

# Cancer Patients' Attitudes and Experiences of Online Access to their Electronic Medical Records: A Qualitative Study

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

## **Keywords**

Electronic medical records, medical information, patient access, patient empowerment.

## **1. Introduction**

Engaging patients and their relatives to play an active role in their healthcare process is a critical element of patient-centred care, yet patients are an underused resource in the healthcare system [1]. In an effort to provide more patient-centred care, some healthcare organizations worldwide have offered patients online accesses to their electronic medical record (EMR) using a secure Internet portal, also called e-Health portal. E-health portals are gaining traction among healthcare institutions as mechanisms to improve the safety and quality of healthcare delivery [2], as well as modalities to activate and involve patients to a greater degree in managing their own health [3]. E-health portals can be defined as “applications that allow patients to access health information that is documented and managed by a healthcare institution” [3, pp. 63]. There is great variation in the features and functionality of available e-Health portals. Most portals allow access to selected health information from the EMR, and enable patients to perform certain administrative tasks, such as appointment scheduling and prescription refills [4, 3]. Besides providing sole access to health information, e-Health portals may also offer additional services such as secure messaging between a patient and an institution [4, 3]. Studies have shown that giving patients' online access to health information from e.g. their EMR can encourage them to participate in their care, to manage their health condition, increase understanding of their medical issues, and improve doctor–patient communication [1, 5]. This is often denoted as patient empowerment, which is a situation in which the patients' role is changing from a patronized patient to an informed and engaged patient [6]. Patient empowerment is in this paper defined as “patients having the ability to understand health information and make effective use of it, as well as to gain control over and participate in a meaningful way in the disease management process in an equal partnership with healthcare professionals” [4]. The definition revolves around three empowerment dimensions: *patient knowledge*, *patient control*, and *patient participation*. There is evidence in the literature that individual's ability to access and use their online medical records serves as a cornerstone of national and international efforts to increase patient empowerment and improve health outcomes. Having access to information about personal health is seen as an important precondition for patients to make informed decisions about treatment options. It also allows patients and their families to better cope with their conditions and their implications [7]. Research has also shown that online access to medical records can increase patients' ability to prepare for healthcare

visits, improve communication with healthcare practitioners and increase the accuracy of information given to healthcare providers [8]. However, there seems to be a disagreement in the literature regarding the effects of making medical records available for patients, especially when it comes to anxiety and concerns. Some studies have reported that patient-accessible medical records can generate anxiety or concerns [9] whereas others have concluded that having full access to a medical record neither decreased nor increased anxiety [5, 10, 11].

Giving patients' access to their EMR is not a novel idea. Nonetheless, many still primarily rely on verbal communication between healthcare practitioners and patients. Hassol et al [2] have in their study concluded that patients and physicians differed substantially in their preferred means of communication, with patients preferring e-mail communication for most interactions followed by in-person communication, whereas physicians preferred in-person communication followed by telephone communication [2 pp. 512]. Some researchers argue that the quality of verbal communication is limited due to the lack of time when visiting a physician and due to difficulties of recalling information provided during a visit [7, 12]. Therefore, it is apparent that it would be beneficial to use multiple channels for communication, including written notes, brochures and online access to information that is available in the medical record. At the same time, healthcare practitioners have had several concerns about giving patients online access to their medical record [13].

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

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

cancer patients' attitudes and experiences of online medical records, as well as an increased understanding of the complexities of developing and launching eHealth services based on a direct access to patients' EMR.

## **2. Research Approach**

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

The Regional Ethical Review Board in Uppsala approved the empirical study. Participants were recruited using an information leaflet that was placed in the waiting area at the Department of Oncology, Uppsala University Hospital during the summer and autumn of 2013. The sampling of participants was conducted in two groups. Patients in the first group (A) had consulted their EMR online whereas in the second group (B), they had not used the service. Thirty (30) patients (15 in each group) who had volunteered to participate in the study were contacted and subsequently interviewed by three researchers from the DOME project. The interviews were conducted in the patients' homes or at the premises of the Department of Oncology at the Uppsala University Hospital. The cancer patients were under treatment during the period that the interviews were conducted. They were also in different stages of their cancer. Some of the patients were diagnosed with cancer recurrence and had been ill for a longer time. Others were newly diagnosed. Several of the patients suffered from advanced cancer and were given palliative treatment. The patients were in the age between 30 and 92 years. Among the thirty patients, nine were men. The length of the interviews was 45-60 min. The semi-structured interview approach meant that in addition to predefined questions, the researchers asked spontaneous follow-up questions. The interviews were transcribed by a professional and then analyzed by four researchers from the DOME project. A question-answer matrix was produced on the basis of the transcribed interview data for an analysis on a question to question basis. Significant phrases and quotes were coded in a separate document that was used in a thematic analysis. The quotations presented in this article have been directly extracted from the interview texts. Some passages have been rephrased to make them easier to understand.

## **3. Findings**

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

### ***3.1 Why Patients Want to Access their Online Medical Records***

#### ***3.1.1 Increased Understanding of Medical Issues and Increased Sense of Control***

Patients from group A emphasized that they want to read their health information because they want to learn more about their health condition. Patients also emphasized that they use the EMR in order to know whether they have understood the information from the physician correctly or not. Other patients emphasized that EMRs helped them feel more in control of their care. The feeling of control is thus

achieved first when the patient is given access to test results and medical notes, regardless of whether the information is disturbing or not. The feeling of control is perceived as crucial for wellbeing. Hence, for some patients, access to the medical records has had an important and crucial role in the management of their disease.

### **3.1.2 Accessing Test Results is Crucial for Wellbeing**

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

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

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

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

Another patient considers the following:

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

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

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

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

“I want to know even if it's bad news. It does not get any easier just because you get the same information two days later verbally from a doctor or because someone says: “it is not so dangerous and so on”. No, I want clear answers”

### **3.1.3 Suspect Inaccuracies**

In contrast to the physicians' predictions, few patients reported being worried, confused, or offended by the notes they read. Only two patients reported that they have read their EMR because they suspected incorrect entries. Six out of fifteen patients who had individual experiences of accessing their EMR reported that they had found inaccuracies in their medical record, none of them, however, had filed for a correction because they did not want to be a burden for the healthcare practitioners. Moreover, all of the patients who had read their EMR emphasized that when medical notes raises concerns, they usually wait to ask questions until the next patient visit instead of calling a physician. This indicates that patients are both respectful of doctors' time and resourceful in addressing questions that notes raises.

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

## **3.2 The Importance of Being Able to Read the Medical Record**

### **3.2.1 Better Preparation for Future Visits**

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

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

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

### **3.2.2 Physician-Patient Relationship**

Three of the fifteen patients from group A felt that the preparation for future visits brought a number of other benefits, including improved physician-patient communication and increased appreciation of the

physician's skill. According to these patients, being prepared for a doctor's visit contributes to more efficient communication and dialogue between patient and doctor, which in turn seems to affect the physician-patient relationship positive. Only one of the patients, however, felt that their trust for the physician has decreased after having identified inaccuracies in the record. The remaining 11 patients do not believe that the record has affected their physician-patient relationship. Another patient stresses that the preparations have enhanced the shared decision making with her doctor.

One interesting observation is that patients from group B argue that they have a good relationship with their physician and that they receive the information they need. This is according to the patients' one of the main reasons for why they currently do not want to access their EMR.

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

### **3.2.3 Aiding Memory**

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

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

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

### **3.2.4 Improved Access to Information When and Where it is Needed**

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

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

### **3.2.5 Learning More about their Medical Issues**

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

Moreover, patients from group A found some parts of the medical records difficult to understand. This is, however, not perceived as a major problem as the patients believe that they still have a comprehensive understanding of the content. They also argue that the understanding of the content is

facilitated by the fact that they usually read their EMR after a patient visit. When the content of the medical records is not understood 13 of 15 patients use the Internet to find information and receive answers to their questions. In some cases, the patients turn to relatives and friends who have some form of healthcare professional background. Two patients mentioned that they used other sources such as dictionaries. An interesting observation is that patients did not tend to take any additional contacts with their healthcare providers to ask questions. If the patient is unable to answer their questions by using the Internet or by asking relatives and friends they wait until the next doctor visit.

### **3.2.6 Security and Privacy**

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

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

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

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

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

## **4. Discussion and Future Work**

Accessing medical records is a controversial issue. When medical records were made accessible online for patients in Uppsala it raised discussions and concerns of security and ethics, both in the media and among healthcare practitioners at hospitals in the region. Many worried about the workload of the healthcare practitioners, and about how patients would handle the information. One of the prominent aspects of concern was that cancer patients would be accessing test results and medical notes without being able to discuss with healthcare practitioners on possible upsetting matters right away. The possibility to receive a cancer diagnosis online was seen as especially problematic. However, little was known about why cancer patients want to read their own medical records, and how

they manage their personal health information. The results from this study deepen our understanding of cancer patients' attitudes and experiences of online medical records. Similar to earlier research [6, 13, 17], the study results confirm that online access can help patients prepare for doctor visits, which in turn seems to improve the communication with practitioners. It can also help patients learn more about and understand their medical issues. An interesting aspect of the results is that the study participants had not experienced the negative aspects of online access anticipated by physicians. For example, in contrast to fears of many physicians, online access to medical records did not generate substantial anxiety, concerns or increased phone calls [5, 18]. In accordance with current research, it seems that patients are more respectful of doctors' time in addressing questions that the medical records raise than many doctors have assumed [8]. Moreover, although patients did find some parts of the medical record difficult to understand, they did not perceive it as problematic. The study findings support the urges that it is crucial to include the patients' perspective in the development of e-Health services, since they have experiences and opinions unknown for healthcare practitioners. Another interpretation of the results is that the healthcare sector needs to consider patients as a heterogeneous group of people, who have different needs and habits. Access to medical records is appropriate and possibly beneficial for some patients but not for all. Therefore, there is a need to consider and respect the differences between individuals, and develop e-Health services that are based on the needs of the individuals. Therefore, it may be relevant to identify the characteristics of those patients who experience anxiety and to determine which patients are and are not suited for comprehensive information through e-Health services [8]. Moreover, when it comes to security and privacy issues, there are two important reasons why patients do not seem to be worried about unauthorized access to medical records: (1) Patients expect that the e-Health service has a high level of security, and (2) patients perceive their own information as non-sensitive. Despite the fact that their own information is not deemed sensitive, there is a recognizable expectation among patients that their patient information should only be made available to authorized healthcare practitioners.

Because of the limitations of this study, it is not possible to reach definitive conclusions about the outcomes discussed above. Further qualitative research with a larger sample size regarding patients' access (both seriously ill patients and other patient groups) to the EMR is needed. This study is, however a step towards that direction. Future research should also focus on studying in what way the information can be adapted and improved so that patients who want can become more involved, gain increased knowledge and gain better control over their own healthcare, i.e., to become empowered [4]. In addition, there is a need for further research on the development of related eHealth services and on the premises and methods for facilitating improved and secure communication between patients and healthcare.

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