

DEVELOPING ELECTRONIC PATIENT RECORDS: EMPLOYING INTERACTIVE METHODS TO ENSURE PATIENT INVOLVEMENT

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Abstract

The perceptions of the role of an Electronic Patient Record (EPR) vary widely with many of the stakeholder groups focusing on the provider needs for information sharing and knowledge management. Often lost in this focus is the perspective and needs of the patient in managing their medical condition and care. The overall goal of this paper is to improve patient education and to enhance the patient experience through the use of information technology (IT) in order to facilitate the sharing of information between providers and their patients. This research project took place at University Health Network (UHN) in Toronto (Canada), which is a large teaching hospital with multiple hospital sites in the city. In this process, we first examined the literature to investigate the human factors issues related to healthcare as well as other settings. Subsequently, we interviewed a number of interested stakeholders from two groups: the physicians (both family and attending) and the patients themselves. Finally, using a written survey, we explored the content that UHN lung-transplant patients would be interested in having within their EPR.

Key words: health information systems, patient decision-making, system design

1 Background

In recent years there has been an increased move towards an electronic patient record (EPR). The possibility of instant, universal access to up-to-the-minute, accurate patient information is a goal that is actively sought throughout health services organizations. In their review of the medical literature, Jerant and Hill [5] showed that the use of electronic medical records is associated with improved surrogate outpatient care outcomes.

Patients are becoming more active participants in the decision making process for medical care and more medical decisions are becoming the result of a shared process between the patient and health care provider [4], [17]. An integral part of

this process is the sharing of information between health care providers and patients. Interactive multimedia has the potential to improve communication of the risks involved in medical decision-making and has been used to assist patients in making treatment decisions [1], [10], [13].

As the patient becomes a more active participant in the decision-making process, it is increasing demand for access to personal health information [15]. Patients' desire to find medical information from electronic resources, particularly the Internet, is well documented [3]. In addition, studies have found that patients are willing to use electronic media for education, assistance in decision-making and as a source of personal health information.

In an effort to improve communication in the patient care process, we have put forward the concept of transferring patient information from the medical record (paper-based and electronic) to a read-only compact disc (CD). This portable physical medium would be available to and usable not only by, patients but also attending physicians, primary care physicians and other allied health care workers caring for patients who are associated with one particular healthcare provider organization. It is our hypothesis that the use of a CD technology will overcome many of the security and data issues while simultaneously illustrating the benefits of electronic patient records.

Many benefits of an EPR can be summarized as follows:

- Data amalgamation and prompt data retrieval;
- Simultaneous and remote access;
- Legibility;
- Confidentiality;
- Flexible and tailored layout;
- Integration with other information sources;
- Data incorporation;
- Continuous data-processing;
- Assisted search;
- Greater range of output methods;
- Tailored output - Displays and printed reports can include many fonts, colors, still and moving images [14].

Unfortunately, there are many disadvantages associated with the EPR. They include:

- Layout not intuitive;
- Need for structured, coded data;
- Temptation to "stamp collect" everything;
- Temptation to embellish data;

- Loss of design control and flexibility;
- Costs;
- Adverse response from patients;
- Reliance on hardware;
- Reliance on software.

Our hypothesis is that patients, once exposed to the benefits of the EPR, will be one of the strongest advocates for change – and will work with their healthcare providers to overcome the drawbacks in order to access the benefits. From a patient perspective some of the direct benefits are:

- Availability when live instructors are busy or absent;
- Consistency and patience in gathering and dispensing information;
- Customized instruction;
- Patient privacy and avoidance of embarrassment;
- Apt use of feedback and reinforcement;
- Precise documentation of the learning processes and outcome.

Patients must have a comprehensive understanding of all benefits if they support the use of an EPR. As such, efforts should be made to comply with design principles based on human-computer interaction research. Poor design can complicate the navigational process for patients (and clinicians) and increase demands on their attention, perception, language and memory. By acknowledging these constraints, the structural design of the EPR CD should aim to match existing user workflow, follow established standards, accommodate flexibility and recognize human limits. Well-designed EPR should focus the viewer's attention on the data. The information should be presented in an easily navigable structure and comprehensible format.

As a result, in this paper our principal objective is to document the research findings pertaining to the design and layout of an electronic patient record. Based on our empirical evidence (from surveying and interviewing stakeholders) and incorporating literature from other areas of computer systems design, we will describe the critical success factors pertaining to EPR development and implementation. Further, we describe a research project where one large Academic Health Center in Toronto, Canada (University Health Network – UHN) has developed an EPR prototype using compact disc (CD) technology. It is hoped that this technology will not only address some of the limiting issues within the EPR but also expose the patient to the inherent value that lies within their health record – value for both themselves and other patients.

2 Rationale for CD Technology

The primary reason to move to CD technology was to overcome the restrictive issues of the EPR while at the same time illustrating to patients the value of information inherent in their health records – valuable to both their own health management as well as that of others. Two of the restrictive issues in using the EPR are data consistency and security. First, the development of the EPR CD at UHN was facilitated by the previous investment in developing a comprehensive organization-wide health record. Most departments and programs had already addressed significant data consistency issues. The option to include data from computer systems (and organizations) outside of UHN was not considered. Second, by using a CD, patients perceived the medium to be highly secured. In essence, only one copy of their file was in use outside of their healthcare provider. The fear of someone accessing their information (e.g., over the Internet) was now no longer an issue. Being one of the first projects to develop an information system for patients, however, issues around exposing patients to computer interface design escalated in their importance. The following are some examples of these issues.

2.1 Structure

User-interface design is a key component of any system. Having a wealth of data is not useful if the pertinent information is not easily accessible to the stakeholders. Issues such as how data can be better organized within a record and on a document page and how computers can be used to enhance data interpretation are critical. They include:

- Navigation - Unambiguous and user-friendly point-and-click interface;
- Mode of information display - visual, symbol- and color-coded for fast and easy interpretation and comprehension;
- Multi-media - information presented in pictures, sounds, videos, instead of texts;
- Format of data – not static but dynamic and query-able;
- Graphic content (radiology and other imaging results) - possible diagnostic quality;
- Language - technical terms made understandable to patients with hyper-linked glossary.

2.2 Security

Security measures must balance the risks of providing access with the need to view valuable data. Canadian privacy and confidentiality laws ensure that personal health information is protected and exchanged between health care workers and patients for medical purposes only. Methods to make personal health information electronically accessible to patients and relevant health care workers in a CD format while protecting privacy were investigated through interviews and questionnaires. Analysis of current data security measures and technologies will be presented.

2.3 Internet – Web-Based Patient Record

There are very few examples in the literature of the patients holding the necessary information to allow physicians to make optimal therapeutic and diagnostic decisions. Most of these concern either their use in ambulatory care settings or with chronic diseases entailing a multi-disciplinary approach to patient care. Several Internet electronic medical services have been started in recent months. The web sites are not uniform. Some allow patient input of information, while others rely on doctors, but they provide emergency access to a patient's information. While many in the medical community have embraced the service, concerns over security still linger.

The field is so new that no standards exist for how online record services operate. The early entrants vary widely in how much and what kind of information they collect, what purpose the information is intended to serve, how it can be accessed, and whether physicians or patients maintain the record. Furthermore, principles of user-interface design are negligible. In addition, fundamental questions about Internet security and reliability remain, despite the sites' claims that it is easier for some unauthorized person to fish your medical record out of a storage room than out of a web site.

3 Review of Stakeholder Needs

Interviewing various stakeholders within UHN carried out the need analysis. These included attending physicians, family physicians and patients. When the initial survey of patients found that many patients were not computer literate, we interviewed patients selected because they would likely be early adopters of the CD.

Most of the research suggests that physician groups are certain to show the most resistance to change. Leonard [7] reports that a reason for this is that nearly all physician systems developed have made the work of the physician more cumbersome as well as there be insignificant financial incentives for physicians to use such systems. Lorenzi and Riley [9] found that technology is perceived to interfere with the traditional role of the physician. Conversely, other research reports that physicians are content with patient health information programs because they result in higher patient satisfaction and compliance, and more legible and accessible patient records [12].

A survey conducted found that 80 percent of the physicians would use information technology if it helped improve management of patient records and diagnostics. Finally, literature on physician acceptance of new medical information systems is beginning to develop. Treister [16] gives eleven reasons why physicians fail to accept new systems.

Among these is the failure to begin with an adequate:

- Physician base of support;
- Lack of user-friendly interfaces;
- Concern regarding the information collected;
- Failure to collect the most important information;
- Physician “techno” phobia;
- Exclusion of physician involvement in the financial analysis;
- Failure to include marketing to physicians in the implementation plan;
- Inadequate training of physicians to use the system;
- Lack of strong, centralized IS leadership respected by physicians;
- Lack of control by the organization over physician practices.

In summary, it is clear that physician resistance is high when an EPR system creates no added value to the physicians work. If it enhances the relationship with the patient and is not cumbersome to use, there will be little or no resistance [2].

3.1 Survey of Physicians

Responses were received from only 20 physicians in total (4 attending, 6 family and 10 residents in internal medicine). All surveyed felt that the care of patients would be improved if the patients or their family physicians had more relevant information. All, except one, felt that the referring physicians do not receive sufficient information on their patients’ hospital stays. The entire physician group felt that the information was not received in a timely fashion. Table 1 summarizes

the types of information that those surveyed felt that they and/or their patients should have access to on the CD.

Information	Physician Group	Patient
Discharge Summary	19	10
Lab Tests	20	5
X-ray Results	20	6
Medications	20	15
Self-Care Instructions	18	20
Future Appointments	19	20
Operative Notes	19	5

Table 1: Physician's perspective on who should have access to information

Across all physicians, only two expressed concern that the confidentiality of patients could be violated. In particular, one physician stated that her patients did not always reveal their entire medical history to all of their doctors. Two expressed concerns about the possible misinterpretation of technical information and comments in medical notes.

One physician felt that the discharge summary would need to be customized for patients, such that potentially offensive statements should be removed. All surveyed felt that the CD should include illness-specific information to educate the patient. All physicians felt that the CD should be password-protected. Four physicians felt that the CD would increase patient satisfaction and enhance patient's perception of communication, while two did not. On the subject of patient compliance, two physicians felt that patients do not carry out appropriate self-care and often require readmission to hospital; two felt that this occurs sometimes, and one did not answer the question.

3.2 Survey of Patients

The literature suggests that patients are willing to embrace technologies that allow them to manage their health, given that the information is dynamic (i.e. multimedia, sound etc) and easy to use. Kreider and Haselton [6] found that technology-based patient management programs could reduce the length of time required for conventional (i.e. via physician) patient education without compromising quality. Patients that used such programs felt well informed about the decisions that they faced, and were more satisfied with their overall care. Weed [18] found that generic and static (i.e. Pamphlets, Charts etc) patient education tools provide minute benefits to the patient due to their impersonal

nature. Hence, patient education software should be dynamic and contain pertinent medical information.

In the literature, patients were positive about having an electronic medical record. Confidentiality was not a major concern of patients. However, other studies have shown drawbacks from patients because they felt that the EPR infringed upon their personal privacy. As an illustration, patients from an academic general practice, a private group practice and a solo practice were randomized into the experimental and control group. Patients withdrew from the study because they were sensitive to the nature of the information in the record and because of crises in psychosocial circumstance [8]. In summary, patients will use media that will improve their health given that they are dynamic and easy to use. However, patients welcome computer-assisted care as an augmentation and not a replacement of individualized health care. Patient acceptance of this technology is high and spans through all age, education, and socio-economic boundary [11].

In our study, ten patients completed the survey. They can be best described as “early adopters”. They were all between ages 20 - 40, had access to computers with CD drives and Internet connections, would like more information about their hospital stay after discharge, and would use the proposed CD program for the management of their health. Table 2 summarizes the types of information that those surveyed would like to be able to review them, and would like their physicians to have access to review on the CD.

Information	Self	Physician
Discharge Summary	9	10
Lab Tests	9	10
X-ray Results	9	10
Medications	9	10
Self-Care Instructions	9	9
Future Appointments	9	9
Operative Notes	8	9

Table 2: Patient’s perspective on who should have access to information

Almost all expressed interest to have more information on their medication, including an explanation of their purpose, warnings on drug interactions, and possible side effects and their symptoms. There was also a strong interest to have more information about their illnesses (severity, length, and course). Some would like to see on the CD their medical history and their physicians’ suggestions.

4 Second Level Study

At this stage, we proceeded to delve deeper into one specific patient group in order to get their contribution to the design and development of a CD EPR. The primary research instrument used to interview was a written survey administered to UHN lung transplant patients. The survey was divided into three sections – demographic profile, computer use profile and information profile - and was designed to address three main questions:

1. What is the level of computer readiness and accessibility among lung patients?
2. Are lung transplant patients' interested in the concept of an EPR?
3. What type of content would lung transplant patients' like to see in an EPR?

4.1 Response Rate and Limitations

The written surveys were distributed in-person by team members at the lung transplant clinics on March 5, 12 and 19, 2001. Respondents were invited to return the questionnaire directly to the team member or to place them in a secure box provided by UHN. A total of 30 surveys were returned. The total UHN post-lung transplant (living) population is estimated to be approximately only 75 individuals. As a result, with the sample size of 30, tentative generalizations to the UHN lung transplant population might be made. The results cannot be generalized to the broader UHN transplant program or the UHN outpatient population.

4.2 Survey Construction

The survey was, in general, well received. Over 80% of patients approached agreed to fill out the survey. The main reason patients declined to complete the survey was poor health at the time of the survey. In general the majority of respondents answered most questions.

4.3 Demographic Profile

A total of 30 post-lung transplant patients responded to the survey. Six questions on the survey assessed the demographic characteristics of respondents. 60% of the respondents were female and 40% of respondents were male. The largest group of respondents (23%) was between the ages of 46 to 55. The second largest group (20%) was between the ages of 56-65. The level of education among the

respondents ranged from a Master's degree (3%) to completing some grade school (3%). 57% of respondents had attended some level of post-secondary education. All of the respondents were receiving care from the multi organ transplant program, however, 70% of respondents also received care from a family physician and 30% of respondents received care from another lung specialist.

4.4 Computer Use Profile

Seven questions on the survey were designed to measure the level of computer readiness and accessibility among the lung transplant sample. Respondents were asked to rate themselves on their knowledge of computers. In this self-assessment 40% of respondents felt they had "beginner" knowledge of computers, while 30% of respondents had "moderate" knowledge of computers. Just fewer than one quarter (23%) respondents had no knowledge of computers. Sixty percent of respondents stated that they had a CD in their computer and 57% of respondents had access to the Internet. Over half (53%) of respondents had access to the Internet at home while only 3% reported they had Internet access at work. Twenty-three percent of respondents indicated they did not use the Internet. Of those using the Internet, usage ranges between 1-2 hours up to 8-10 hours per week.

4.5 Information Profile

The questions contained in the information profile section of the survey were designed to address the two key questions: Are lung transplant patients interested in the concept of a EPR, and, if yes, then what type of content might they want to see in a EPR? The survey gauged patients' interest in their medical record. Sixty-three percent of patients have seen some part of their medical record. Blood work and x-rays were the most common aspects of a medical record that patients had seen. Over 60% of patients believe that having access to information about the medical care that they receive would help in managing their care at home.

Next, we asked patients what they believe would be the most valuable aspect of having access to their medical information. Respondents were encouraged to check all that apply:

- 57% of patients believe that access to their medical information would help enhance their understanding of their medical condition;
- 12% of patients indicated that access to their medical information would help ensure the information was available to their family doctor;

- 12% of patients felt access to this information was important in case of an emergency.

Patients were asked if they received enough information about their condition upon discharge from the hospital. Seventy-seven percent of patients believed they received enough information. Of the 20% of patients, who did not believe they received enough information, the majority wanted more information about necessary follow-up care. Forty percent of patients did not believe that having medical information about their stay in hospital would affect their health at the time of discharge from hospital.

However, as previously discussed, over 60% of patients believe that having access to information about the medical care that they receive would help in managing their health care while at home. The difference in the phrasing of each question may illustrate the importance patients' place on information necessary for self-management over information about their hospital stay. Sixty percent of patients believe that if they were provided with their medical record, they themselves and their family physician would use it the most. Related to the use of the patient's medical record, 73% of respondents did not have any concerns about a family physician, family members or other medical specialists having access to their record.

Patients were also given the chance to choose what type of information from the hospital they would find useful to help manage their care at home. The most popular choice was the lab test and results (67%) followed by a summary of active diseases (53%). Given a choice, 63% of patients would want this information as a paper copy. Other preferences included CD (13%), secure Internet (13%), and floppy disk (10%). Forty-seven percent of respondents indicated that they would find it useful to have the UHN lung transplant manual in an electronic format.

4.6 Discussion

The survey showed an approximately equal distribution of male and female respondents and covered a wide range of age groups with 75% falling between 26 – 65 years of age. Approximately 60% of respondents had engaged in some type of post-secondary education. The majority of the patients had access to the Internet from home. Overall the sample group can be described as young, educated, computer literate and Internet-accessible.

Almost two-thirds of patients (63%) had seen some portion of their medical record (most commonly blood work or x-ray results) and a similar percentage believed a personal medical record would help them manage their personal health care. The most common reason respondents wanted access to their medical chart

was to enhance their understanding of their medical condition. This desire to have further access to personal medical information was expressed despite a comprehensive patient education program provided by the transplant program and despite the fact a high degree of patients felt they were provided with an adequate degree of information upon discharge from hospital (77%). As a whole, the sample group appears to have a high level of interest in their medical information and can be described as active participants in their care.

When given a choice of formats the majority of patients (63% of all respondents) expressed a preference for a paper copy of their medical chart. Other choices, such as CD, Internet or floppy disk were far less preferred - 13% of all respondents selected an Internet access, 13% preferred a CD and 10% selected a floppy disk. The specific information that patients identified as most likely to help them manage their care at home was lab results, a summary of their medical history, medication information (history and current), contact information (specialists and emergency contacts) and blood pressure/ temperature charts. Family and personal history and height/weight charts were not strongly endorsed. Only 17% of all respondents felt the inclusion of an allergy history was necessary in their personal health record. It is hypothesized a survey of health care providers would produce a different response as this information is crucial to providers when considering medications.

The reason behind patient preference for paper versus electronic formats of their health information was not explored in the survey conducted in our study. The literature would suggest the majority of patients who want a paper copy of their medical record rather than electronic copies do so because of concerns regarding security. In our study only 13% of patients would prefer a copy of their health record on a secure Web site but a further 23% selected either a CD or a floppy disk. It is hypothesized the CD and floppy disk are not considered as high risk regarding invasion of privacy. In contrast approximately half of the patients would find an electronic copy of a lung transplant manual helpful. Further explanation for the preference of paper format may be the familiarity with hard copy and therefore patients can conceptualize what their personal health information might look like on paper. It may be more difficult for them to conceptualize how health information would be presented and navigated in an electronic format. The desire for personal health information is reflected in our study where almost 2/3 of respondents felt that access to their medical record would help them manage their health care at home. Our study did not specifically address the issue of e-mail connectivity with health care providers.

5 Conclusions

The results of this study demonstrate a desire on the part of some patients to have access to personal medical information. This desire stems from increased self-reliance in the management of personal health and the desire to take a more active role in the medical decision-making process. While the effect that this information may have on patient health outcomes is not clear, access to personal health information is associated with improved patient satisfaction. As patients move to a more self-reliant role in the management of their health the demand for personalized information will increase and the health care industry has to be prepared to meet this new consumer demand.

The survey conducted in this study indicates that lung transplant patients at UHN are interested in accessing their personal health information to support their health management. Over half of the total sample group is connected to the Internet and according to the literature it can be expected they are accessing health information through that medium. The preferred format for a copy of a personal health record is on paper although over a third of the information-seekers sub-group also endorsed some type of electronic format.

In addition to the survey of lung transplant patients, a prototype electronic patient record was developed as means of bringing to life some of the recommendations of the previous student group and the survey results of the current study. This prototype could be used to further explore the acceptability of personal electronic health records among UHN patients. The prototype could also be used in a focus group format with a variety of different patient populations to refine the tool and determine the best way to deliver customized medical information to patients. This prototype does not contain specific patient information for a variety of reasons. However, it would provide patients with a concrete tool by which to envision the possibilities of an electronic patient health record. Reaching beyond the lung transplant population, additional patient groups need to be targeted to see how well the results of this study reflect the level of interest and desired specific content of other patient groups.

A further possible area of study is that of security and regulation of health information. As discussed, concerns about inappropriate access to health information continues to be a significant issue amongst the public, even with those described as on-line users of health information. Future study groups may consider a more in-depth analysis of the technical solutions to security concerns as well as attempting to ascertain the level of concern about security among the hospital patient population.

A final area of future study is specific to providers and could address the key steps necessary for further development of an EPR. Future steps would include the analysis of the technical requirements and implications of developing an EPR and would require an in-depth review of system compatibility. Consequently, we must address any issues around legal and ethical implications of releasing hospital information to patients in an electronic format. Finally, hospitals must consider an internally focused strategy to gain the support of their own healthcare professionals to the concept of the electronic patient record.

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