistics refer to the results of the EFA (V1-V51 in Table 3) and the ones with statistics, to the results of ANOVA and binary logistic regression analyses.

We call the first factor, P1, *Hypothetically positive to e-health services generally*, since the variables (V30-V45) associated with P1 all relate to supportive e-health services. The variables indicate wanting access to letters of referral, medications, vaccinations, test results, and contacts with healthcare. They furthermore

indicate a positive attitude to managing and ordering medical certificates, reporting errors in medical record, writing text in their own medical records, reporting health information, having online contact with healthcare, blocking parts of their medical record, seeing who has accessed their medical record, and managing service for children and elderly relatives, as well as for other persons. This repertoire is characterized by a stated willingness either to read all contents of the record at once (MD .8529, Sig. .004) or to read under the condition that there is someone to contact right away (MD .940, Sig. .001), rather than to wait for a verbal message. The score for an acceptable waiting time of one day was statistically significantly higher than for two weeks (Games-Howell and Welch, p .011).

The second principal factor, P2, is associated with variables V1, V10, V11, and V17-V22, which we associate with being *Positive to reading medical records due to implications*. This is due to the variables indicating a desire to access medical record as a means to improve communication with healthcare, receive better care, better understand their health situation and to be better at taking care of oneself. Accessing medical records is seen as a way of becoming more active in healthcare and to have the possibility to construct your own records of health data. The repertoire is connected to likelihood to seek information on the internet or among friends if there are problems understanding the text of the medical record. The repertoire is also characterized by a propensity to order medical records to get an overview of their health condition and a somewhat higher likelihood to have read medical literature (B .536, Wald 3.904, Sig. 0.48).

We interpret the principal factor P3 as representing *Positive to all internet use including medical records online*. The variables associated with P3 are V16, indicating proneness to use social media to get help if there are problems in understanding something in the medical record, V24-V29, which show a positive attitude to reading their medical record online and them not worrying about security issues, and V49-V51, showing a positive attitude to communicating with medical staff via email, searching for health information on the internet, including using social forums. The repertoire is related to greater likelihood to spend 3+ hours a day using a computer than less than an hour (MD .9125, Sig. .002) and to have sought health information on the internet within the last week (B .566, Wald 6.852, Sig. .009), but lower likelihood to work or have worked in healthcare (B -.542, Wald 6.415, Sig. .011).

The label we chose for factor P4 is *Distrustful and wants to be in control of health treatment*. The variables associated with P4 are V1-V4, V23, and V48. These indicate likelihood to have ordered the medical record to get an overview of their health condition, check details in their medical record and the received treatment, and to follow up what was said during a healthcare visit. It is also related to distrust of the healthcare providers and a desire to be able to check who has accessed the medical records. The likelihood to have ordered several times (rather than never) (MD 1.082, Sig. .000), to have sought information on the internet (B .516, Wald 5.213, Sig. .022) and to be female (B -.688, Wald 7.008, Sig. .008) is also higher.

The variables V46-V48 associated with the factor P5 indicate persons who are not in good health and think worriedly about their health. P5 is thus labeled *Worried about health*. The likelihood to have called county council telephone exchange (when ordering the record, MD 8.414, Sig. .002), to have chronic conditions (B 1.557, Wald 24.757, Sig. .000) and not be on parental leave (Sig. <.01 when compared to all other categories than unemployed and students) is higher. In contrast, this repertoire is related to lower likelihood to work or have worked in healthcare (B -.515, Sig. .016), to have been born in Sweden (B -.634, Wald 3.907, Sig. .048) or to have ordered a copy of the medical record on the internet (#1 in Table 2) ANOVA F 7.256, Sig. <.000. In comparison to internet orders, the likelihood to have called the medical record unit (MD -.94, p .009 and county council telephone exchange (MD -.84, Sig. .002) is higher. The age range related to this repertoire (ANOVA F 8.978, Sig. .000) is more likely not to be the one of 26-35-year-olds, but either younger or older (B -1.573, Wald 18.105, Sig. .000).

The factor P6 is associated with variable V10 and V15-V17, representing those that ask healthcare professionals either online, via phone, or at their next visit if they do not understand something in their medical record. The label we chose for P6 is *Wants communication with health care professionals*.

The last factor, P7, *Does not understand their medical record* is associated with variables V8 and V9 that indicate difficulties in understanding both the medical record in general and the part they are specifically interested in. P7 is also associated with variable V11, indicating likelihood to ask friends/relatives to help understand their medical record, and with V14, pointing to likelihood to ask for a translation of their medical record to one's own language.

## 6 Discussion

Our interpretation of the results of the principal component analysis is that people have diverse concerns about their health and the possibilities to manage and access their medical and health information. The factors can be interpreted in the light of the notions of subject positions with different interpretative repertoires, a supply of codes available for individuals to understand different phenomena. The approach of combining statistical analysis with discourse theoretical conceptual apparatus is unconventional, but as discussed earlier, even if the quantitative surveys and qualitative means of data gathering have fundamental differences, they both provide individuals with means to articulate their views that can be used as a basis for categorizing these perspectives or, in terms of Wetherell and Potter (1988), interpretative repertoires. As in qualitative analysis in general (in this case of statistically calculated categories), the interpretations need to be made with rigor, and because the survey data tend to be far less rich (or thick) than interview records, video data or field notes, it is necessary to be especially critical of the emerging categories and their credibility. Overall this does not differ remarkably from the similar procedures conducted in the interpretation of factors in exploratory factor analysis (see e.g. Conway & Huffcutt, 2003). In the present study, the plausibility of the interpretative repertoires was supported both by their face value and, as discussed below, how similar categories could be found in the literature. In the future, the approach could be investigated further using triangulation and independent analysis of exhaustive qualitative and quantitative data sets gathered from the same population.

The findings of this study support earlier observations of largely positive patient attitudes that are mixed with occasional security concerns (e.g., Delbanco et al., 2012; Ball et al., 2007). They do similarly confirm the presence of both concerns (e.g., Delbanco et al., 2010; Ross & Lin, 2003; Allvin, 2011; Hackl et al., 2011) and positive expectations (e.g., Langel, 2013; Vaart van der et al., 2012) of the professionals. It is also apparent that the reluctance of some patients to access medical records online persists (e.g., Munir & Boaden, 2001; Ross et al., 2005) even if internet use has increased and security and privacy concerns tend to be related to lack of interest and to negative attitudes towards online access (a similar finding to that of Ross et

al., 2005).

The major finding of this study is that it has shed light to the diversity of subject positions from which people perceive the role of their medical records in the context of their health and health information related practices, and how these subject positions can explain the mixed evidence of worry and enthusiasm documented in the earlier literature. The relevance of analyzing different subject positions and their related interpretative repertoires is to help us understand the different functions and meanings attached to the medical records and how the perception of the notions of health, healthcare and medical record offer particular subject positions in the context of a certain interpretative repertoire. The perceived usefulness of medical records or the concerns of providing online access to them are not isolated opinions. They stem from broader patterns of concerns about how individuals identify or position themselves in relation to specific categories and ways of conceptualizing things. This therefore suggests that both advocates and critics of medical record access and e-health services should put more focus on accommodating diverse positions instead of focusing on demographics or specific groups of users. As Tuominen (2001) stresses, it is impossible to isolate interpretative repertoires and subject positions into particular texts (i.e. individuals), or if extended to the context of this study, expressions of opinions. They are not intact and particular individuals can easily position themselves into several conflicting subject positions one after another and in parallel. The findings remind us of Robinson's (2010) remark that medical knowledge is messy and consists of a blend of knowledge and that medical records serve different purposes for different users (Reddy & Bradner, 2005).

This study has limitations that have to be taken into account when interpreting the results. The sample contains an unknown unquantifiable bias. Similarly to earlier studies (e.g., Nazi et al., 2013; Bhavnani et al., 2011), it seems plausible to assume that the respondents can be more interested in their medical record, health and e-health services than an average citizen. As there are no detailed statistics of the entire population of patients who have ordered a copy of their medical record in the studied county council, it is difficult to estimate the representativeness of the sample within this particular group. Further studies are also needed to confirm the findings of the EFA and the general validity of the identified subject positions. When doing comparisons, it is necessary to take into account that the majority of the earlier studies have focused



on magnitudes and analyses of variation in the study population whereas the present analysis is based on the mapping of different subject positions. Consequently the presence of specific subject positions cannot be held as an evidence of their prevalence in the general population. In spite of the limitations, it is plausible to argue that the material is useful for the purpose of this study of mapping the variation of collective ways of thinking using exploratory methods within an open-ended theoretical framework. The following sections discuss the findings, first regarding the patient engagement with healthcare and medical records, secondly considering how the patients conceptualize the role of medical records, and finally concerning the practical and research related implications of the findings.

### **Engagement with Healthcare and Medical Records**

The interpretative repertoires show the diversity of motivations for engaging in healthcare. P1 and P3 evince a preference for e-health services. For P1, the major motivation could be interpreted to be a preference for an uncomplicated access to health services online. P3, on the other hand, is related to digital information practices and heavy internet use. P3 seem to be very positive to all internet use including medical records online.

P2 seem to be most closely associated with being empowered in the sense of participatory healthcare. For P2, reading your medical record has positive implications on communication, better care and better understanding of health care. P7 on the other hand strongly suggest the opposite 'passive' attitude and a willingness to rely on the expertise of healthcare professionals (as documented by Henwood et al. 2003). Hence P7 want to communicate with health care professionals and prefer to seek information through contacting health care professionals.

The priorities related to the interpretative repertoires related to subject positions P2, P4 and P5 find parallels with the findings of Fowles et al. (2004). The interest in reading medical records was related to a desire to be informed and engaged, but also to worry and distrust. In both studies, both gender and activeness in health information seeking were differentiating factors. The subject positions also epitomize the polarity of attitudes

for and against accessing medical records documented earlier by Ross et al. (2005) and a disinterest in them for a large part of the population (as in Munir & Boaden, 2001). This polarity includes P2 that is very positive to reading their medical records, and P4, which represents a worried attitude to health and a distrust towards health care.

The earlier contradictory evidence of good/poor health condition as a contributing factor to the preference to read medical records (e.g., Fowles et al., 2004 vs. Bhavnani et al., 2011; Ball et al., 2007; Østerlund et al., 2010; Guy et al., 2012) can be explained in the light of the present findings in terms of how patients interpret their medical records (i.e. the interpretative repertoires related to individual subject positions).

Similar to attitudes expressed in the literature (e.g., Wibe et al., 2011; Fisher et al., 2009), the respondents motivated their preference to have access to their medical records online from two broad perspectives. Firstly, access is perceived to have an indirect rather than direct instrumental value. The subject position and a positive attitude to accessing medical records are related to an active information seeking behavior rather than a medical condition or an apparent need to utilize the information. This position was most apparent in P3. In the conceivable interpretative repertoire of this subject position, access predominantly is seen as having a non-instrumental value and the medical records or their contents are not necessarily used for any particular purpose. Secondly, others perceive the access in more instrumental terms. The subject positions P3 and P5 see access as an opportunity to get more engaged in one's own healthcare (P3) or more knowledgeable (P5) about their condition. In P4, the principal motivating factor is distrust. The instrumental perspective highlights the functionality of the medical record as an information source.

### **The Role of Medical Records**

In addition to positioning patients towards healthcare, the subject positions provide evidence of how their underlying interpretative repertoires position themselves in relation to medical records. Part of the subject positions suggest interpretative repertoires in which the medical record plays a major role (P2-P5, P6) whereas others (P1, P7) are primarily interested in services based on, or related to, the information contained

in the medical record and less concerned with the document itself. In P2-P5, the medical record is, or can be, a useful source of information whereas in P6 it appears primarily as a hindrance. For the subject position represented by the strongest component P1, the significant aspect is the diverse services that can be developed on the basis of the information contained in the medical record instead of the record itself.

Subject position P7 underlines the significance of personal communication instead of any textual documentation. The subject positions P1 and P3 may be assumed to represent a relatively matter-of-factual interpretation of the medical record. P1 is not necessarily interested in the medical record per se at all, but sees it as an enabler of a range of useful services. P3 takes the record as is and appreciates access to it from an intrinsic perspective. In P2, it is an information source, but at the same time, its value is determined by its function as a tool of empowerment. In P4, the relevance of the medical record is evidentially similar to the way many archival theorists conceptualize the role of archival records (Cox, 2001). In this situation, a medical record is not primarily informative, but functions as a verification of an event or a transaction.

Similar to P2, subject position P5 appreciates the informative nature of a medical record, but the informative perspective is mixed with indications of a certain amount of distrust to healthcare (e.g., V3, V25-26), a willingness to involving other parties (V5) and to take better care of one's health (V21), as well as a general unwillingness to assume a highly proactive role in seeking health information (V8-V16, V49-V51). In addition to the information and evidential roles of the records, the subject positions P3 and P5 strongly indicate that the medical record can also have a certain symbolic function. The intrinsic rather than instrumental view of the value of accessing medical records in both positions can be explained by the premises of the contemporary freedom of information movement and the Swedish constitutional Principle of Public Access (that dates back to 1766), and a general willingness to support (even if not necessarily use) the possibility of accessing government and local authority information for public and personal purposes. In this context, the perceived importance of medical records and gaining access to them stems from the symbolic significance of the records as an accessible document and an enabler of the symbolic central "watchdog function" (Cate et al., 1994) of the freedom of information legislation.

## Implications to Research and Practice

The principal practical implication of the present findings is that when designing and implementing online access to medical record information and other e-health services, the service should be planned with different subject positions rather than simple demographic groups in mind. The diversity of preferences underlines the need to deploy flexible solutions. When these different professional types of knowledge are brought together with patients constellations of knowing, a certain level of friction is unavoidable. For many subject positions the access itself has considerable intrinsic value, but it is also often conceivable that the patients would benefit from various types of complementary services. The record and related services should be capable of helping patients participate in their healthcare, be informative and pedagogic in helping patients understand their condition, and to alleviate the sense of distrust. In contrast to the subject positions P2-P5 and P7, P1 and P6 remind us that in addition to the availability of the medical record, it is important to focus on derivative and related e-Health services and to provide personal guidance and information for those who are not comfortable using online services.

The complexity of the interpretative repertoires confirm the observation of Blandford and Attfield (2010, p. 21) and clearly show that only a fraction of the concerns of the patients are directly satisfied with mere access to information. The EFA suggests that a strong motivation to access the information and e-Health services in general is related to the perceived implications of being informed, including improved health and care. At the same time, it is clear that similar to the use by professionals (Winman & Rystedt, 2012), the medical record is a translatory rather than a merely informational device between patients and professionals, and it is not entirely clear whether the present type of medical record is capable of functioning as a fully fledged boundary object (Star, 2010) between these communities. The findings of Davies and McKenzie (2004) on how midwives and their clients used antenatal records as boundary objects support this idea even if findings are not entirely generalizable to other types of medical records and settings within healthcare. Individuals who identify themselves as being worried might benefit from guidance and informing practices that inspire confidence. Empowerment-oriented patients could find it useful to be given various types of explicit invitations to engage themselves with healthcare. Moreover, uninterested patients (P7) could be informed of the benefits of consulting their own medical record, but in practice, probably more often, would

be better served by providing them with personal service. Finally, the subject position P6 indicates the need for explanation and in some cases, translation of the record. Even if the earlier evidence of the use of such measures is controversial (e.g., Zeng-Treitler et al., 2007; Bloch et al. 1994; Ridsdale et al. 1997; Kvist & Velupillai 2013), it might be useful to investigate further the possibilities to write texts in simplified language or provide them in the patient's first language. Most of these subject positions are relatively unproblematic from the perspective of the development of access services. The most problematic one is the factor P4, which epitomizes the concerns of many professionals. The patients would undoubtedly benefit from the support that would dissipate their distrust, but at the same time, it is necessary to take into account their legitimate concerns without eradicating the working conditions of the professionals.

## **7 Conclusions**

This study shows the diversity of subject positions from which patients perceive the role of their medical records in the context of their health and health information related practices. We identified seven subject positions and their related interpretative repertoires in the material: (P1) *Hypothetically positive to e-Health services generally*, (P2) *Positive to reading medical records due to implications*, (P3) *Positive to all internet use including medical records online* (P4) *Distrustful and wants to be in control of health treatment*, (P5) *Worried about health*, (P6) *Does not understand their medical record*, and (P7) *Wants communication with health care professionals*. At the same time, the analysis shows how these interpretative repertoires can explain the mixed evidence of worry and enthusiasm documented in the earlier literature. The medical records seem to function as boundary objects that from the perspective of the subject positions, interpret world and in order to be meaningful, need to be interpreted. The diversity of subject positions imply that medical records and healthcare information services should be planned with different subject positions rather than simple demographic groups in mind, with a special attention to the need for flexible solutions that would address the opportunities and worries of the identified subject positions.

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