

The patient clinical information system (PatCIS): technical solutions for and experience with giving patients access to their electronic medical records

James J. Cimino^{a,*}, Vimla L. Patel^a, Andre W. Kushniruk^b

^a *Department of Medical Informatics, Columbia University, 622 West 168th Street, VC-5, New York, NY 10032, USA*

^b *Department of Mathematics and Statistics, York University, Toronto, Ont., Canada*

Abstract

As health records evolve into electronic form, increasing demand is being made to provide patients with access to them. We sought to study the character and impact of such access to determine how patients use such records, what cognitive effects it has on them, and how it affects their relationship with their health care providers. We created the Patient Clinical Information System (PatCIS) to interface with the clinical data repository at New York Presbyterian Hospital (NYPH) to allow patients to add to and review their medical data. We also provided educational resources and automated advice programs. We provided access to the system to thirteen subjects over a 36-month period and reviewed their activities in the system's usage log. We also collected data via questionnaire and telephone interview. We collected data for a total of 223 patient months. We found that patients varied in their use of the system, from once a month or less to one or more times per day. All patients primarily used the system to review laboratory results. Both they and their physicians believed that use of the system enhanced the patients' understanding of their conditions and improved their communication with their physicians. There were no adverse events encountered during the study.

© 2002 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Consumer informatics; Electronic medical records; Personal health records; World wide web

1. Introduction

Patients in the US have the right to review their medical records. Although preliminary studies in the US and elsewhere have shown that provision of psychiatric records to pa-

tients is generally met with a positive response [1–4], the overall effect of such access on patients' understanding of their conditions and their relationships with their providers is unknown. With the increased availability of electronic medical records, researchers are experimenting with the provision to patients of some or all of their records via mechanisms such as the World Wide Web [5–8].

* Corresponding author

E-mail address: jjc7@columbia.edu (J.J. Cimino).

Masys et al. recently reported 6 months of experience (May–August, 1999) with giving patients access to their records [9]. They reported number of sessions (with six patients logging on five or more times) and general patient satisfaction, and found a generally positive response. However, they did not examine how the system was specifically used, nor how it impacted on the clinician–patient relationship.

Others researchers have begun to examine how patients respond to the content of clinical records. For example, Adams and colleagues studied parental response to clinical summaries from their children’s medical records. They found essentially universal satisfaction with the summaries [10].

Although technical challenges have been overcome, and patient enthusiasm is clear, clinician enthusiasm is far from universal. Clinicians are concerned that patients will be confused or misled by their record, object to information it contains, or quiz their caregivers incessantly about the meaning of test results and reports. Such experience has already been reported by clinicians whose patients have access to the World Wide Web and show up at office visits with stacks of printouts, demanding interpretations and explanations. Concerns that the problem will only increase as patients have better access to their records do not seem misplaced. Yet Pandora’s box has already been opened by commercial laboratories that give patients Web access to their test results. It therefore seems prudent to study the impact of access on patients and clinician–patient relationships in order to shape such access in ways that make it a positive experience.

We have developed a Web-based interface to the New York Presbyterian Hospital (NYPH) clinical data repository intended for use by patients to review their own records. Called the Patient Clinical Information Sys-

tem (PatCIS), it serves as a framework for a variety of applications for data entry, data review, education, and advice. We have previously reported on early experience with PatCIS usage [11] and patient experience [12] during its pilot period. This paper summarizes the capabilities of the system and reviews the experience of patients and their physicians over the entire life of the project¹.

2. Materials and methods

2.1. PatCIS architecture

The architecture of PatCIS has been described elsewhere [13]. It is a Common Gateway Interface (CGI) program that presents a set of applications to patients, organized into the following categories: Data Entry (writing information into the clinical record), Data Review (reading information stored in the clinical record), Education (information resources on various topics), and Advice (application of patient data to online guidelines), using a table of application names and corresponding CGI references. We also incorporated ‘infobuttons,’ which pass patient-specific information to programs that generate patient-specific educational messages [14,15].

Patients access PatCIS using a standard Web browser (Netscape Navigator) using Secure Socket Layer (SSL) 128-bit encryption. They are asked to provide a user ID, password, and a 6-digit number displayed on their security token (SecurID, Security Dynamics, Bedford, MA). The number on the token changes every minute and the security server (a Lightweight Directory Access Protocol

¹ This work was presented, in part at the Medinfo 2001 Conference, held in London, UK, September 2–5, 2001.

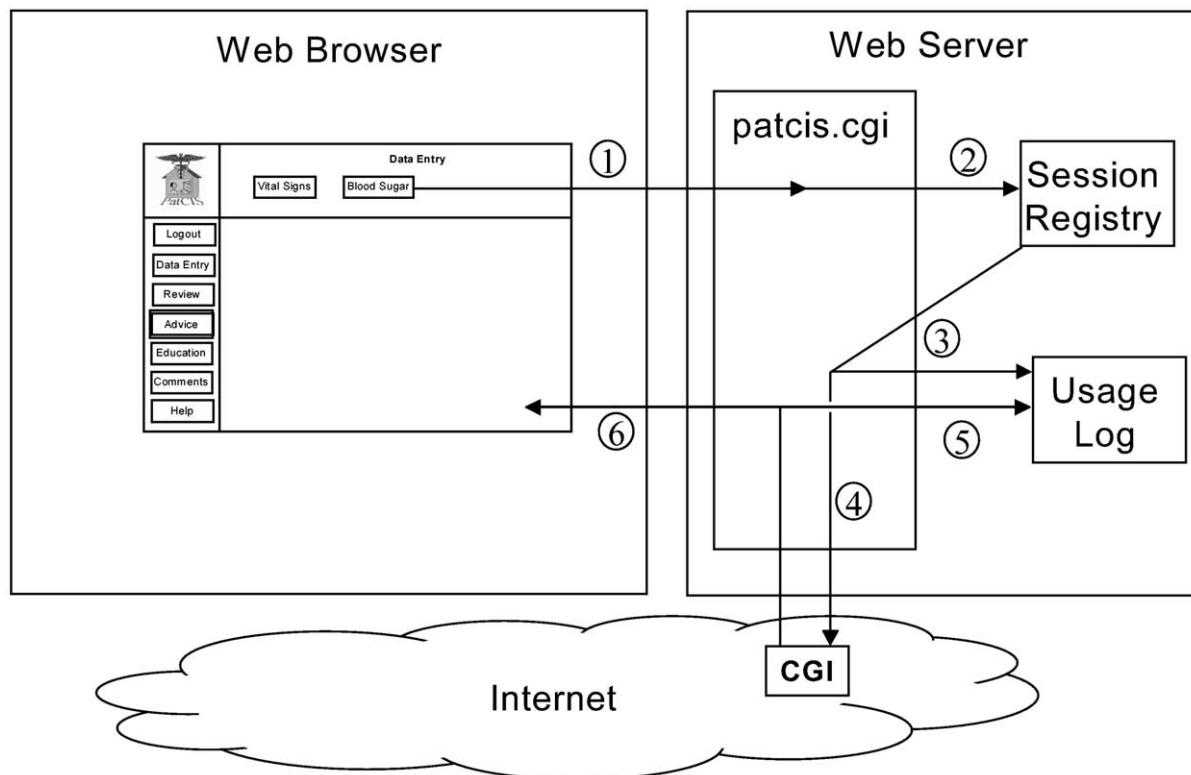


Fig. 1. PatCIS architecture: All PatCIS functions are executed by patients using a Web browser (Netscape Navigator) to access PatCIS, which is running as a CGI program on a Web server (1). PatCIS checks the Session Registry (2) and if the current session is valid and has not timed out, it records the patient's action in the Usage Log (3). PatCIS then accesses the appropriate function, which may be a document or other CGI somewhere on the World Wide Web (4). The result is then noted in the Usage Log (5) and returned to the patient (6).

(LDAP) server at NYPH) matches the number to one calculated based on the time of day and the token associated with the patient. In this way, we provide strong authentication ('something the user knows plus something the user has') for PatCIS access.

Once the patient logs on, PatCIS provides several buttons on the left-hand side of the screen ('Data Entry', 'Data Review', 'Advice', 'Education', 'Help', and 'Comments'). When selected by the patient, each of these buttons produces a second set of buttons (we refer to these as 'subbuttons') along the top of the screen. The set of subbuttons is determined by

the access levels specified by the patient and the physician (described below); each subbutton is associated with a specific application.

When a patient selects a subbutton, the name of the associated application (actually, its Uniform Resource Locator, or URL) is passed to PatCIS, which carries out several steps (see Fig. 1):

- Timeout: Checks for the time since last activity and, if greater than 5 min, requests reentry of the password.
- Security: Verifies the session is valid and that no session parameters (user ID, med-

```

sandcar!Fri Oct 27 11:32:22 2000!cim.cpmc.columbia.edu!|patcis^login
sandcar!Fri Oct 27 11:32:24 2000!cim.cpmc.columbia.edu!|patcis^Data
  Review
sandcar!Fri Oct 27 11:32:28 2000!cim.cpmc.columbia.edu!|patcis^Data
  Review^ Laboratory Detail^lab_detail.cgi
sandcar!Fri Oct 27 11:32:30 2000!cim.cpmc.columbia.edu!|patcis^Data
  Review^ Laboratory Detail^labSum.cgi
sandcar!Fri Oct 27 11:32:35 2000!cim.cpmc.columbia.edu!|patcis^logout

```

Fig. 2. Sample records from PatCIS usage log, showing a simple session in which a subject (user ID 'sandcar') signed on, selected the 'Data Review' button, the 'Laboratory Detail' button, a single test result (to produce a summary report), and then logged off. The session took 17 s.

ical record number, IP address of the patient's browser) have been altered.

- **Logging:** Records the requested function in the usage log.
- **Action:** Calls the requested application and passes the results back to the patient's browser.

In some cases, the documents returned by the CGIs contain links and function calls (such as infobuttons). In cases where the links are external to PatCIS (such as some outside educational resource), PatCIS cannot track their usage. However, when the documents are internal to PatCIS, or created by CGIs that are part of PatCIS, they too will call the PatCIS CGI, repeating the process above.

Individual PatCIS applications are created as separate stand-alone modules and then integrated into PatCIS through inclusion in an application table that relates the application to a PatCIS main button, stores the URL for the application, and contains a label for the associated subbutton. A second table is used to store the relationship between each patient and each application. The system allows four different levels of access, to be specified by the patients' physicians and then managed by the system administrator:

0—The application is hidden from the patient.

1—The application is shown as an option to the patient but, if selected, displays a

message saying that physician has requested that the patient not be given access to the application.

2—The application shows header-level patient information only (such as type and date of procedures), but no detailed patient data.

3—The application shows all data to the patient.

In addition to these four levels of access, PatCIS patients can specify (through a 'customize' function) which applications should be displayed and which should be hidden (akin to level 0, above). The patient cannot specify an access level higher than the one specified by the physician.

2.2. Review of log files

To determine how subjects used PatCIS, we examined the log files from April 1999 through October 2000, inclusive (19 months). We considered a session to start with a successful log on, followed by use of one or more PatCIS functions. Sessions were considered to have ended at the time the subject selected the 'log out' function or, if the subject did not use the log out function prior to the next log on, the time of the last function in the session. Session activities were tabulated based on the function or CGI call the subject selected. Fig. 2 shows a sample of a log file.

2.3. On-line questionnaires

We surveyed subjects with two questionnaires. Subjects completed the first questionnaire the first time they logged on to PatCIS. This questionnaire contained questions designed to assess subjects' demographics (including age, sex, level of education), as well as prior computer experience (including types of computers they used and frequency of general computer use). In addition, subjects' perceptions of their relationship with their health care provider and their expectations about the system were assessed using 5-point Likert scales. All subjects completed the baseline questionnaire on-line. We e-mailed the second questionnaire to subjects after 9 months of system usage in order to assess the usability of the system and changes in subjects' perceptions about their expectations and their relationships with their providers. This questionnaire contained the same 5-point scales used in the first questionnaire to obtain specific information about the subjects' perceptions of their relationships with their health care providers. The questionnaire also contained questions designed to obtain specific information about the subjects' perception of the usability of PatCIS. These questions were based on standard usability scales for assessing user interfaces and also contained text-entry boxes where subjects could enter their responses regarding the usefulness of information provided by the system, its understandability and any interface problems encountered while using PatCIS.

2.4. Telephone interviews

Phone interviews were conducted with subjects and their physicians after 9 months. Interviewers sought to determine subjects' perception of the usefulness of various PatCIS features, to understand patterns of use, to

identify impact on subjects' decision making, and to characterize any influences on the patient-provider relationship. The interviews were audio taped in their entirety and transcribed verbatim to facilitate subsequent qualitative analysis [12]. Patients were probed about their use of PatCIS, specifically what features they used, or did not use, their perceptions of how usable the system was, and whether or not they felt use of the system had impacted on their decision making or their relationship with their health care providers. The physicians were probed about whether they were aware that their patients had used the system. They were also asked whether they felt that use of the system had affected their patients' understanding and compliance, and whether or not it had any impact on the doctor-patient interactions.

2.5. Longitudinal review

After the completion of the study period, new subjects were no longer enrolled and close monitoring of patient usage was discontinued. However, PatCIS continues to function and patients who enrolled in the study have continued to be given access to their records in a 'production' mode. Patient log-ons (including log-on failures) have continued to be monitored for security reasons. We have, therefore, been able to continue to note the frequency of system usage through March 2002 (an additional 17 months; 36 months total).

3. Results

3.1. Application features

To date, we have created the following applications (corresponding to subbuttons) for each of the main PatCIS buttons:

Fig. 3. A typical PatCIS screen showing Data Entry subbuttons. On the left are general classes of functions. Here, the subject selected 'Data Entry,' which produced the list of buttons at the top of the screen. The subject then selected 'Blood Sugar,' which produced the data entry screen shown in the main window frame.

- Data Entry (see Fig. 3): Vital signs (height, weight, blood pressure, pulse, and temperature) and diabetes diary.
- Data Review (see Fig. 4): Data entered by the patient (vital signs and diabetes diary) and data from the NYPH clinical data repository (laboratory results, microbiology results, and text reports).
- Advice (see Fig. 5): Applications that customize educational materials, based on the patients' data (mammogram guidelines, [16] cholesterol guidelines, [17] and cardiac risk assessment [18]).
- Education (not shown): A variety of external reference sources about general health, diabetes, geriatrics, AIDS, etc.

The reports displayed under Data Review include Admission and Discharge, Cardiology, Gastrointestinal Endoscopy, Neurophysiology, Obstetrics and Gynecology, Operative and Clinical, Pathology, and Radiology (see Fig. 6). Infobuttons were created for vital signs entry (body mass index), laboratory results, microbiology results, and Pap smears (shown in Figs. 4 and 7).

3.2. Subject enrollment

Thirteen subjects were enrolled between April 1999 and October 2000. One subject never used the system. Another subject dropped out of the study after 5 months,

| Test | Result | Normal | Units | Info |
|------------------------------------------------|--------|---------|-------|------|
| MAGNESIUM 1997-12-12 10:00 Status: final | | | | |
| MAGNESIUM | 1.9 | 1.8-2.4 | mg/dl | ? |
| CARDIAC PROFILE 1997-12-12 10:00 Status: final | | | | |
| LD | 188 | 122-220 | U/l | - |
| CK | 45 | 24-170 | U/l | ? |
| CHEM 20 PROFILE 1997-12-12 10:00 Status: final | | | | |
| NA | 142 | 135-146 | mM/l | ? |
| K | 3.6 | 3.2-4.6 | mM/l | ? |
| CL | 103 | 96-108 | mM/l | ? |
| CO2 | - | - | - | - |
| BUN | - | - | - | ? |
| GLUC-RANDOM | - | - | - | ? |
| CREATININE | - | - | - | ? |
| CALCIUM | - | - | - | ? |
| PHOSPHORUS | - | - | - | - |

Fig. 4. A PatCIS screen showing the Data Review subbuttons. In this case, the patient has selected 'Laboratory Detail' to produce a reverse-chronological-order set of results. Note the infobuttons in the right-most column. If the patient were to select one of these, information about the interpretation of the specific test would be displayed (not shown).

due to retirement from employment (with attendant loss of computer access). Follow-up periods for the remaining 11 patients were considered to be from date of enrollment through October 2000. The average follow-up period for all 12 active subjects was 10 months.

3.3. Subject characteristics

Eight of the 13 subjects were male. Two of the male subjects listed their ages as '> 65,' while the rest of the subjects listed '40–65.' Eight of the ten subjects who answered the

question about educational level had a college degree or higher. All of them reported using computers for more than 2 years on a daily basis. They unanimously agreed that the Web was likely to improve communications between patients and providers, and all but one agreed that the Web would change health care.

3.4. System usage

Twelve subjects logged on a total of 630 times during the study period. These included 131 failed log-on attempts of which 61 (46.6%)

The screenshot shows a web-based interface for a medical guideline. At the top, there are four subbuttons: 'Cholesterol', 'Mammogram', 'News Groups', and 'Heart Attack Risk'. The 'Cholesterol' subbutton is selected, and the main content area is titled 'Cholesterol Guideline'. Below the title, there is a paragraph of text: 'The following form has been filled out with data available from your record. You may fill in any fields that are currently unknown, or you may go ahead and click on the "Start Guideline" button - the system will ask you if it needs any additional information. You can also change any of the information. You might do this, for example, if you would like to enter information about another patient or if you want to do a "what if" scenario for your own situation (as in "What if I could get my LDL cholesterol down to 120?").' The form itself is a table with four columns: 'Coronary Disease', 'LDL', 'DIET', and 'Total Cholesterol'. The 'Coronary Disease' column has radio buttons for 'No' and 'Yes'. The 'LDL' column has a text input field containing '133'. The 'DIET' column has radio buttons for 'None', 'Step 1', and 'Step 2'. The 'Total Cholesterol' column has a text input field containing '201'. Below this, there are four more columns: 'HDL', 'Gender', 'Age', and 'Premature Menopause'. The 'HDL' column has a text input field containing '56'. The 'Gender' column has radio buttons for 'Male' and 'Female', with 'Female' selected. The 'Age' column has a text input field containing '51'. The 'Premature Menopause' column has radio buttons for 'No' and 'Yes'. Below the table, there is a section for 'Risk factors' with radio buttons for 'No Risk Factors' and 'Risk Factors'. A list box below this section contains the following items: 'Hypertensive Disease', 'Ischemic Heart Disease', 'Diabetes Mellitus', 'Family History of Ischemic Heart Disease', and 'Current Smoker'. At the bottom of the form, there is a 'Start Guideline' button. The interface also includes a 'Logout' button and a sidebar with buttons for 'Data Entry', 'Data Review', 'Advice', 'Education', 'Help', and 'Comments'. The window title bar shows 'File Edit View Go Communicator Help' and the status bar shows 'Document: Done'.

| Coronary Disease | LDL | DIET | Total Cholesterol |
|-------------------------------------------------------|-----------------------------------------------------------------------|--------------------------------------------------------------------------------------------|-------------------------------------------------------|
| <input type="radio"/> No <input type="radio"/> Yes | 133 | <input type="radio"/> None <input type="radio"/> Step 1 <input type="radio"/> Step 2 | 201 |
| HDL | Gender | Age | Premature Menopause |
| 56 | <input type="radio"/> Male <input checked="" type="radio"/> Female | 51 | <input type="radio"/> No <input type="radio"/> Yes |

Risk factors:
 No Risk Factors
 Risk Factors

Hypertensive Disease
 Ischemic Heart Disease
 Diabetes Mellitus
 Family History of Ischemic Heart Disease
 Current Smoker

Fig. 5. A PatCIS screen showing Advice subbuttons. In this case, the patient has selected 'Cholesterol' and PatCIS has displayed a data entry screen for information used by the guideline. Where possible, PatCIS has filled in the form using information from the patient's electronic medical record.

were due to five events in which subjects tried repeatedly to log on with incorrect user IDs or passwords. In each case, the subject persevered and ultimately logged on successfully. The remaining failed log-on attempts were isolated events scattered across all subjects throughout the study period, always followed by successful attempts. In an additional 33 log ons, subjects did not select any functions. The activities occurring in the remaining 466 sessions were studied.

Active subjects had between 1 and 222 active sessions (average: 38.8) during the study period, with between 0 and 45 sessions per month (average: 4.0). Fig. 8 shows the

distribution of active sessions for all subjects during the study period.

The session duration ranged from less than 1 to 66 min (average: 5.7); 391 (83.9%) of the sessions were 10 min or less, 58 (12.4%) of the sessions were 11–20 min in duration, with only 17 (3.6%) being longer than 20 min. During the sessions, subjects carried out a total of 2098 actions. This represents an average of 4.5 actions per session: 320 sessions (68.7%) had five or fewer actions, 102 sessions (21.9%) had six to ten actions, and 44 sessions (9.4%) had greater than ten actions (31 maximum). As shown in Fig. 9, Data Entry functions were the most popular, accounting

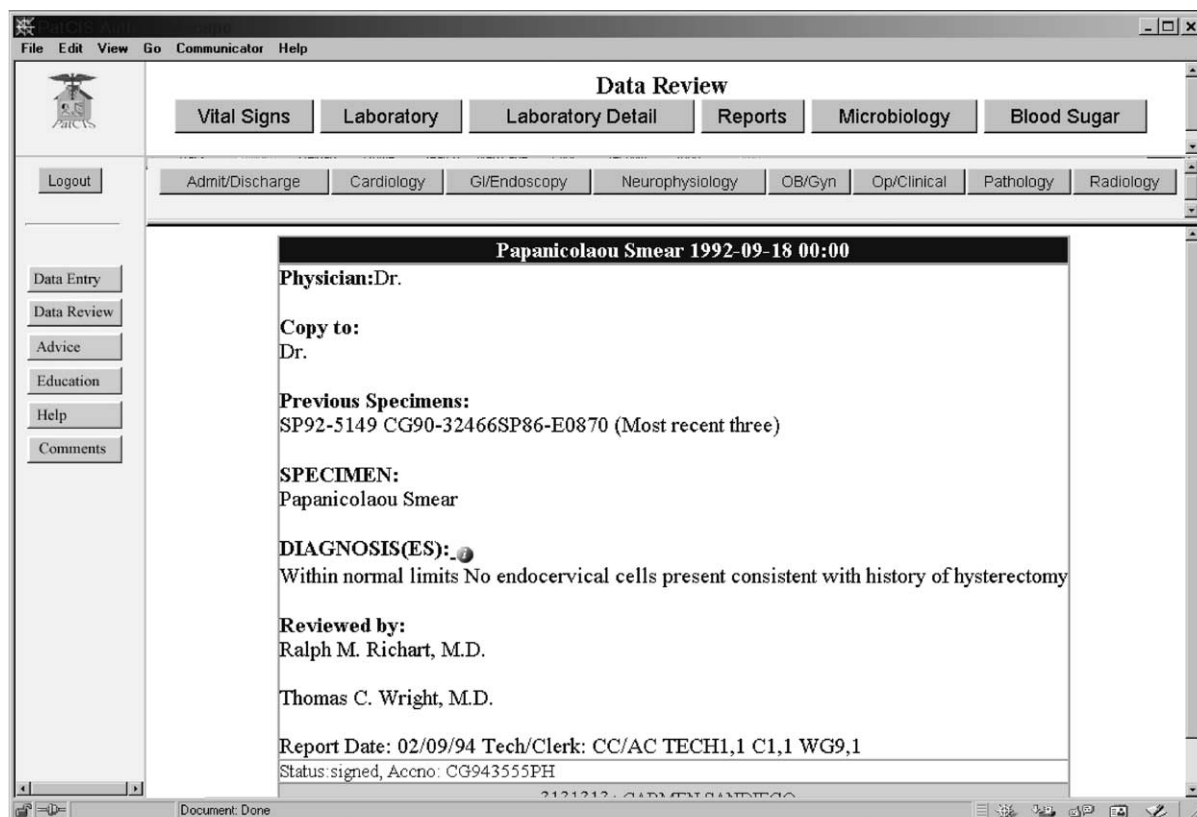


Fig. 6. A PatCIS screen showing a Pap smear report. Here, the subject selected 'Data Review,' which produced the list of buttons at the top of the screen. The subject then selected 'Reports,' which produced a second list of buttons. The subject selected 'Pathology' to obtain the list of reports (not shown) and then selected a Pap smear report (shown). This particular report contains an 'infobutton' that, when selected, provides explanatory information about the findings in the report (see Fig. 7).

for 87.3% of all activities. As shown in Fig. 10, laboratory results accounted for 82.9% of data review activities, and accounted for 72.4% of all activities.

3.5. Patient experience

Of the eight patients who were in the study 9 months or more, five responded to the follow-up questionnaire. One of these was Subject 5, who never actively used the system. He was, therefore, unsure about the benefit of PatCIS. Responses from the other four patients are shown in Table 1. The majority of

patients interviewed indicated that they agreed that use of PatCIS had improved their interactions with their health care providers.

These five patients were also interviewed by telephone. Those that used the system reported that the system was easy to use, easy to understand, and improved their health care by allowing them to take a more active role. They experienced some difficulties with some of the system features (particularly the graphing function) and some problems with system response time. Their overall impressions ranged from 'very impressed, a step in the right direction' to 'excellent program.' The majority

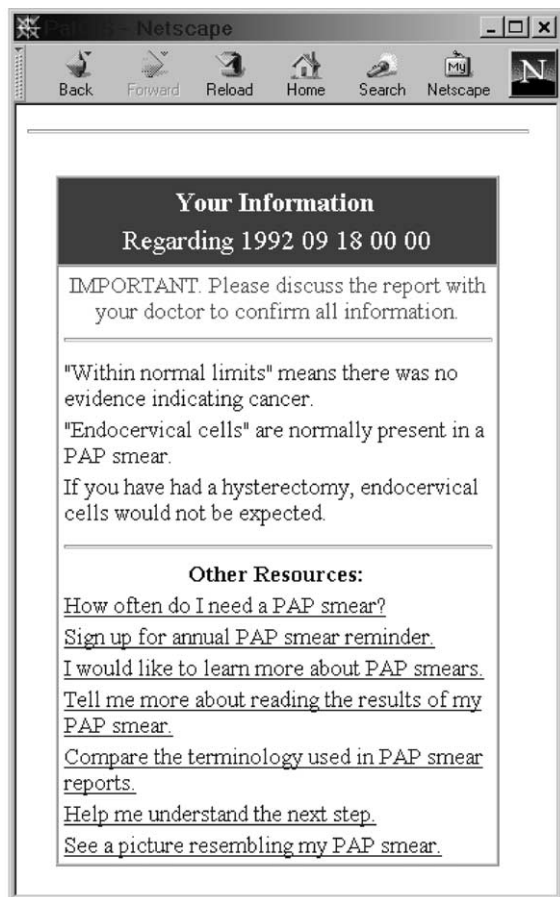


Fig. 7. Display produced by the infobutton shown in Fig. 6. The information includes customized descriptions of the findings in the patient's Pap smear report and also links to Web resources relevant to Pap smears in general.

of the patients interviewed indicated that they felt that the ability to view and track their lab values prior to seeing their physician had improved the level of communication during their subsequent visits. One patient commented that 'Communication is less in the way of getting information now, and more in the way of discussing treatment options and agreeing on a course of action, so to me its more efficient.' A second subject commented on the capability provided by PatCIS for observing

trends in lab values, stating 'I look for trends in my medical data and if I see something I can contact the doctor to see what's going on, what we can do, change meds or whatever.' In general, patients felt increased ownership of their health care as a consequence of being able to access their own medical data.

3.6. Clinician experience

All three of the physicians who provided subjects for the study were interviewed. They were generally aware that their patients were using PatCIS and that it was helping them understand their illnesses better and gain better control over their own care. In particular, the physicians were aware that their patients were monitoring their own health data and felt that patients' use of PatCIS had favorably affected their communication with their patients. For example, one of the physicians commented the following during the interview 'Right now most of the communication takes place during the 10 or 15 min visit and if I throw a lot of information at the patients about their condition or what I want them to do, its very hard for them to absorb all that. [PatCIS] gives them a chance to go back and look at things about their health record that they can then ask better questions about in the limited time that we have during the visit, its another channel of communication.'

3.7. Longitudinal review

After conclusion of the study period, nine patients continued to use PatCIS, in their typical usage patterns, with four continuing to use it through March 2002; three others who have used PatCIS after periods of 8–12 months of inactivity may still be active users. These results are included in Fig. 8 (months 20–36) and represent an additional 405 ses-

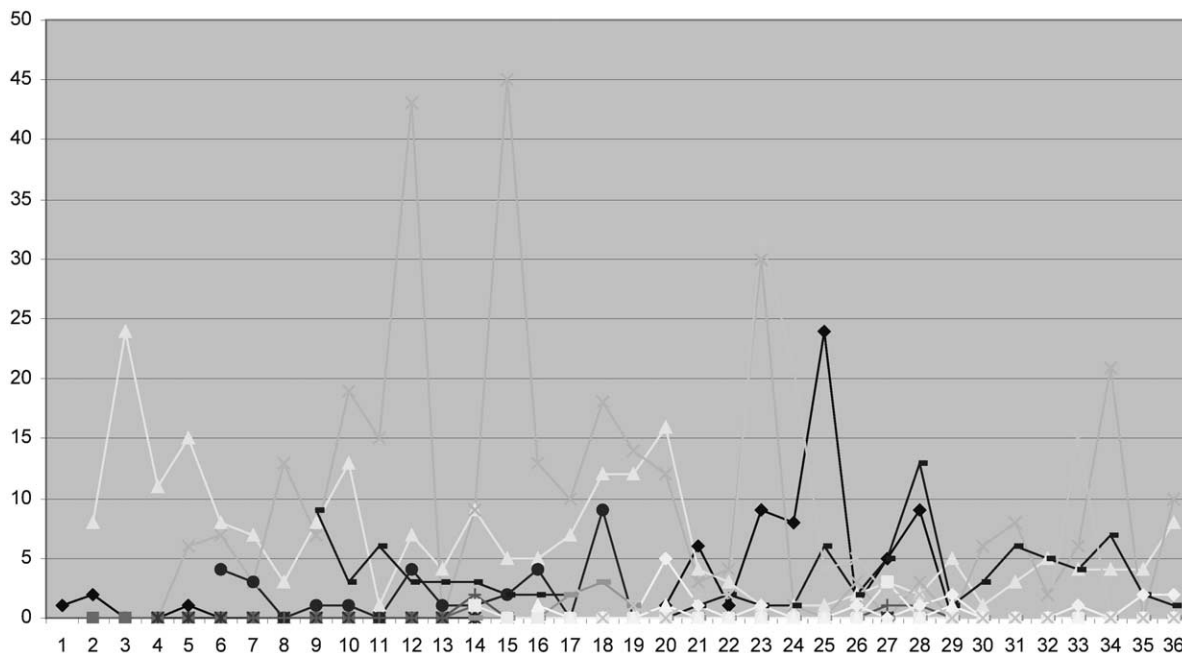


Fig. 8. Active PatCIS sessions by month (April 1999 through March 2002).

sions. Overall, our 13 subjects used the system during 144 of the 223 patient-months during which they participated. The average time that patients continued to use PatCIS from the time of first to last use (or the end of the study) was 17.1 months. This number may be an underestimate, since four to seven patients seem likely to continue to use PatCIS.

4. Discussion

A number of researchers are beginning to investigate the feasibility of giving patients access to their medical records via the Internet. The number of patients in this study was relatively small (13), due to the stringent recruitment process required by our Institu-

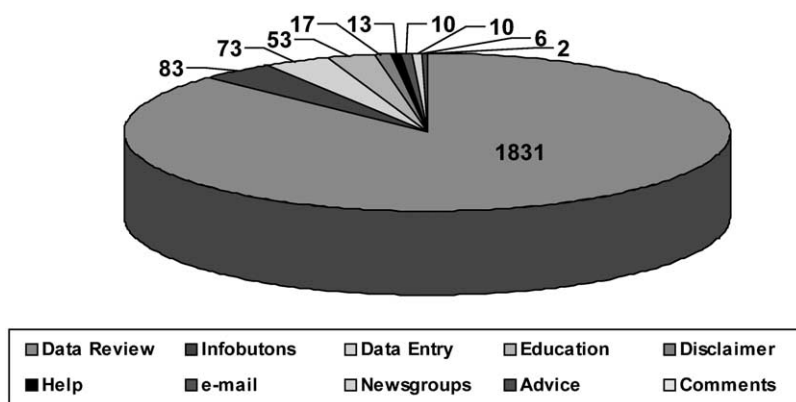


Fig. 9. Activities of PatCIS Patients in 466 Sessions (2098 total activities).

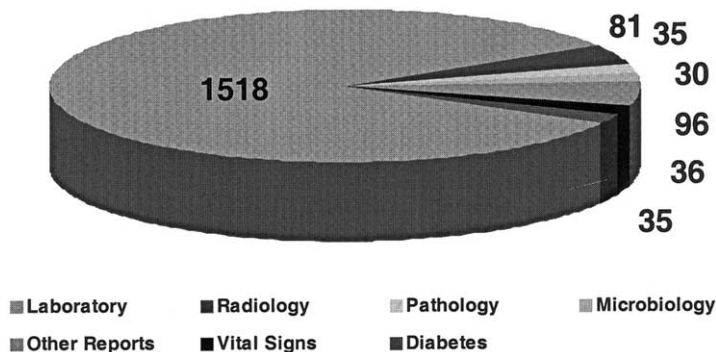


Fig. 10. Data Review Activities of PatCIS Patients in 466 Sessions (1831 total reviews).

tional Review Board. For example, we could not advertise directly to patients, but had to rely on suggestions by physicians. Although the rate of follow-up rate for interviews with long term users was a respect 62%, this was an even smaller set of patients (five out of eight). However, the study described here provides the longest follow-up to date of such access, with detailed information about how patients made use of it.

At the outset of this study, we were concerned with three cognitive and two technical issues related to the use of PatCIS:

- 1) Would patients be able to use the system?
- 2) Would patients be able to understand their records?
- 3) Would use affect the clinician–patient relationship?
- 4) Does the architecture support rapid integration of applications?

- 5) Is the approach to user authentication practical, providing adequate, but not excessive, security?

4.1. Usability

The PatCIS project was created to give patients access to their medical records and to observe the results. No attempt was made to provide a comprehensive framework for a patient-centric view; the clinical data are presented in the same manner that is used by clinicians. Nor was any attempt made to provide training or guidance in the use of the system, under the assumption that such support would not be feasible if the system were to be made generally available. Despite these potential obstacles, the majority of patients who have tried PatCIS have used it successfully. The resulting experience extends

Table 1

Number of subject responses (using a five-point scale) on the follow-up questionnaire

| Question | SD | D | U | A | SA |
|----------------------------------------------------------------|----|---|---|---|----|
| I find PatCIS useful | | | 1 | 1 | 2 |
| I am willing to enter my own data into my record using the WWW | | | | 3 | 1 |
| I am willing to review my own health information using the WWW | | | | 2 | 2 |
| PatCIS has improved my interactions with health professionals | | | | 1 | 3 |
| PatCIS has improved my understanding of health and illness | | 1 | | | 3 |
| PatCIS has changed how my health care is managed | | | 1 | | 3 |

SD, strongly disagree; D, disagree; U, unsure; A, agree; SA, strongly agree.

our knowledge about patient access to electronic medical records.

As shown in Fig. 8, the frequency with which subjects used PatCIS varied greatly. Some patients had one or two active sessions and then did not use it further during their remaining follow-up periods (4–6 months), while others used it on a monthly, and sometimes daily, basis. This variability may reflect differing perceptions of usefulness, but the interview data do not support such a conclusion. Another possibility is that the variation in usage is due to variation in the accumulation of new health data: a patient who has laboratory tests done once a year may have little reason to check his or her record more often than that, whereas a patient who has weekly laboratory tests may log on much more frequently. Patient comments support this conclusion.

The variability in length of usage may be due to a variety of factors, including the patient who never tried the system, and another who had to stop using the system when she retired from work and no longer had computer access. We do not know other reasons for attrition, but we would expect that some is due to the usual reasons of patients moving, becoming incapacitated, dying, etc. It is likely, as well, that some patients simply decided not to use the system, however, this was after an average of almost 18 months, and 31–54% of subjects seem to be permanent users.

Despite a variety of reasons stated for wanting to use the system, our subjects were consistent in being primarily interested in reviewing laboratory results, as shown in Figs. 9 and 10. Based on the subjects' comments, we believe this reflects the high volume of laboratory results in the medical record, compared with other data.

4.2. *Understandability*

Our subjects generally seemed to understand the information they found in their records. Apparently, they did not require educational resources or infobuttons to do so. Although this result is encouraging, it must be interpreted with caution. The subjects in our study were a highly selected group: they were patients of physicians willing to participate, they were selected by these physicians as being good candidates, they were self-selected by agreeing to participate, and they were able to overcome technological barriers to access (since they were required to enroll on line).

4.3. *Patient–clinician relations*

Prior to the study, we conjectured many potential positive and negative impacts that PatCIS use might have on the relationships and interactions between patients and their health care providers. Subjects and clinicians were unanimous in their belief that PatCIS's impact was positive for both. Both patients and physicians indicated that PatCIS improved the level of communication during patient-physician interviews. In particular, by allowing patients to review their data in detail prior to their actual visits, patients and physicians felt that the limited time available during the subsequent patient–physician interaction was used more efficiently, allowing for an enhanced level of discussion about the patient's problems and issues such as compliance. No adverse events were reported.

4.4. *Architecture*

PatCIS makes use of a single program that serves as the conductor for the various applications in the PatCIS 'orchestra.' This arrangement has supported rapid prototyping and deployment of the individual applications

by relieving their developers from the responsibility of security checking and activity logging. Each application was developed in a stand-alone mode, tested, and then modified to be callable by PatCIS. This process was further facilitated by the table-driven method for defining applications as subbuttons and then linking them to main buttons using a simple graphical management tool.

4.5. Security

Whenever electronic access to patient information is discussed, security issues are among the first ones raised because of concern about confidentiality. Masys et al. have developed a multifaceted approach to assuring that unauthorized access to data can be kept to a minimum, using, among other things, a graphical (as opposed to keyboard) entry of user ID and password, an encrypted diskette, and a ‘challenge’ question [9].

Our approach is technically much simpler and is identical to that required of physician users of NYPH’s clinical information system. It prevents unauthorized access to the system, so that indiscriminate browsing is not possible. The SecurID card number cannot be guessed or stolen, since it is only good for 1 min and for one log-on attempt. Once logged on, the patient cannot access data on other patients, and the patient’s session cannot be stolen, or ‘spoofed,’ since the user ID, medical record number, and Internet address are all part of the encrypted session identifier. Of course, the SecurID card itself can be lost or stolen, but it is of no use without the user ID and password.

Our approach has the advantage of not requiring special software on the patient’s computer, so that patients can access PatCIS from any location, as long as they have their SecurID card. Our patients’ experience de-

monstrates that the triple requirement of ID, password, and SecurID is usable.

4.6. Current directions and the future of PatCIS

Based on the experience reported here, we believe that we have overcome the technical and security challenges of giving patients Web-based access to their electronic medical records. We believe that, at least with selected patients, the concerns of clinicians about negative effects of patients’ access to their records are unfounded. Our evidence supports the idea that patients can access this information independently, and feel that they have improved understanding of their records and improved patient–provider relations.

The PatCIS project has been a proof-of-concept prototype, although to many of our patients, it has been a useful, production system. The architecture of PatCIS appears sound, but the breadth and depth of the applications it subsumes will likely need improvement before it can be extended to other patient groups. Based on the experience to date, we know that any improvements in data presentation and explanation should focus first on laboratory data. We are currently working with the Naomie Berrie Diabetes Center at NYPH to explore how patients with diabetes mellitus might use the system to obtain educational material, record their flow sheet data, and communicate those data to their physicians.

5. Conclusion

This study demonstrates that patients can be given access to their electronic health records via the World Wide Web, that they will use such access over long periods of time, and that the patients feel that such access can

improve their understanding of their health and their communication with their health care providers. These outcomes suggest the potential for systems such as PatCIS to have beneficial effects on health outcomes through shared workload between the doctor and the patient, resulting in better communication and negotiation. A challenge for future studies will be to actually test the extent to which patients' perceptions are correct and to extend PatCIS access to patients from different educational, economic, and social backgrounds.

Acknowledgements

This work was supported in part by contract N01-LM-6-3542 from the US National Library of Medicine. The authors express their appreciation to Dr Paul Clayton for inspiring the creation of PatCIS; the students, fellows, and programmers who have contributed components to the PatCIS project; Andrew Brooks for his assistance with data collection; and Andria Cimino for editorial assistance. We are indebted to the physicians and patients who have participated in this study, especially to Dr Jai Radhakrishnan, for his assistance with recruitment.

References

- [1] D.P. Stevens, R. Stagg, I.R. Mackay, What happens when hospitalized patients see their own records, *Ann. Intern. Med.* 86 (4) (1977) 474–477.
- [2] R.D. Miller, B. Morrow, M. Kaye, G.J. Maier, Patient access to medical records in a forensic center a controlled study, *Hosp. Community Psychiatry* 38 (10) (1987) 1081–1085.
- [3] L. Ridsdale, S. Hudd, What do patients want and not want to see about themselves on the computer screen: a qualitative study, *Scand. J. Prim. Health Care* 15 (4) (1997) 180–183.
- [4] S. Bloch, C.E. Riddell, T.J. Sleep, Can patients safely read their psychiatric records? Implications of freedom of information legislation, *Med. J. Aust.* 161 (11–12) (1994) 665–666.
- [5] D.R. Masys, D.B. Baker, Patient-Centered Access to Secure Systems Online (PCASSO): a secure approach to clinical data access via the World Wide Web, *Proc. AMIA Annu. Fall Symp.* (1997) 340–343.
- [6] D.M. Rind, J.H. Kirn, E.A. Sturges, A.A. Morales, P.M. Russel, SeniorMed: connecting patients to their medication records, *Proc. AMIA Anna Fall Symp.* (1999) 1147.
- [7] R.L. Herting, J.W. Hales, J.M. Overhage, A framework for classifying and evaluating consumer-oriented medical records, *Proc. AMIA Annu. Fall Symp.* (2000) 1029.
- [8] K.D. Mandl, A. Riva, I.S. Kohane, A distributed, secure file system for personal medical records, *Proc. AMIA Annu. Fall Symp.* (2000) 1075.
- [9] D. Masys, D. Baker, A. Butros, K.E. Cowles, Giving patients access to their medical records via the Internet: the PCASSO experience, *J. Am. Med. Inf. Assoc.* 9 (2002) 181–191.
- [10] W. Adams, A. Mann, H. Bauchner, Parental knowledge and satisfaction following receipt of a computer-based personalized pediatric primary care report card, *J. Am. Med. Inf. Assoc.* 8 (Suppl.) (2001) 844.
- [11] J.J. Cimino, J. Li, E.A. Mendonca, S. Sengupta, V.L. Patel, A.W. Kushniruk, An evaluation of patient access to their electronic medical records via the World Wide Web, *Proc. AMIA Annu. Fall Symp.* 7 (Suppl.) (2000) 151–155.
- [12] A.W. Kushniruk, V.L. Patel, J.J. Cimino, Evaluation of Web-based patient information resources: application in the assessment of patient clinical information systems, *Proc. AMIA Annu. Fall Symp.* 7 (suppl.) (2000) 443–447.
- [13] J.J. Cimino, A. Sengupta, P.D. Clayton, V.L. Patel, A.W. Kushniruk, X. Huang, Architecture for a Web-based clinical information system that keeps the design open and the access closed, *Proc. AMIA Annu. Fall Symp.* 5 (Suppl.) (1998) 121–125.
- [14] J.J. Cimino, G. Elhanan, Q. Zeng, Supporting infobuttons with terminological knowledge, *Proc. AMIA Annu. Fall Symp.* 4 (Suppl.) (1997) 528–532.
- [15] D. Baorto, J.J. Cimino, An 'Infobutton' for enabling patients to interpret on-line Pap smear reports, *Proc. AMIA Annu. Fall Symp.* 7 (suppl.) (2000) 47–50.
- [16] Y. Chen, S.S. Wang, J.J. Cimino, Linking guidelines for mammography to an electronic medical record for use by patients, *J. Am. Med. Inf. Assoc.* 6 (Suppl.) (1999) 1041.
- [17] J.J. Cimino, S.A. Socratous, P.D. Clayton, Automated guidelines implemented via the world wide web, in: R.M. Gardner (Ed.), *Proceedings of the Nineteenth Annual Symposium on Computer Applications in Medical Care*, Hanley & Belfus, New Orleans, LA, Philadelphia, 1995, p. 941.
- [18] J. Chuang, R. Kukafka, Y.A. Lussier, R.A. Jenders, J.J. Cimino, A web-based system for prediction of coronary heart disease risk using the Framingham algorithm, *J. Am. Med. Inf. Assoc.* 7 (suppl.) (2000) 983.