An Evaluation of Patient Access to their Electronic Medical Records via the World Wide Web

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This paper describes initial experience with the Web-based Patient Clinical Information System (PatCIS). The system was designed to serve as a framework for the integration of applications that help patients access their electronic medical record, add data to their record, review on-line health information, and apply their own clinical data (automatically) to guideline programs that offer health advice. The architecture supports security functions and records user activities, relieving application developers from concerns about safe information practices and the evaluation process. PatCIS is being used to study the social and cognitive impact of allowing patients to have access to their health records via the Web.

To date, PatCIS has grown to include 15 clinical functions and 4 dynamic links to literature (called infobuttons). Eleven patients have been enrolled since April, 1999; five have been active users.

Experience shows that the PatCIS architecture supports application integration while providing adequate security and evaluation functions. Initial caution with the patient enrollment process has limited recruitment and, consequently, usage. However, experience thus far suggests that PatCIS has good usability and utility. No adverse events, including undesirable impact on doctor-patient interactions, have been reported. There do not appear to be any technical impediments to scaling up the enrollment to continue to observe patient usage.

INTRODUCTION

Patients have ready access to their medical records at most institutions: they fill out a form, pay a processing fee, and several days or weeks later they receive a poorly copied, illegible, highly technical, disorganized, incomplete pile of paper. Most patients probably do not attempt to read this themselves and therefore such access probably has little direct impact on patients. However, access to electronic medical records as mandated by the health Insurance Portability and Accountability Act of 1998 (HIPAA)[1] is likely to lower at least some of these barriers.

Despite enthusiasm of legislators and regulators for giving patients this access, little is known about the effect it may have on patients' understanding of their own health and their relationships with physicians. Past studies of the provision of psychiatric records to patients have shown a generally positive response,[2,3,4,5,6,7] and anecdotal experience reported at the 1999 AMIA Symposium by Leavitt et al. from Providence Health Systems, has been encouraging.[8] However, as projects such as Providence's and the PCASSO system at the University of California at San Diego[9] begin to make Web-based access to health records routine, there is the potential for problems to arise. These include breaches of confidentiality, inappropriate complacency about health status, unnecessary concern about health status, and interference with the patient-physician relationship. It is easy to imagine patients quizzing their physicians about details of their records that are finally available to them in a form that is at least legible, if not comprehensible.

As part of a National Information Infrastructure (NII) contract with the National Library of Medicine (NLM), we are to studying the impact that health record access has on patients and their providers. We have previously described an architecture for our Patient Clinical Information System (PatCIS), postulated that its design would simplify the integration of functions for system developers, and would prove to be usable for patients.[10] We report on experience with both the application development and usage by patients in our pilot phase, with details on our ability to integrate applications, enrollment experience, security capabilities, and usage statistics.

METHODS

System Architecture

PatCIS is designed around a central Common Gateway Interface (CGI) program that manages patient login, establishes sessions, monitors usage for possible breaches in security, and records activity in a log file. The user functions are represented in a table that specifies the category (Data Entry, Data Review, Education, Advice, Comments, and Help), name, and Uniform Resource Locator (URL) of the function application.

Figure 1 shows a typical PatCIS screen. When the user selects a button on the left side of the screen,

a set of "sub-buttons" appears at the top of the screen, each of which corresponds to an entry in the table. When the user selects a sub-button, the URL is passed to PatCIS as a parameter, PatCIS carries out security and logging tasks, calls the URL, and returns the resulting document. Adding a function to PatCIS requires construction and testing of the function in a stand-alone mode and then adding a row to the table. This design is described in greater detail elsewhere.[10]

Patient Recruitment

Patients were recruited from private practices of internists at New York Presbyterian Hospital. The Institutional Review Board raised concerns that approaching patients directly might cause consternation with their physicians, who might be placed in an awkward position if they did not wish their patients to participate. We therefore initially recruited physicians through direct mailings, asking for names of patients who would be good candidates for the study. We then sent letters to these patients, inviting them to participate. Patients enrolled by completing a Web-based form, printing the resulting consent form, signing it, and mailing it to us.

Once we obtained the forms, we requested specific consents from the physicians regarding the permissions for specific functions. The patients' accounts were then created and the logon IDs and passwords were mailed to the patients, along with a SecurID card (Security Dynamics, Bedford, Massachusetts), which is a physical token used for strong authentication.[11]

Review of Patient Logs

We are carrying out an extensive evaluation of the cognitive aspects of the impact of PatCIS on patients and their relationships with their physicians.[12] Data collection methods include entrance and exit questionnaires, interviews, and usage logs. In this paper, we summarize the results of the usage logs.

PatCIS records all login attempts and keeps track of each button and sub-button selected by the user. Depending on the function, PatCIS also keeps track of additional actions selected by the patient. For each action, the log shows the main button, sub-button, URL and time. Sessions were analyzed by the success of login, the number of functions used during the sessions, the duration of the sessions, and whether the user explicitly logged out of the session.
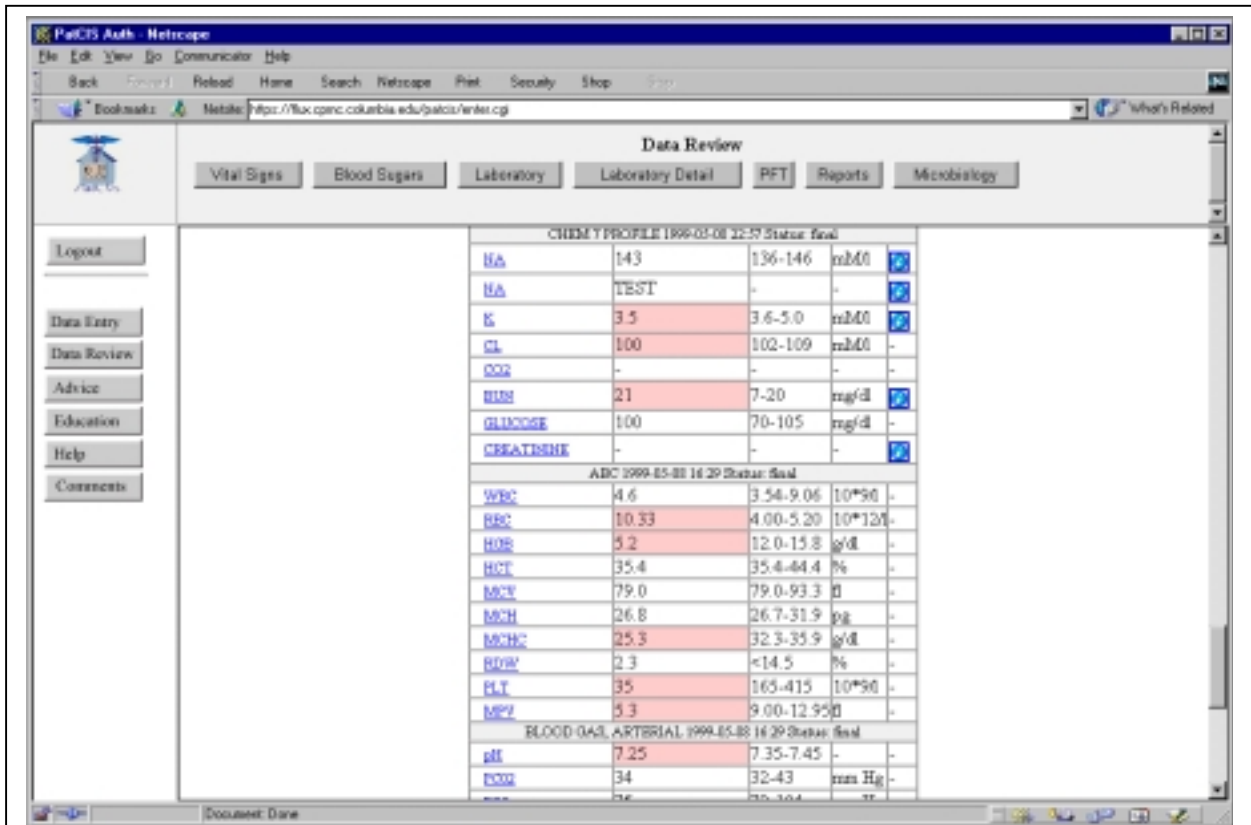

Figure 1: Sample PatCIS screen, showing Laboratory Detail function under Data Review

RESULTS

Applications

PatCIS currently includes 15 clinical functions (Table 1), some of which have been described elsewhere.[13,14,15,16] In addition to the main functions, "infobuttons"[17] have been added to link clinical data to on-line information resources. These include a link from vital signs entry to a body mass index calculator, a link from laboratory results to a layman's guide for understanding tests, links from culture results to automated PubMed searches, links from microbiology sensitivity tests to appropriate pages of drug textbooks, and links from Pap smear results to interpretation software.[18]

Creation of the functions required the usual iterative development and evaluation process. Adding then into PatCIS required only a few minutes, with no programming changes.

Enrollment

Recruitment letters were mailed to over 200 physicians. Permission forms were returned by 11 physicians, who then offered up a total of 11 patients. Letters were sent to these patients, telling them how to register via the World Wide Web. Eight of these patients responded and were enrolled.

System Usage

Five patients signed on to PatCIS, completed the on-line entry questionnaire, and made use of at least one function during an initial or subsequent session. One patient never signed on, one patient did not complete the questionnaire, and the remaining patient completed the questionnaire and had four additional sign-ons but never used any PatCIS functions; these three patients were excluded from further analysis.

The remaining five patients participated in using PatCIS and logged on a total of 243 times during the course of the study. The first patient session was in April, 1999; the pilot phase was continued through the end of February, 2000 with a total of 31 patient months of use (Patient 1 retired from work in Month 5 and no longer has access to a computer).

Thirty-three of the logins failed due to incorrect password or SecurID code; 14 sessions involved a successful login, but no subsequent activity. There were no attempts to login with an illegal ID and all failed login were followed immediately by successful logins. The remaining 196 sessions involved use of one or more functions. Table 2 shows the frequency and duration of these sessions.

For security reasons, a "Logout" function is included to allow patients to use PatCIS in public places (such as a library) and end their session

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Table 1: PatCIS Functions

Data Entry:
    Diabetic Data (glucose, insulin, symptoms)
    Vital Signs (height, weight, pulse, blood
        pressure and temperature)
Data Review:
    Vital Signs (entered by the patient)
    Diabetic Data (entered by the patient)
    Laboratory (displays panel headers and
        then details of selected panels
    Laboratory Details (shows all details,
        bypassing the panel header display
    Pulmonary Function Tests
    Reports (including radiology, cardiology
        discharge summaries, and pathology)
    Microbiology Reports
Education:
    Geriatrics
    Diabetes
    Home Medical Guide
    Aging
    Advanced Directives
Advice:
    Cholesterol
    Mammogram
Help
Comments

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without closing the browser application. They used this function 122 times and did not use it 74 times.

Function Usage

The most frequently used function was the review of laboratory data, which was done at least once in 140 (71%) of the sessions. The "Laboratory" sub-button shows a list of panels (CBC, Chem7, etc.) and allows the user to select a panel for detailed display. Users selected this function 270 times and examined details 340 times. The "Laboratory Detail" sub-button (Figure 1), shows all the panel details as a single list, rather than requiring the intermediate panel list. This option was selected 69 times. Selecting a specific test produces a summary of results for that test (for example, clicking on "NA" on the screen in Figure 1 generates a list of all sodium tests). Patients used this function 129 times (114 from Laboratory and 15 from Laboratory Detail).

"Reports" was the next most often used function (40 times). Patients selected a variety report headers to obtain details, including radiology (24 times), cardiology (17 times), and pathology (10 times). "PFT" (Pulmonary Function Test) was selected 22 times and microbiology results 8 times.

	1	2	3	4	5	6	7	8	9	10	11
Table 2: Number of PatCIS sessions for each of the five subjects during each of the 11 months of the pilot study (Numbers in parentheses are average session duration in minutes)											
1	1(1)	2(39)			1(12)						
2		8(8)	23(8)	11(8)	15(7)	8(8)	7(4)	3(8)	8(4)	13(9)	1(6)
3					6(6)	7(8)	3(5)	13(3)	7(2)	19(5)	15(12)
4						4(12)	3(10)		1(1)	1(1)	
5									9(48)	2(13)	5(6)

The data entry functions were used sparingly: vital signs were entered 31 times and diabetes information (blood sugars and/or insulin doses) were entered 14 times. These data were also rarely reviewed (26 and 18 times, respectively).

Educational functions, which provide passive links to other Web sites were used 35 times (Diabetes 11 times, Geriatrics 8 times, Home Medical Guide 4 times and Aging 2 times). Advice functions, which use data taken from the patient's record as input to active guideline programs, were used 6 times (Cholesterol 5 times and Mammography 1 time).

Anecdotal Experience

A full summative evaluation is under way, but user comments and some initial questionnaires have been received. In general, they have been positive, except during two brief outages that prevented users from accessing the system. One patient was interviewed on national television, using the system, and reported a high level of satisfaction and improvement in the process of his health care (PBS Healthweek, February 26, 2000). Unfortunately, no feedback has been received from patients who were enrolled but did not use the system.

Part of the evaluation process includes the reporting of "adverse events"; specifically, we provided each physician with forms to report instances where the use of PatCIS either caused problems for the patient or interfered in some way with the physician's relationship with the patient. No adverse events have been reported to date.

DISCUSSION
Predictions about the Architecture

PatCIS was designed to serve as a framework for integrating a variety of modules into an environment that supports requirements for security and evaluation. We are satisfied that PatCIS meets these needs. The security provided meets or exceeds the requirements set by institutional policy. The activity tracking and questionnaire functions support the needs of the evaluation team; the data provided for this report are part of those requirements. All of this is done without requiring application developers to do more than make a few trivial alterations to turn their stand-alone functions into ones that can be made available to our test subject population in a secure, assessable manner. Adding the name of the sub-button and the URL of the function are all that is required to complete the task of integration.

Patient Enrollment

The experience reported here constitutes a pilot phase for PatCIS testing. The study group was intended to be small to allow us a "shake out" period to debug functions as we began to learn about the sociocognitive impact of our technology. Nevertheless, the recruitment process was sufficiently ponderous to dissuade physicians from participating. We believe that there are many patients who would like access to PatCIS; expanded enrollment will require some lifting of recruitment restrictions as comfort with the technology improves.

We must make inferences carefully, not only because of the small size of the study group, but because of its composition. Patients were selected first by their physicians, next through self-selection, and finally through "natural" selection: only those patients who could access and complete the online questionnaire were enrolled. This process has produced a set of subjects that is not representative of the population at large. However, we have two reasons for starting with such a group. First, we can provide only a minimal level of technical support and therefore prefer users who are relatively self-sufficient. Our users demonstrated this by enrolling online. Second, we believe that the patients most likely to derive benefit from unsupervised access to a computer-based health record are those who are the better-educated and , technology-savvy. We want to be sure that PatCIS is capable of helping these "most likely to succeed" before we turn our attention to the underserved, disenfranchised "have nots".

Patients' Use of the Medical Record

We are currently undertaking a cognitive evaluation to study the impact that the system has on the way patients think about their health and how they interact with health care providers. However, the

activity logs by themselves allow us to draw some conclusions based on the experience to date. First, patients appear to fall into one of two patterns of use: infrequent users who log on once or twice a month, and frequent users who log on several times a week. It is likely that frequent users differ in having frequent testing for some chronic condition.

Second, laboratory results are by far the most popular reason for using PatCIS. We do not know the health issues our patients have, but the logs show that they are looking at new lab tests, not the same ones over and over. It may also be due to the relative understandability of laboratory results, as compared to other reports, such as radiology and pathology. We did not know, *a priori*, whether patients would prefer the "Laboratory" format or the "Laboratory Detail" format. It was simple enough to create both and let patients vote with their feet.

Based on the activity logs, patients seem to have some trouble with logging on, perhaps due to the complexity of having to use the SecurID card. However, they seem to learn how to use the system quickly and efficiently, as reflected by the drop in session times from initial to later sessions.

CONCLUSIONS

Based on our pilot implementation, the PatCIS architecture appears to be an appropriate framework for giving patients access to health information. Thus far, giving patients Web-based access to their own health records appears to be useful, with no apparent adverse effects.

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