

# **The Role of Patients in Designing Health Information Systems: *The Case of Applying Simulation Techniques to Design an Electronic Patient Record (EPR) Interface***

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## **Abstract**

One overall objective of Electronic Patient Records (EPRs) is to improve patient education and to enhance the patient experience through the use of information technology (IT) so as to facilitate the sharing of information between providers and their patients. The research project reported on herein took place at University Health Network (UHN) in Toronto (Canada), which is a large academic health science center with multiple hospital sites in the city. As a first step in this process, we 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 simulation environment, we explored the content that UHN lung-transplant patients would be interested in having within their own EPRs. In this paper, we report on the research, the methodology and the findings pertaining to the both the content and the design of an electronic patient record.

**Keywords:** EPRs, adoption and diffusion of EPR, healthcare, user participation.

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## **1.0 Background**

In recent years, there has been much research outlining the healthcare system's move towards an electronic patient records (EPRs) [for example, 12,3,4,5]. 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 [6] showed that the use of electronic medical records is associated with improved surrogate outpatient care outcomes.

Secondly, the information systems (IS) literature has an over-abundance of findings that indicate that involving stakeholders in the design and development of information or decision support systems enhances the likelihood of building and delivering more effective systems [for example, 7,8,9,10,11,12,13,14,15,16,17,18].

Thirdly, patients are becoming more active stakeholders or participants in the decision making process for their medical care; more medical decisions are being made as the result of a shared process between the patient and health care provider [19,20]. An integral part of this process is the recognition of the need to share information between health care providers and patients [21,22] and to do it through electronic media [23,24,25].

In an effort to improve decision-making by patients both during and after the care process, we have put forward the concept of transferring patient information from the medical record (paper-based and/or electronic) to an active web-site [26,27,28]. The contribution of this research is to document patient needs and preferences pertaining to the design and layout of an EPR by allowing patients to exercise their input through a simulated patient environment.

## **2.0 Previous Research on Patient Preferences for an Electronic Patient Record**

Innovative approaches, including real-time access to EPRs, to patient social support and knowledge development are necessary to ensure the highest quality of life and long-term health outcomes for patients and their families [29]. Consequently, patient-centered knowledge development and support tools administered in partnership with traditional physician-centered clinical programs to coordinate disease information, education and promote greater social support may augment quality of life and enhance health outcomes for patients [30,31].

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 [32,33]; most of these concern either their use in ambulatory care settings or with chronic diseases entailing a multi-disciplinary approach to patient care. The field is so new that few standards exist for how online record services operate; in fact, 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. Further, research following the principles of involving users (i.e., patients) in the design process are so few as to be negligible [34]. In short, electronic patient record systems are not uniform in structure where some allow patient input of information, while others rely solely on doctors; some provide emergency access to a patient's information while still others require "in-physician-office access" only [35,36].

Much research suggests that physician groups are certain to show the most resistance to change [37,38,39,40]. Leonard [41] reports that the main reason for this is that nearly all physician systems developed have made the work of the physician more cumbersome as well as the fact that to date there have been little financial incentives for physicians to learn such systems. Lorenzi and Riley [42] 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 [43]. 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 [44] gives eleven reasons why physicians fail to accept new systems. Among these are 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 and 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 physician's work. If it enhances the relationship with the patient and is not cumbersome to use, there will be little or no resistance [45].

### **3.0 Methodology**

To begin the research, contacts in different departments and programs at UHN were approached to gauge their interest. The lung transplant programme was then selected due to the interest of the programme directors and to the nature of their population: namely young adults with a history of chronic illness. This meant that the research project would incorporate a population that was aware of the importance of managing their own health as well as being very fluent with technology. Individual patients and physicians within the programme were then contacted for their participation. Their involvement was entirely voluntary. Both volunteered patients and physicians were interviewed with open-ended questions designed to examine their breadth of experience, feeling and opinion regarding the following two questions:

1. What is the level of computer readiness and accessibility among lung transplant patients?
2. Are lung transplant patients' interested in the concept of an EPR?

Both of the physician groups (attending and family) as well as the patient questionnaires are provided in Appendix A, B, and C. The questions contained therein were drafted through preliminary discussions and interviews with representatives from all three groups.

The next step was to research the needs and wants related to the patient group only in order to get their contribution to the design and development of an EPR. The primary research instruments used was a simulation environment within a mock computer interface that allowed lung transplant patients to experience, and to experiment with, different layouts and scenarios (i.e., a computerized simulation). The objective was to investigate the final question:

3. What type of content would lung transplant patients' like to see in an EPR?

### 3.1 Physician response and concerns

In step one of our research, the needs analysis was carried out by interviewing both attending physicians and family physicians as well as residents at the academic health center. Responses were received from only 20 physicians in total (4 attending, 6 family and 10 residents in internal medicine). All twenty 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 within the EPR.

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 physician types, 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 concern 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 EPR should include illness-specific information to educate the patient. All physicians felt that the EPR should be password-protected. Four physicians felt that the EPR 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. Finally, all physicians felt that patients should receive self-care instructions, yet only half agreed to receiving discharge summaries (10 out of 20) and a minority felt that the patients should be able to receive access to operative notes (5 out of 20, or 25%).

### **3.2 The Patient Perspective**

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 [46] 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 [47] found that generic and static (e.g., pamphlets, charts) 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 addition, previous research found patients to be positive about having an electronic medical record [48]. 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, in one study, 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 circumstances. In summary, patients will use media that will improve their health given that they are dynamic and easy to use [49]. 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 boundaries [50].

### **3.3 Patient Response Rate and Limitations**

The one on one contact by the research team members with the patients took place at the lung transplant clinics on March 5, 12 and 19, 2001. A total of 30 patients were interviewed and studied. The total post-lung transplant (living) population at this one clinic is estimated to be approximately only 75 individuals. As a result, with the sample size of 30, some tentative generalizations to the lung transplant population might be made; however, the results cannot be seen as representative of the broader transplant program or the patient population as a whole. The research was, in general, well received. Over 80% of patients approached agreed to the study. The main reason that patients declined to participate was poor health at the time of the survey. In general, the majority of respondents completed the entire interview.

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 under one quarter (23%) respondents had no knowledge of computers. Sixty percent of respondents stated that they had created their own EPR 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 ranged between 1-2 hours up to 8-10 hours per week.

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 to 65 years of age. Overall, the sample group can be described as young, educated, computer literate and Internet-accessible.

### **3.4 Patient Survey Results**

Once again, the principal objective of this research is to involve stakeholders (i.e., the patient group) in the design and development of information systems (in this case, EPRs). According to Rogers [51] and many others [for example, 52, 53], system effectiveness and usability increase when stakeholders work with developers to create the specifications and functionality. Further, asking stakeholders what information they would like to receive is not efficacious due to the fact that users are normally not well versed in “system options”; what stakeholders are very good at, however, is identifying functionality they would “like to have” at the moment that they experience it [54,55,56,57]. As a result, we have engaged patients in both passive (survey interview) and active (simulation) environments to elicit their needs and wants.

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. 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.

The questions contained in the information profile section of the survey were ultimately 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. Over 60% of patients believe that having access to information about the medical care 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;
- 13% of patients indicated that access to their medical information would help ensure the information was available to their family doctor;
- 13% 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.

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 healthcare providers would produce a different response as this information is crucial to providers when considering medications.

### 3.5 Simulation Results

Only ten of the thirty patients who were interviewed then performed the detailed simulation exercise (dropout due primarily to poor health). These patients, now armed with a better appreciation for what may or can comprise an EPR, were asked the same questions that we posed to physicians (results illustrated in Table 1). The numbers of patients agreeing to either the physician or the patient themselves receiving the results (out of a total of 10) are provided below in Table 2.

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**

It is very clear that these patients want the networking of health data to be improved – both for themselves and their physicians. These numbers are in stark contrast to the physician results who were much more reticent about patients accessing certain segments of their own EPR.

### 4.0 Interpretation of Patient Perspective

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.

Further, the patients indicated a preference for paper versions (versus electronic formats) of their health information, which was not explored in the survey conducted in our study. The literature would suggest that the majority of patients who want a paper copy of their medical record rather than an electronic copy 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 an EPR on CD-ROM 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 allowing patients to 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 two-thirds 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.

## **5.0 Conclusions**

This project builds on a systematic patient-centered, iterative approach to system design, development and evaluation. It targets chronic disease, a problem of high prevalence and major costs for the healthcare system. The on-going research project team is solid, multidisciplinary and experienced in disease management, clinical work, technology, system design and analysis, patient-centered care, statistical analysis, qualitative research and project management. This team relies on efficient use of technology while avoiding duplication of effort, builds on existing experience on Internet communication with patients, and has a high potential to create new services and a modern model of supportive care to be applied in other areas of healthcare.

In addition to the survey of lung transplant patients, a prototype electronic patient record was also developed as means of bringing to life some of the recommendations of the survey results. This prototype will now 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 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.

Possible areas of study include topics within the realm of security and regulation of health information. As alluded to herein, concern 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. Our research will begin to 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.

Future areas of investigation will pertain to the issues specific to providers and may address the key steps necessary for further development of EPRs. This will include the

analysis of the technical requirements and implications of developing an EPR incorporating robust system compatibility. As a result, system interoperability then promotes the need to address many issues surrounding 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 (i.e., overcoming physician resistance or, perhaps, provider non-compliance) to the concept of the electronic patient record and to the creation of a future multidisciplinary decision making partnership across stakeholders in an effort to improve overall healthcare efficacy and patient outcomes.

The immediate next steps are to conclude the design work and make real EPRs available to patients over a secured Internet site. Patient will be able to navigate through it by asking questions and will be monitored for usage, time spent and direct feedback to questions. The purpose is to provide the patient with the best information in the optimal format and layout so to promote their decision making with the other health care workers. Finally, after the completion of the design stage, other chronic patients from a variety of disease groups will be provided access to their EPRs over the Internet, with measurement focused on functionality and improved health outcomes.

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# APPENDIX A

## Questionnaire for Attending Physicians and House Staff at Hospital

### Introduction:

This healthcare organization has interest in using computers to help care for patients by improving the availability of information. One of the possibilities is to design a mini Electronic Patient Record (EPR), which could be accessed through the Internet and used by your patient and his/her family doctor information about his/her illness and stay in hospital. We feel that it is important to have input from physicians such as yourself to make sure that the EPR is user-friendly, and that any concerns that you may have are addressed.

We would like a few minutes of your time to have you answer this questionnaire. If this is not a convenient time for you, please let us know whether we can contact you by phone or meet with you in your office to complete the questionnaire.

Name of Physician \_\_\_\_\_ Phone/Pager # \_\_\_\_\_

Year of Training: Clinical Clerk    PGY 1    PGY2    PGY3    PGY4    Fellow    Staff  
Physician

1. Do you think that the care of patients would be improved if they or their family doctor had more information about their stay in hospital? Yes ? No ?

2. We presently collect the following information electronically. Should the patient or doctor have access to this information?

Patient

Doctor

Discharge Summary

Lab Tests

X-ray results

Medications

Self Care Instructions

Future Appointments

Operative Notes

ECG (Future Plans)

3. What other information not on the checklist would you like to see made available to the patients and their family doctors?

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4. Do you think that the EPR would increase patient satisfaction? Yes ? No ?

5. Do think that the EPR should be password protected? Yes ? No ?
6. Do you think that the EPR should include illness specific information to educate the patient? Yes ? No ?
7. Which of the following represents challenges that you regularly experience when a patient is discharged from hospital?
- 1) Your referring physician doesn't receive sufficient information on your patients hospital stays? Yes ? No ?
- 2) Your referring physician doesn't receive the information in a timely fashion? Yes ? No ?
- 3) The patient does not carry out appropriate self care and often requires readmission to hospital? Yes ? No ?
8. Do you think that a EPR like this would enhance the patient's perception of communication? Yes ? No ?
9. We believe that the EPR must be available within a week of discharge to be maximally utilized. Would you be willing to ensure that all necessary information will have been dictated in time for this to be done (i.e. Maximum of 48 hours after discharge)? Yes ? No ?
10. When do you believe that the patient EPR should be available to the patient?
- |                         |       |      |
|-------------------------|-------|------|
| At Discharge            | Yes ? | No ? |
| 1 Week after discharge  | Yes ? | No ? |
| 1 Month after discharge | Yes ? | No ? |
| Other _____             |       |      |
10. Would you support the implementation of the EPR even if it means changing your work habits and learning how to use a new program? Yes ? No ?

Please elaborate on this.

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11. What are your greatest concerns about the patient having access to an electronic patient record?

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12. Do you have any other suggestions?

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## APPENDIX B

### Questionnaire for Family Physicians

#### **Introduction:**

This healthcare organization has interest in using computers to help care for patients by improving the availability of information. One of the possibilities is to design a mini Electronic Patient Record (EPR), which could be accessed through the Internet and used to give your patient information about his/her illness and stay in hospital. We feel that it is important to have input from physicians such as yourself to make sure that the EPR is user-friendly, and that any concerns that you may have are addressed.

We would like a few minutes of your time to have you answer this questionnaire. Thank-you for participating in this survey.

Name of Physician \_\_\_\_\_ Phone/Pager # \_\_\_\_\_

1. Do you think that the care of patients would be improved if your patient or you had more information about their stay in hospital? Yes ? No ?
2. We presently collect the following information electronically. Should the patient or doctor have access to this information?

Patient

Doctor

Discharge Summary  
Lab Tests  
X-ray results  
Medications  
Self Care Instructions  
Future Appointments  
Operative Notes  
ECG (Future Plans)

3. What other information not on the checklist would you like to see made available to the patients and their family doctors?
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4. Do you think that the EPR would increase patient satisfaction? Yes ? No ?

5. Do think that the EPR should be password protected? Yes ? No ?

6. Do you think that the EPR should include illness specific information to educate the patient? Yes ? No ?

7. Which of the following represents challenges that you regularly experience when a patient is discharged from hospital?
- a) You don't receive sufficient information on your patient's hospital stays? Yes ? No ?
  - b) You don't receive the information in a timely fashion? Yes ? No ?
  - c) The patient does not carry out appropriate self care and often requires readmission to hospital? Yes ? No ?
8. Do you think that a EPR like this would enhance the patient's perception of communication? Yes ? No ?
9. We believe that the EPR must be available within a week of discharge to be maximally utilized. Would this be adequate? Yes ? No ?
11. When do you believe that the patient EPR should be available to the patient?
- At Discharge Yes ? No ?
  - 1 Week after discharge Yes ? No ?
  - 1 Month after discharge Yes ? No ?
  - Other \_\_\_\_\_
12. What are your greatest concerns about the patient having access to an electronic patient record?
- 
- 
- 
13. Do you have any other suggestions?
- 
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## APPENDIX C

### Questionnaire for Patients

#### **Introduction:**

This healthcare organization has interest in using computers to help care for patients by improving the availability of information. One of the possibilities is to design a mini Electronic Patient Record (EPR), which could be accessed through the Internet and used to give patients and their doctors information about their illness and their stay in the hospital. We feel that it is important to have input from patients like yourself to ensure that the EPR is user-friendly, and that any concerns that you may have are addressed.

Age Group:

Language:

1. Would you like more information about your stay in hospital when you leave?  
Yes ? No ?

2. What kind of information would you like?  
\_\_\_\_\_  
\_\_\_\_\_

3. Do you have access to a computer with a CD-ROM drive? Yes ? No ?

4. Does your computer have an Internet connection? Yes ? No ?

5. We presently collect the following information electronically. It would take about a week to put it on an EPR. Would you like to be able to review this information yourself?  
Would you like to be able to take the EPR to your doctor to review the information?

Self

Doctor

Discharge Summary

Lab Tests

X-ray results

Medications

Self Care Instructions

Future Appointments

Operative Notes

