Use of a Patient-Accessible Electronic Medical Record in a Practice for Congestive Heart Failure: Patient and Physician Experiences

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Abstract

Objective: The aim of this study was to evaluate the experiences of patients and physicians in a clinical trial of an online electronic medical record (SPPARO, System Providing Patients Access to Records Online).

Design: Quantitative data were obtained from questionnaires. Qualitative data were obtained from individual interviews and focus groups.

Measurements: Questionnaire items were based on issues identified by patients and physicians in previous studies. Individual interviews and focus groups were performed using a semistructured format developed through an iterative process.

Results: Of the eight physicians who participated in the trial, seven completed questionnaires and interviews. Of the 394 patients in the practice, 107 enrolled in the study, and 54 were assigned randomly to the intervention group. Of these, 41 used SPPARO during the trial period. In questionnaires and interviews, patients were significantly more likely than physicians to anticipate benefits of SPPARO and less likely to anticipate problems. Attitudes of subjects did not diverge from controls after the intervention period. In posttrial focus groups, SPPARO users described its practical benefits. Comprehending medical jargon was a minor obstacle. Physicians anticipated that implementing SPPARO might increase their workload and distort their clinical interactions. In posttrial interviews, physicians and staff reported no change in their workload and no adverse consequences. All of the physicians ultimately supported the concept of giving patients online access to their clinical notes and test results.

Conclusion: SPPARO was useful for a number of patients. Physicians initially voiced a number of concerns about implementing SPPARO, but their experience with it was far more positive.

We recently completed a randomized controlled trial of a patient-accessible electronic medical record, SPPARO (System Providing Patients Access to Records Online). This system provides access to clinical notes and test results and also provides a method of sending and receiving electronic messages to and from the clinic staff. As part of the study, we used a mixture of quantitative and qualitative techniques to answer the following questions:

1. How was SPPARO used in practice? What functions were used most frequently? Which patients used the system most frequently? What was it like to use the system?
2. What are the attitudes of patients and physicians toward patient-accessible medical records, and how do they differ? How do naive and experienced attitudes differ?

**Methods**

**Setting**
The randomized controlled trial was conducted in an academic subspecialty clinic for patients with congestive heart failure at University of Colorado Hospital in Denver, Colorado. Most patients were seen by multiple practitioners in the clinic over the course of the trial.

The Colorado Multiple Institutional Review Board approved the study design. Security systems including the use of passwords, firewalls, and encryption were used to prevent unauthorized access to the medical record. All participating patients signed an informed consent that included information on how to protect the privacy of the medical record. All physicians in the clinic gave informed consent for clinical notes to be shared during the study period as well as reports of laboratory, radiology, and procedure.

**Recruitment of Study Patients**
Patients were eligible for the study if they were followed up in the clinic, spoke English, and were 18 years of age or older. They needed to have used a Web browser before, although they did not need to have access to the Internet at home.

Patients were recruited from September 2001 through December 2001 from the waiting room of the clinic.

**Intervention**
Patients in the intervention group were given a user identification and password to SPPARO and a written user guide to the system. The trial period ran from January 1, 2002, through December 31, 2002. Patients in the control group continued to receive standard care in the clinic. They were offered use of SPPARO after the study was completed as an incentive to participate.

SPPARO is a secure Web interface to three components: the medical record, a guide to heart failure, and a messaging system. The medical record component consists of clinical notes, laboratory reports, and test results (including radiographic reports and echocardiogram reports). The clinical notes were dictated by medical providers and transcribed after every office visit. All medical records were stored in the heart failure clinic from the start of the study period onward. The guide component is an online version of the patient information packet that all patients in the clinic receive at their first visit. The messaging system component allows patients to send messages to the clinic and to receive them via a Web browser using a secure 128 bit SSL encryption.

This system allows the number and nature of messages that a patient sends to be tallied. Messages were received and triaged by the nursing staff of the clinic.

**Data Collection and Analysis**

**Questionnaires**
Patients and physicians completed written questionnaires before and after the trial period. These questionnaires assessed expectations of potential benefits and risks of reading the medical record (Appendix 1). These questions were based on previous studies and were pilot tested among patients in a general cardiology clinic. The baseline survey for patients also assessed demographic characteristics. Comparisons between the intervention and the control groups were made using Fisher’s exact test. To account for patients who died or withdrew from the study, evaluation of changes in patients’ attitudes over time used a mixed model approach (SAS version 8.1, SAS Institute, Cary, NC). Statistical significance was adjusted to account for multiple comparisons as per Hochberg.

**Qualitative Studies**

To assess the attitudes toward electronic access to medical records at baseline, 16 patients in the control group participated in semistructured interviews conducted by telephone. The same investigator conducted all of the interviews. To assess the experience of using SPPARO, three focus groups of SPPARO users were conducted toward the end of the trial period. Focus groups contained four or five users each, for a total of 13 users (30% of the patients who used SPPARO). Focus groups were held in a conference room of the clinic and lasted approximately one hour. One member of the team facilitated all of the focus groups, with an additional member observing and taking field notes.

Eight physicians participated in the SPPARO project. Seven agreed to participate in semistructured individual interviews, which were conducted in their offices pre- and posttrial. We conducted a single focus group with the clinic staff (two nurses and two receptionists) at the end of the trial period to assess their experience with the intervention.

All interviews and focus groups were audiorecorded and transcribed. For analysis, we used an iterative process informed by Grounded Theory. Each transcript was analyzed independently by all four members of the team for thematic content. Significant themes were assigned codes. The team then met to merge the analyses. We reviewed each transcript line by line as well as each of the different codes assigned by the different reviewers. Discrepancies and disagreements were resolved through discussion; we reached consensus in all cases. When new themes emerged, we modified the interview format to further test and explore the theme. Our methodology follows the criteria for a valid qualitative study as outlined in *Users Guide to the Medical Literature* published by JAMA.

**Results**

**Characteristics of Patients and Physicians**
Of the 394 patients in the practice, 107 patients enrolled in the randomized trial. 54 in the intervention group and 53 in the control group (Fig. 1). Demographic characteristics of the enrolled patients are presented in Table 1. Because the intervention and the control groups had no significant differences, the
characteristics of the enrolled patients as a whole are shown. The majority of patients were middle-aged men. Symptoms of heart failure were assessed using the Kansas City Cardiomyopathy Questionnaire. The mean score of 65 is similar to that of a reference group of patients with New York Heart Association Class II symptoms of heart failure. Previous experience using the Internet was a criterion for entry into the study, but access to a home computer was not. Although we attempted to encourage patients without a home computer to participate, nearly all of the patients had a home computer.

The providers consisted of eight physicians. While all of these physicians gave consent for their clinical notes to be accessible to patients in the study, one physician declined to participate in the questionnaires and interviews.

Use of SPPARO

Figure 2 presents a histogram of the use of SPPARO over the course of the study. Of the 54 patients in the intervention group, 51 remained at the beginning of the trial period (January 1, 2003). Of these, 41 (80%) used SPPARO at least once. Users accessed SPPARO with a median of eight hit-days. To see which demographic factors were associated with frequency of use, nonusers were compared with low users (one to eight hit-days) and high users (nine or more hit-days), and demographic factors were correlated with SPPARO use (Table 2). Although no correlations were statistically significant, there was a trend for higher use of SPPARO to be associated with white race, non-Hispanic race, more symptoms of heart failure, and more clinic visits.

We also evaluated which modules of SPPARO were most popular. There were 415 patient-hit-days to clinical notes (41 patients), 371 patient-hit-days to test results (37 patients), 161 patient-hit-days to radiology reports (21 patients), and 40 patient-hit-days to the guide to heart failure (27 patients).

Quantitative Assessment of Patient and Physician Attitudes

The baseline expectations of patients and physicians are presented in Table 3. Because subjects and controls did not differ in their initial expectations, the responses of all patients are grouped together. Patients were more likely than the physicians to anticipate that access to the medical record would be patient empowering. Physicians were more likely to anticipate concerns (particularly that access to records would increase patient worry and that patients would find laboratory and x-ray reports confusing).

At the end of the trial period, patients responded to the same questions. No differences developed between the subject and the control groups, but the Patient Empowerment Score declined for patients as a whole (as a dichotomy, the proportion endorsing the statements fell from 89% to 74%, p = 0.01). Subjects were also asked new questions about their overall attitudes toward patient-accessible records. The majority of subjects (90%, CI 82%–95%) endorsed the concept of a patient-accessible record and remained interested in reading their records in the future (85%, CI 77%–91%). Many expressed a preference for an edited form of the record that...

Table 1 - Demographics of Patients at Baseline

<table>
<thead>
<tr>
<th>Variable</th>
<th>Result (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean</td>
<td>56 (54-58)</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>77% (68-84)</td>
</tr>
<tr>
<td>Race (% White, non-Hispanic)</td>
<td>90% (82-95)</td>
</tr>
<tr>
<td>Education (% college graduate)</td>
<td>49% (39-59)</td>
</tr>
<tr>
<td>Household income (% &gt; $45,000/year)</td>
<td>53% (42-63)</td>
</tr>
<tr>
<td>Safety net insurance program*</td>
<td>19% (12-27)</td>
</tr>
<tr>
<td>KCQ Symptom Score</td>
<td>65 (62-68)</td>
</tr>
<tr>
<td>Previous experience using the Internet (%)</td>
<td>100% (97-100)</td>
</tr>
<tr>
<td>Access to home computer (%)</td>
<td>95% (89-99)</td>
</tr>
</tbody>
</table>

*KCCQ = Kansas City Cardiomyopathy Questionnaire.

*Patients who had no insurance, who were enrolled in a state assistance program for needy patients, or who were enrolled in Medicaid.

Figure 1. Flow of patients through the study.

Figure 2. Use of SPPARO over calendar year 2002. Figure excludes two extreme observations (one patient who had 84 hit-days and one patient who had 123 hit-days).
In interviews, the attitudes of patients toward SPPARO were overwhelmingly positive. From patients in the control group, we derived categories of potential benefits of online access: learning more about their condition, coordinating care, learning about medical decision making, reinforcing their memory regarding instructions or information from the visit, increasing their participation in their care, streamlining certain processes, and confirming normal results and the accuracy of the medical record. There were few concerns. Among patients in the intervention group who had used SPPARO and whom we interviewed, their list of uses for SPPARO was essentially identical to the list of potential benefits identified.

Qualitative Assessment of Patients

In interviews, the attitudes of patients toward SPPARO were overwhelmingly positive. From patients in the control group, we derived categories of potential benefits of online access: learning more about their condition, coordinating care, learning about medical decision making, reinforcing their memory regarding instructions or information from the visit, increasing their participation in their care, streamlining certain processes, and confirming normal results and the accuracy of the medical record. There were few concerns. Among patients in the intervention group who had used SPPARO and whom we interviewed, their list of uses for SPPARO was essentially identical to the list of potential benefits identified.

Changes in physician attitudes over the course of the study are presented in Table 4. Because of the small sample size of physicians, changes were not statistically significant. However, it is notable that although initially fewer than half of the physicians anticipated that access to medical records would be patient empowering, at the conclusion of the study all physicians did. The converse was true for questions addressing potential problems with patient-accessible medical records. In all but one case, fewer physicians responded that problems ''probably would'' or ''definitely would'' occur. In addition, at the conclusion of the study, all of the physicians anticipated that access to medical records would be patient empowering, at the conclusion of the study.

Learning More about Their Condition

Users reported that access to their records helped them learn about heart failure in general and their own condition in particular. They were able to get insights into the heart failure disease process, and this helped them focus their efforts at self-education. They also appreciated being able to keep track of the progress of their illness and treatments by reviewing their records:

I think it helps (my understanding of my condition). Especially in the reports that discuss things that they would not bring up while we were talking… I can research it and say, “Oh, that’s because of this, so I need to take care of this problem.”

Coordinating Care

Many patients felt that having access to their records improved their ability to coordinate their care. For example, one patient left town just after her blood was drawn for a coagulation test. While on vacation, she was able to use SPPARO to check her results, contact the office, and make appropriate medication adjustments. Another patient became separated from his medications while traveling. Accessing his record allowed him to confirm the doses of his medications and facilitated getting them replaced.

Patients also used SPPARO to provide copies of tests and laboratory results to their other doctors. This helped avoid duplicate tests and unnecessary phlebotomies in some cases. In others, it simply reassured the patients that they could hand the doctors an exact copy of the specialist’s note, rather than have to paraphrase the specialist’s instructions from memory.

Table 2: Demographic Factors Associated With Use of SPPARO

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Nonusers (n = 10)</th>
<th>Low Users (n = 20)</th>
<th>High Users (n = 21)</th>
<th>Correlation coefficient*</th>
<th>p-Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean</td>
<td>54</td>
<td>58</td>
<td>56</td>
<td>0.06</td>
<td>0.55</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>80</td>
<td>81</td>
<td>81</td>
<td>-0.06</td>
<td>0.63</td>
</tr>
<tr>
<td>Race (% White, non-Hispanic)</td>
<td>60</td>
<td>100</td>
<td>95</td>
<td>0.22</td>
<td>0.06</td>
</tr>
<tr>
<td>Education (% college graduate)</td>
<td>56</td>
<td>65</td>
<td>38</td>
<td>-0.06</td>
<td>0.54</td>
</tr>
<tr>
<td>Household income (% &gt; $45,000/yr)</td>
<td>33</td>
<td>70</td>
<td>55</td>
<td>0.12</td>
<td>0.25</td>
</tr>
<tr>
<td>Baseline KCCQ symptom score (mean†)</td>
<td>73</td>
<td>72</td>
<td>61</td>
<td>-0.18</td>
<td>0.07</td>
</tr>
<tr>
<td>Number of clinic visits (mean)</td>
<td>5.7</td>
<td>5.5</td>
<td>7.0</td>
<td>0.17</td>
<td>0.10</td>
</tr>
</tbody>
</table>

KCCQ, Kansas City Cardiomyopathy Questionnaire.

*By Kendall’s Tau.
†Lower symptom score indicates lower health status (more symptoms of heart failure).

Table 3: Baseline Expectations of Patients and Physicians

<table>
<thead>
<tr>
<th>Statement</th>
<th>% Endorsing Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Empowerment Scale*</td>
<td>89% 43% 0.01</td>
</tr>
<tr>
<td>More questions</td>
<td>37 71 0.11</td>
</tr>
<tr>
<td>Worry more</td>
<td>5 71 &lt;0.01</td>
</tr>
<tr>
<td>Reports confusing</td>
<td>13 57 0.01</td>
</tr>
<tr>
<td>Notes offensive</td>
<td>3 29 0.03</td>
</tr>
<tr>
<td>Notes confusing</td>
<td>6 14 0.35</td>
</tr>
</tbody>
</table>

*Analyzed as a dichotomy. Baseline mean Patient Empowerment Scale score was 5.9 for patients, 3.6 for physicians.

Table 4: Changes in Physician Attitudes Over the Course of the Trial

<table>
<thead>
<tr>
<th>Statement</th>
<th>Pretrial</th>
<th>Posttrial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Empowerment Scale*</td>
<td>43% 100%</td>
<td></td>
</tr>
<tr>
<td>More questions</td>
<td>71 57</td>
<td></td>
</tr>
<tr>
<td>Worry more</td>
<td>71 57</td>
<td></td>
</tr>
<tr>
<td>Reports confusing</td>
<td>57 43</td>
<td></td>
</tr>
<tr>
<td>Notes offensive</td>
<td>29 29</td>
<td></td>
</tr>
<tr>
<td>Notes confusing</td>
<td>14 0</td>
<td></td>
</tr>
</tbody>
</table>

*Analyzed as a dichotomy. Mean Patient Empowerment Scale score for physicians was 3.6 at baseline, 5.6 at end of trial.
Learning About Medical Decision-Making

SPPARO provided a transparency to medical decision-making that multiple respondents valued. They liked being able to follow and understand the thought processes of their doctors. Users felt that understanding the process of medical care brought a number of benefits, including reassuring them, giving them a greater sense of control, allowing them to participate in their own care at a deeper level, improving their communication with their doctor, and increasing their appreciation of the doctor's skill and expertise:

Having access to their reports after the fact is really helpful and helps me understand more clearly where they are going and what they are thinking.

I think I have a much better understanding in the monthly exams of what the doctors are looking for and because of that I am more aware of what to look out for between exams. So I feel more in control and enabled to talk to what the doctors are looking for.

Reinforcing Memory

Most respondents reported using their records as a memory aid. Whether to confirm medication doses, changes in their regimen, or test results, many respondents commented that they had difficulty remembering all the information that was conveyed during their appointment. They liked having the record available as a reminder between appointments:

When you are with your doctor there is so much information coming at you, that there is absolutely no way that you can process all of it. And, so then you go to the notes, usually that evening or the next day. Even with my husband sitting there, there were a lot of things that we did not hear.

Increasing Participation in Medical Care

Many respondents felt that having access to their records increased their participation in their medical care:

I feel like I'm having a more active role. My health is my responsibility. And this helps me a great deal. You are giving me another tool so that I can manage my health.

Streamlining the Flow of Information

Many felt that having access to their records increased the efficiency of getting information. They did not need to leave phone messages to retrieve test results, and it was easier to get copies of records for their own use.

Confirming Normal Results and the Accuracy of the Record

Several patients mentioned that they might not hear about normal results and were left to infer that “no news is good news.” They were reassured by being able to look up their results and confirm for themselves that everything was okay. A few users also liked having the ability to review their records for accuracy or completeness and were reassured by seeing that the details were recorded accurately.

Difficulties in Understanding Clinical Notes

Three users mentioned that medical jargon was difficult to decipher. Nevertheless, among all users and controls there was a common sentiment that jargon was a surmountable obstacle. Users dealt with it through using medical dictionaries, using online references, asking friends or family members who were medical professionals, and asking their doctors or nurses for clarification:

I was able to ask questions of the medical people I have in my family, and when I didn’t, I was able to go on the Internet and type in what I didn’t understand, and then probably find out more than I ever wanted to know. So, with a little research I was able to understand.

Since jargon could be a problem, we asked patients if they would like clinical notes to be modified to make them more comprehensible. Many replied that they would appreciate access to a record that was either specially edited to reduce the jargon or a system that allowed them to find definitions quickly if they needed to. However, respondents were uniformly concerned that if the medical record was modified it might be watered down or “sugarcoated.” Overwhelmingly, they preferred the record to be candid and unvarnished:

I would rather have the doctors just write what they write and me work to understand it, than them writing it for me and leaving something out that I would like to know.

One respondent expressed his concern that giving patients access to their records might change physician documentation styles, reducing the value of the record:

Are they (doctors) more cautious in what they write because this is the age of lawsuits? Will they be reluctant to put something that is more controversial in writing or to transfer it to another doctor? I’d hate to see them hold back information because someone will see it. It’s my life at stake and I want to know the good and the bad.

Some patients recognized their own potential for error in interpreting their records but did not feel that it detracted from their support for online access or their desire to access their records:

I realized I don’t have the technical training or proficiency to truly understand the record. I can’t come to conclusions that are clear cut.... You will be presented with a whole bunch of new knowledge, and I could come to a wrong conclusion. But it does open up another line of communication, and it’s well worth it.

Concerns

Patients voiced few concerns about accessing their medical records online. Several individuals in the control group voiced theoretical concerns about the security of their records online. Patients were particularly concerned that their records not be made available to employers or government agencies without their permission, although many discussed sharing the record with close family members.

Suggestions for Improvements

Respondents offered a number of suggestions that they thought would improve the system. One patient suggested electronic notification when anything is added to the record so that he would not waste time reviewing his records when nothing was new. Several individuals suggested some sort of aid that would help interpret laboratory and other diagnostic tests, so that they could better assess the significance of a laboratory or test finding. Other suggestions included attaching hyperlinks to define technical terms and providing some means for patients to annotate their records when they find errors.
Qualitative Assessment of Physicians

Physician Expectations

Before the trial period, physicians were mixed in their opinions about providing patients online access to their records. All predicted that the intervention would not change hard outcomes (such as mortality, cardiac events, and hospitalization), their decision making, or their relationships with their patients. Physicians identified potential benefits and concerns in four main domains: bypassing the physician as information gatekeeper, educating patients with the medical record, preventing versus creating medical errors, and documenting sensitive information.

Some physicians were concerned that by bypassing them as information gatekeepers, online access to records would distort the clinical encounter. It might create the expectation that patients should set the clinical agenda, forcing the doctor to address patients' issues with the record, distracting the doctor from more important issues. Others felt that increasing the availability of information would increase trust in the doctor–patient relationship and make it easier for patients to participate in their own care.

Physicians wondered how effective medical records would be at educating patients. Some noted that because the record is not intended for patient education, it is more likely to confuse than educate. Others felt that it would educate patients both about their condition and the process and complexity of the care they provide.

Whether patient access to records would increase or decrease errors was another concern. Some worried that patients would act on transcription errors (e.g., take the wrong dose of a medication). Others hypothesized that patients would identify and correct inaccuracies in their records and noted that physicians might be more compulsive in their record keeping, knowing that patients might be reviewing their records later.

Physicians were also concerned about how patients would respond to reading sensitive information about substance use, psychiatric illness, or judgments about body size. They worried that patients would be offended, thus, creating tension in the physician–patient relationship. Others felt that candor was always best and that the record was “not a place for secrets.”

Physician Experience

The principal change in the providers’ attitudes after the trial period was that their concerns about potential deleterious effects from giving patients access to their records were largely gone. In the interviews after the trial period, none of the participating physicians voiced any of the concerns that they mentioned in the initial interviews.

The consensus opinion was that the SPPARO project was invisible from their perspective. In practice, they were unaware of the intervention and did not feel it affected their workflow or their relationship with their patients. Four could recall an instance of recognizing that a patient had access to SPPARO, but only one could recall a specific conversation related to it. With one exception, none of the physicians felt that any of these interactions were problematic (confusing, worrisome, overly time consuming, or embarrassing) in any way; instead, they recalled them in a positive light. The single example of a negative encounter involved a patient who was concerned that documentation of his alcohol use might have been inaccurate and could have negative consequences for him later. In this case, the physician dictated an addendum that documented the patient’s concerns, allowed the patient to review it, and then added the addendum to his medical record.

Four of the seven physicians did not notice any lasting change in their style of documentation. Three physicians felt that they had changed their documentation style somewhat to make it more understandable to the patients. None of them viewed that as a problem, and none felt that it cost them a significant amount of time:

... saying this stuff in a dictation is probably all of about 15 seconds, it's not like it adds even a half hour to your day. It's just a few sentences at the end of our conclusions which makes it a little more interpretable.

Of the three who changed their documentation, each felt that this was a positive outcome. One felt that it would improve the level of honesty in the medical record:

If you ... know that the patients may be reading the notes, then you should be more precise. You need to dictate more complete notes, and you can't lie. When we examine some patients, we really don't examine all the systems, so when you dictate, when you state something and you know the patient will read it, that you examine how you did it.

All the providers considered patients’ interest in their medical records to be understandable and reasonable. None felt that patients should be denied access or that facilitating patient access to records was intrinsically a bad idea. One physician even mentioned wishing similar online medical records were available for her child. Physicians were divided, however, on their degree of support for continuing to offer SPPARO to patients. Two offered unqualified support, citing their belief that patients were more involved in their care and benefited from more information. The others felt that ongoing support should be contingent on the demonstration of some benefit to the patients. Each questioned whether the merits of the intervention would warrant the resources spent on it. One was concerned that it might exacerbate disparities in care, noting that such systems are more likely to be used by socioeconomically advantaged patients and may lead to those patients claiming a disproportionate share of the doctors’ time.

Physicians also speculated that their clinic’s experience might not be generalizable. Their clinic has a high ratio of support staff to patients, a relatively small patient population, longer-than-average clinic visits, and a patient population in which noncompliant patients were excluded. They wondered if their experience would be replicated in a practice with fewer personnel resources, a higher patient volume, and a less-sophisticated patient population.

To further assess the impact of SPPARO on the clinic, we interviewed the clinic nurses and support staff in a single focus group. Each of them could recall specific questions that were generated from patients reading their medical record. None could recall any questions or interactions that were inappropriate or problematic. Although more messages were sent to the practice in the intervention group (350 total: 287 phone calls and 63 computer messages) than the control group (267 phone calls), they did not perceive an increase in their workload during the trial period.
Discussion

Our study contributes several key findings to the literature on the outcomes of providing patients access to medical records. At the start of the trial, patients were uniformly positive about the idea of having facilitated access to their records, and the experience of access did not dampen that enthusiasm. Users of SPPARO reported that access to their medical records had a number of practical uses in managing chronic disease. Medical jargon was an impediment, but a surmountable one. Patient self-selection may have effectively eliminated those who were likely to have problems reading their records. Although physicians expressed concerns initially, they viewed patient-accessible records much more favorably after none of these concerns materialized. The only persistent concern voiced by any of the physicians was whether the intervention merited the resources that would have to be devoted to it.

Previous studies have shown that physicians have concerns about giving patients access to their records, and, as was the case in our study, tend to be much more concerned about the potential for negative outcomes from patient-accessible records than patients. Like the users of PCASSO and the University of Washington patient portal, our users found the system to be useful, although some would have liked a key or guide to laboratory data. Using face-to-face interviews, we were able to probe the attitudes of patients (both potential users and nonusers) and physicians, both before and after implementation, in more depth than in previous studies.

Our study was also able to provide detailed information on the frequency of use of online medical records by patients. Use of SPPARO in this study was higher than of PCASSO, but because our population consisted of patients with a serious chronic illness, we had expected use to be even higher than what was observed. Among users, the median number of hit-days was about the same as the mean number of clinic visits, suggesting that patients did not consult SPPARO repeatedly between visits. However, the fact that heavy users of SPPARO had, on average, more clinic visits and were more symptomatic than less frequent users suggested that SPPARO was not simply a novelty for the worried well, but instead was used by those with the most potential to benefit from it.

There are a number of limitations to our study. The trial was conducted in an academic subspecialty practice that may not be representative of most practice settings. The patient population enjoyed a higher level of education and computer literacy than the general population. This practice had a high ratio of staff to patients, so an increase in workload that may have gone unnoticed in this setting could be more substantial in practices that care for a larger number of patients with fewer staff resources. Much of our data are qualitative, and while this can provide an accurate description of the experiences of those involved in the intervention, these data cannot quantify or statistically compare differences in these experiences.

Although the small size of our sample and the short duration of the trial are not adequate to assess outcomes such as morbidity or mortality, the benefits reported by SPPARO users could potentially translate into improved medical and psychosocial outcomes. As informatics technology progresses and as initiatives to increase collaborative decision making between patients and physicians increase, we anticipate there will be more interest in providing patients access to their records online. These findings suggest a number of potential benefits and few if any adverse consequences to providing this access. Studies involving larger numbers of more heterogeneous patients and clinical settings will be necessary to further evaluate the impact of this type of intervention.

References


Appendix 1

Survey Questions and Empowerment Scale

Patients and doctors were surveyed regarding their expectations regarding patient-accessible medical records. Patients answered each question as: “If I read my records, I would...” Doctors answered each question as: “If your patients read their medical records, they would...” Responses were
"definitely not," "probably not," "unsure," "probably would," and "definitely would."

Several of the questions were considered individually. For these questions, the proportion endorsing the statement is the proportion that responded that they "probably would" or "definitely would."

More questions—Contact the practice with more questions between visits.
Worry more—Read things that would make you or them worry more.
Reports confusing—Find the lab and radiograph reports confusing.
Notes offensive—Be offended by some of the things that the doctor wrote about them.
Notes confusing—Find the doctors' notes confusing.
The responses to eight questions about patient and physician attitudes toward a patient-accessible medical record were highly correlated. Cronbach's alpha for this set of questions was 0.80 for all patients at baseline. We therefore created a composite "patient empowerment scale" to summarize the results of these questions. The scale was obtained by counting the number of responses that were marked "probably would" or "definitely would." The overall proportion endorsing the patient empowerment scale is the percent that had patient empowerment scale scores of 4 or higher (agreed with at least half of the following items.)

1. Feel more in control of their medical care.
2. Better understand their medical conditions.
3. Be better prepared for their doctor visits.
4. Feel more reassured.
5. Better understand their doctors' instructions.
7. Trust their doctor more.
8. Find mistakes which their doctors could correct in their records.