

Final Report:

"Patient Access to Clinical Information: the PatCIS Project"

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Final Report on the PatCIS Project

The Patient Clinical Information System (PatCIS) was created to serve as a testbed for exploring issues related to the access of patient records by the patients themselves. The first stage of the project were involved with developing solutions to security issues, including identification, authentication, and authorization. The second stage of the project involved development of the information architecture to give patients access to their records, as well as a variety of on-line information resources and educational aides. The third stage of the project involved patient recruitment and enrollment, with observation of their use of the system. The final stage involved a detailed cognitive evaluation of the experiences with PatCIS of the patients and their physicians. This report consists of three parts: a usage report, a usability study, and the Summary of Salient Results.

Usage Report

The report, entitled "What Do Patients Do with Access to their Medical Records?" (attached), summarized the functions created for PatCIS, the experience with recruitment and enrollment, and the usage of the system, according to the usage logs kept on thirteen subjects over a period of nineteen months. This report has been submitted to Medinfo 2001.

Usability Study

The evaluation component of the PatCIS project involved several different modalities: on-line questionnaires, e-mail surveys, telephone interviews with patients and physicians, and videotaping actual patient usage. The usability report, entitled "Evaluation of the Patient Clinical Information System - PatCIS" (attached), describes the results of these studies. The report is currently being converted to a form suitable for publication.

Summary of Salient Results

The PatCIS study demonstrated that patients can be given access to their electronic health records via the World Wide Web and that such access can improve their understanding of their health and their communication with their health care providers. We found that our approach to security (logon ID, password, and SecurID Card) provided adequate security in a usable manner. We also found that our architecture for linking clinical and educational modules served us well in the integration of independently-created system features into PatCIS, as well as supported our ability to control and monitor system usage. Similarly, we found that our techniques for "teleevaluation" of PatCIS were sufficient to conduct our evaluation studies successfully, largely at a distance.

With regard to the actual access of medical records by patients, we found that patients varied in their use of the system, from once a month or less to once a day or more. 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.

What Do Patients Do with Access to Their Medical Records?

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Abstract

We sought to study the phenomenon of patients having access to their own medical records in order to determine the impact on them and on 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 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 nineteen-month period and reviewed their activities in the system's usage log. We also collected data via questionnaire and telephone interview.

We found that patients varied in their use of the system, from once a month or less to once a day or more. 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.

Keywords

Consumer Informatics, Electronic Medical Records, Personal Health Records, World Wide Web

Introduction

Patients in the US have the right to review their medical records. Although preliminary studies have shown that provision of psychiatric records to patients 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]

We have developed a Web-based interface to the New York Presbyterian Hospital clinical data repository intended for use by patients to review their own records. Called the Patient Clinical Information System (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 [9] and user experience [10] during its pilot period. In this paper, we

report on the usage of and experience with PatCIS by 13 subjects over a period of 19 months.

Materials and Methods

PatCIS Architecture

The architecture of PatCIS has been described elsewhere.[11] Briefly, 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 records), Education (information resources on various topics), and Advice (application of patient data to online guidelines), by referencing a table of application names and CGI references. We also incorporated "infobuttons," which pass patient-specific information to programs that generate patient-specific educational messages.[12]

When users select a button with the application name, the CGI reference is passed to PatCIS, which carries out several steps:

- **Timeout:** Checks for the time since last activity and, if greater than 5 minutes, requests reentry of the password
- **Security:** Verifies the session is valid and that no session parameters (user ID, medical record number, IP address of the user's browser) have been altered
- **Logging:** Records the requested function in the usage log
- **User function:** calls the requested CGI and passes the results back to the user's browser

In some cases, the documents returned by the CGIs contain links and function calls. When these documents are created by CGIs that are part of PatCIS, they too will call the PatCIS CGI, repeating the process above. Figure 1 shows a typical PatCIS screen.

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

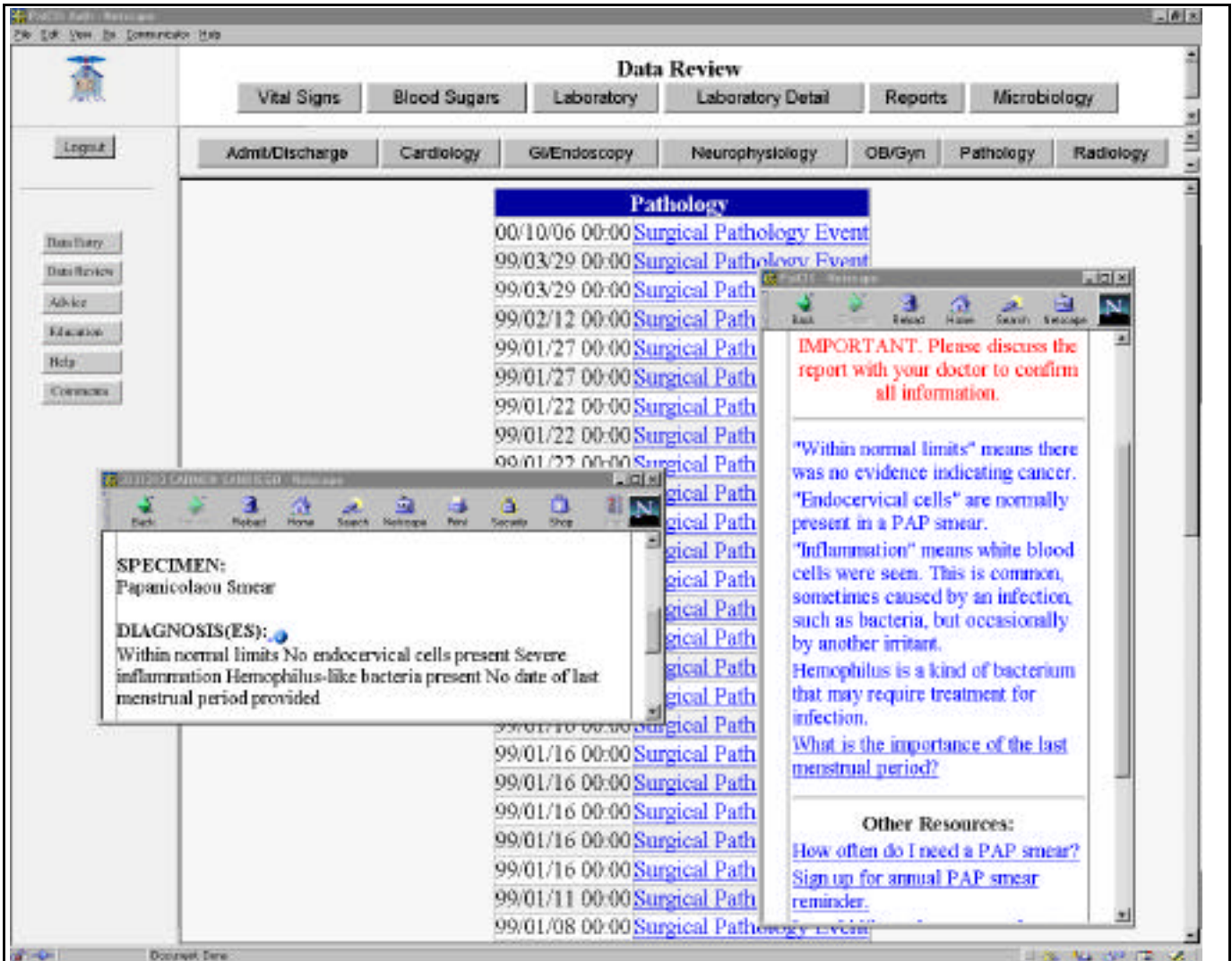


Figure 1 – A typical PatCIS screen. On the left are general classes of functions. Here, the subject selected “Data Review,” which produced the list of buttons at the top of the screen. The subject then selected “Reports,” which produced a second list of buttons. The subject selected “Pathology” to obtain the list of reports. When the subject selected a report, the small window on the left was displayed, showing the details of the report. This particular report contains an “infobutton” that, when selected, provides explanatory information (small window on right) about the findings in the report.[13]

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. Figure 2 shows a sample of a log file.

On-line Questionnaires

We surveyed subjects with two questionnaires. The first was completed by the subjects the first time they logged on to PatCIS. These questionnaires assessed subject demographics, subjects' perceptions of their relationship with their health care provider, expectations about the system, and prior computer experience. The second questionnaire was sent to subjects after nine months of system usage and assessed the usability of the system and changes in patient perceptions about their expectations and their relationships with their providers.

Telephone Interviews

Phone interviews were conducted with subjects and their physicians after nine 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.

Results

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 five months, 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

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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

```

Figure 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 (Figure 1), the “Laboratory Detail” button, a single test result (to produce a summary report), and then logged off. The session took 17 seconds.

through October 2000. The average follow-up period for all 12 active subjects was 10 months.

Subject Characteristics

Eight of the thirteen subjects were male. Two of the male subjects listed their ages as “>65,” while the rest of the subjects listed “40-64.” 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 two 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.

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%) were due to 5 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

Table 1 – Number of active PatCIS sessions by month

Subject:	1	2	3	4	5	6	7	8	9	10	11	12	13
Apr-99	1												
May-99	2	0	7										
Jun-99	0	0	24										
Jul-99	0	0	11	0	0								
Aug-99	1	0	15	6	0								
Sep-99	0	8	7	0	4								
Oct-99	0	7	3	0	3	0							
Nov-99	0	3	13	0	0	0							
Dec-99	0	8	7	0	1	0	9						
Jan-00	0	13	19	0	1	0	3						
Feb-00	0	1	15	0	0	0	6						
Mar-00	0	7	43	0	4	0	3						
Apr-00	0	4	0	0	1	0	3						
May-00	1	9	9	0	1	2	3	0	1	1			
Jun-00	0	5	45	0	2	0	2	0	0	0			
Jul-00	0	5	13	0	4	0	2	0	0	0	1		
Aug-00	0	7	10	0	0	0	2	2	0	0	0	3	
Sep-00	0	12	18	0	8	0	3	3	0	0	0	0	
Oct-00	0	12	14	0	0	0	1	1	0	0	0	1	
Totals	4	1	158	222	0	29	2	37	6	1	1	1	4

subjects throughout the study period. 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

Table 2 – Activities in 466 PatCIS sessions	
Data entry:	73 total
	34 vital signs
	39 diabetes flow sheets
Data review:	1831 total
	1518 laboratory results
	36 vital signs
	35 diabetes flow sheets
	212 reports (incl. 81 radiology, 35 pathology)
	30 Microbiology
Advice:	6 total
	5 cholesterol guideline
	1 mammography guideline
Education:	53 total
Other:	135 total
	10 newsgroups
	83 infobuttons
	2 comments
	10 e-mail to physician
	17 disclaimer
	13 help
Total:	2098

(average: 38.8) during the study period, with between 0 and 45 sessions per month (average: 4.0). Table 1 shows the distribution of active sessions for all subjects during the study period.

The session duration ranged from less than one minute to 66 minutes (average: 5.7); 391 (83.9%) of the sessions were ten minutes or less, 58 (12.4%) of the sessions were eleven to twenty minutes in duration, with only 17 (3.6%) being longer than 20 minutes. During the sessions, subjects carried out a total of 2098 actions (shown in Table 2). This represents an average of 4.5 actions per session:

Table 3 – 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

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).

User Experience

Of the eight patients who were in the study nine 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 3.

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.”

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.

Discussion

At the outset of this study, we were concerned with three cognitive 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?

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 to present to clinicians. Neither 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 our knowledge about patient access to electronic medical records.

As shown in Table 1, the ways in 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.

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 Table 2, this accounted for over 72% of their activities. Based on the subjects’ comments, we believe this reflects the high volume of laboratory results in the medical record, compared to other data.

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).

Patient-Clinician Relations

Prior to the study, we conjectured many potential positive and negative impacts that PatCIS use might have on the relationship and interactions between patients and their health care providers. Subjects and clinicians were unanimous in their belief that PatCIS contributed to improvement of both. In particular, both patients and physicians indicated that PatCIS improved the level of communication during patient-physician interviews. No adverse events were reported.

Conclusion

This study demonstrates that patients can be given access to their electronic health records via the World Wide Web and 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 extend access to patients from all educational, economic and social backgrounds.

Acknowledgments

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Final Report: Evaluation of the Patient Clinical Information System - PatCIS

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INTRODUCTION

This document describes the work that has been carried out in the evaluation of PatCIS, a patient clinical information system developed at Columbia University. The effects of changes being brought about by emerging technology, such as Internet-based information resources for patients, must be considered in relation to patient understanding and provider therapeutic goals. In order to develop individualized, context-sensitive, useful information and guidelines that will end up being applied by patients, we must be able to evaluate how that information is understood, who is trying to understand it, and what problems occur in its comprehension and application. Over the past decade we have been involved in cognitive studies of reasoning and comprehension of medical information by both lay people and health care professionals. We have evaluated the use of PatCIS by patients to assess both its usability and its impact on the patient-provider relationship. For this work, we have applied a variety of approaches to evaluation throughout this project in order to develop a principled basis for understanding the effects of advances in health care information technology and telemedicine.

Background

The evaluation of Internet-based technologies designed for use by patients, raises a number of concerns that go beyond conventional evaluations typically undertaken in medical informatics. In addition to assessing the usability and effectiveness of the computer system in the context of specified tasks, a number of other issues emerge when considering the evaluation of systems directly accessed by patients from home. These include: (1) determining the extent to which the patient's view of the system differs from that of the designers and how potential "mismatches" between the two influence the system's effectiveness, (2) going beyond assessment of user satisfaction to consideration of how patient's interaction with the system changes over time and how use of such technology impacts or changes the patients' interaction with human caregivers [1], (3) identifying problems in the users' interactions with the system, and (4) identifying technical and methodological issues for performing these evaluations remotely [2].

A number of studies have investigated use of Internet-based information systems by health care providers and development of evaluation instruments for assessing their use of information technology. However, an in-depth understanding of the effects of use of the WWW in providing users with advice and access to their medical data necessitates investigation. As health care rapidly moves towards widespread distribution of medical information via the WWW, such an understanding will become increasingly important.

In this report we describe work in the evaluation of PatCIS. Specific questions we seek to answer regarding our investigation of patients' access to medical data and advice include the following:

- how do patients' perceptions of use of technology change over time as they begin to interact and use this type of information system?
- how does patients' previous experience in using computers and expectations about using such technology affect their actual use of such systems over time?
- is the content provided by the system of value to patients?
- what problems do patients have in comprehending and applying information provided on-line?
- which aspects of the user interface of such systems can be improved or enhanced?
- how does use of the system affect the interaction between patients and their physicians?

- what are the limitations of Internet-based information systems in providing patient-specific information and how can they be improved from the point of view of usability (i.e. their efficiency, effectiveness and enjoyability [3]) ?

We have worked on refining a number of evaluation instruments, including web-based questionnaires, for obtaining baseline patient profiles and for addressing the issues raised above. This has involved working with the system design team in refining questions for patients regarding clinical aspects of their illness, their use of information technology as well as questions relating to their relationship with health care providers.

EVALUATION OVERVIEW

We have been involved in evaluation of use of a variety of Web-based information resources, ranging from on-line clinical guidelines to patient information systems. The evaluations we have developed and are currently employing include several methods of on-line data collection (e.g. of patients' usage of the system accessed from home) [2]. In the evaluation of PatCIS we felt that a multi-method approach was needed, in order to adequately address the objectives of evaluation, such as those described above. From our prior evaluation experiences we have found that individual methods alone can provide valuable information (e.g. logging of user interactions, questionnaires, or interviews etc.), however, in order to gain in-depth understanding underlying use of a system more than one complementary method may be required [4].

We have been involved in evaluation of PatCIS for the past two years. Analysis of the log files of patients' interactions to date indicate that certain functions of the system have been used frequently by the patients. The majority of patient accesses were to review their laboratory data (see **Figure 1** for an example of a PatCIS screen showing the lab detail function). Other features of PatCIS, such as the educational features, advice functions and patient data entry have been used more sparingly [5]. Using the multi-method approach described below, we have worked on identifying problems and issues of those patients who have adopted use of the system. In addition we have examined the effect the system may have on the doctor-patient relationship.

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. 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. In total, 12 patients responded, enrolled and became active users of the system.

The following sections describe the data that was collected from the PatCIS users over the duration of the evaluation.

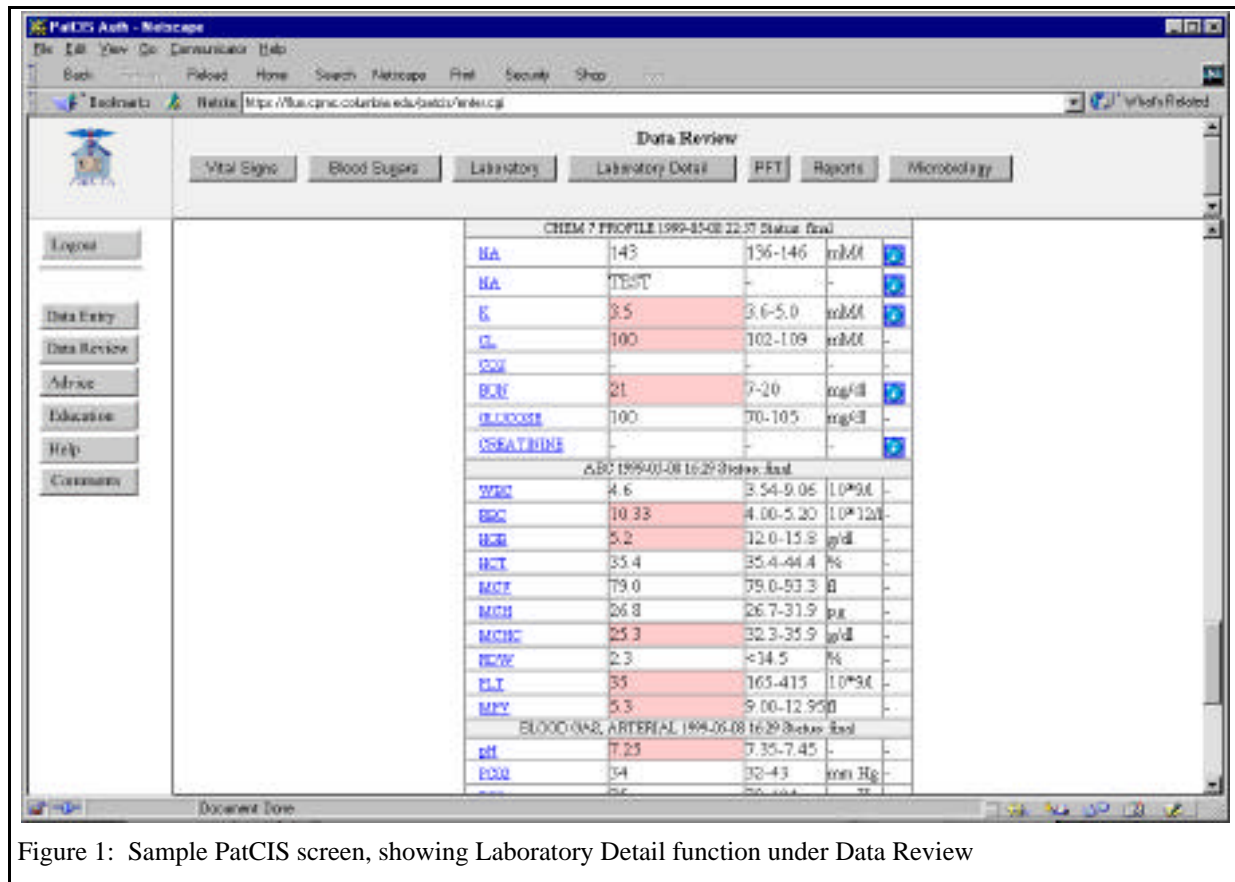


Figure 1: Sample PatCIS screen, showing Laboratory Detail function under Data Review

I.

I. On-line Baseline Questionnaires

We began the evaluation by deploying on-line questionnaires to obtain baseline information about users. In our study of patient users, several on-line questionnaire scales were developed using HTML so they can be accessed by subjects from their homes via the World Wide Web [6]. In our evaluation of PatCIS, the following baseline questionnaire scales (which are presented to users once, on first login to PatCIS) focus on assessing several major aspects of patient care and patient interaction with clinical information systems (see Appendix A for the questions presented to users):

- *User Demographics*: Items regarding demographics include standard questions about the patient's age, sex, ethnic background and family status. This questionnaire was filled out by subjects at the beginning of the evaluation, to obtain basic demographic information.
- *Relationship with Health Care Providers*: This questionnaire contains items to assess patients' interaction with health care professionals, including who they interact with and how often. Subsequent to an initial baseline presentation of this questionnaire, users may

also be asked whether they perceived their interaction with health care professionals as changing (using a five point scale ranging from "no change" to "considerable change").

- *Expectations About System Use:* The objective of this questionnaire is to assess users' subjective expectations about their use of information systems (prior to using the system for the first time). For example, this questionnaire was presented to patients at the beginning of our study of PatCIS to assess the extent to which patients believe use of the system will affect how they manage their illness (on a five-point scale, ranging from "considerable change" to "no change"), as well as how willing they are to use such an information system. A modified version of the questionnaire (deployed using email) was presented to subjects several months later to determine how subjects' expectations compare to their perceived experience.
- *Prior Computer Experience:* The accurate assessment of computer experience is an important aspect of assessing users' interaction with innovative information systems. Questions regarding the prior use of computers are typically given at the beginning of our evaluations to assess level of computer literacy. Questions include how often the patient uses a computer, when he/she first started using a computer, and what type of computer systems (e.g. IBM-compatible systems running Windows, or Mac) and programs (e.g. word processing, email etc.) are typically used.

Appendix A contains a listing of all the questions that subjects were given on the baseline questionnaire that appeared on their first login to PatCIS. In **Appendix B**, the results from the questionnaire are presented consisting of the answers to key questions on the questionnaire by ten PatCIS users. As can be seen from the table in Appendix B, the subjects were all over 40 years of age, had a relatively high level of education and all had been computer users for at least several years. The actual responses of each subject to all the questions contained in the on-line baseline questionnaire are contained in **Appendix C**.

I. Email Questionnaire on Usability

We have developed a usability questionnaire designed to assess both problems in users' interaction with information systems and changes in their perception of their interaction with systems over time. In our study of PatCIS the questionnaire was emailed to patient users approximately nine months after they first started using the system. Email was used to deploy this questionnaire since log files of usage of PatCIS indicated that some users rarely logged on to PatCIS, while others logged on at variables intervals (a paper copy of this questionnaire is being mailed to patients who do not respond to the questionnaire deployed via email).

The questionnaire contained question items dealing with the following:

1. *Usability Problems:* The intent of these questions was to obtain information about problems users may be encountering in interacting with the system (i.e. problems in performing functions that the system is designed for, and other problems of an ergonomic nature). The questions are based on standard usability scales for assessing user interfaces [7] and also contain text-entry boxes where subjects can enter their responses to the following questions: Is the text on the screen easy to read? Are the graphs and tables easy to understand? What features do you like? What features don't you like? What new features would you like? Was medical advice provided helpful? What is your overall impression of the system?

2. Changes in Patient Perceptions: In order to further investigate underlying these usage patterns and to assess patients' subjective experience in using PatCIS, the emailed questionnaire included several 5-point scales for assessing the following:

- Willingness to enter data into PatCIS
- Willingness to review their own health data over the WWW
- Perceptions of their interactions with health care providers

Table 1 provides examples of several of the questions used (see Appendix D for a listing of the questions users were emailed, and Appendix E for subjects actual responses to the questions they were emailed), along with responses from five users. Subjects were also asked to respond to questionnaire items (on a 5-point scale) related to aspects of human-computer, to assess the following:

- Ability to understand graphs and tables
- Clarity of screen sequences
- Usefulness of help and information buttons
- Learnability of the system
- Usefulness of linkages to other sites
- System reliability and speed

Results to date indicate that all users found that information presented was presented on the screen in a way that was easy to read, graphs and tables were comprehensible and that overall the system was reliable. However, from our preliminary analysis, areas where user responses indicated that the system might use improvement included improving error and system messages, as well as streamlining the sequence of screens.

Table 2 provides the overall impressions of PatCIS from four patients who have used the system for at least nine months. The most positive ratings came from subject 4 who, from examination of the baseline questionnaire, had one of the most extensive computer backgrounds. In addition, analysis of log files indicated that this subject used the various features of the system most extensively. In contrast, user 3 had the least computer experience and reported considerable trouble in attempting to login and access PatCIS (this subject stated he had trouble in using the Secure ID card for gaining access to PatCIS). Complementary work, described below, includes interviews with users to assess for example, why they find PatCIS useful or not useful (these interviews were conducted over the phone and users' responses to questions and their "thinking aloud" was audiotaped and transcribed).

Table 1. Examples of questionnaire items and responses from five PatCIS users (deployed nine months after user's first login).

Question	User 1 (Plectical)	User 2 (PM)	User 3 (uamuam)	User 4 (Ska882521)	User 5
How often do you use	Once a month	Several times a	Never	Once a month	Once a month

PatCIS?	or less	week		or less	or less
For what purposes do you use PatCIS?	- Review data - Education	- Review data	- Review data - Education - Advice	- Review data - Advice	- Review data - Education - Advice
I find PatCIS useful	Definitely agree	Unsure	Unsure	Definitely agree	Agree
I am willing to enter my own data into my record using the WWW	Definitely agree	Agree	Unsure	Agree	Agree
I am willing to review my own health information using the WWW	Definitely agree	Agree	Agree	Definitely Agree	Agree
PatCIS has improved my interactions with health professionals	Definitely agree	Agree	Unsure	Definitely agree	Definitely agree
PatCIS has improved my understanding of health and illness	Definitely agree	Disagree	Agree	Definitely agree	Definitely agree
PatCIS has changed how my health care is managed	Definitely agree	Unsure	Disagree	Definitely agree	Definitely agree
Have you had problems in using PatCIS?	“Occasionally, it is very difficult to access, typically in evening”	None	None	“Sending e-mail from the site.”	None

Table 2. Overall Impression of PatCIS of four users after a nine month period.

User 1	User 2	User 3	User 4
“PatCIS makes it much easier to actively participate in my wife’s medical care by allowing me to closely monitor her lab results. It also allows me to more intelligently interact with her doctors.”	“I find it very good for my purposes. By and large I have no idea to improve it. However, I remain confused about getting it from a remote computer.”	“I feel as though I am in a very unique position, I know what my problem(s) are, and it’s just a matter of time. ”	“Overall program is excellent. Would be better if you could access it over Internet Explorer as that is what most people have. Could present a problem on old machines with limited memory.”

I. Tracking of System Use

Log Files of System Use

Log files capturing information about usage of system features have been automatically collected from all subjects’ interactions with the system under study. The information includes

a record of functions accessed by the user, buttons pressed, and time spent in each function. Previous evaluation of web-based clinical information systems (designed for use by physicians) has shown that for purposes of obtaining feedback for system improvement, such analysis of log files can provide a rich source of data, particularly in determining which functions of a system may or may not be getting accessed by end users [5]. Other forms of data collection (including interviews, as described below) were used to determine why or why not these functions may be receiving use.

Applications

PatCIS currently includes 15 clinical functions, some of which have been described elsewhere. In addition to the main functions, "infobuttons" have been added to link clinical data to on-line information resources [8]. 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.

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

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%) were due to 5 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. In an additional 33 log ons, subjects did not select any functions. The activities occurring in the remaining 466 sessions were studied. Table 3 provides a summary of the number of user accesses to each PatCIS function.

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).

The session duration ranged from less than one minute to 66 minutes (average: 5.7); 391 (83.9%) of the sessions were ten minutes or less, 58 (12.4%) of the sessions were eleven to twenty minutes in duration, with only 17 (3.6%) being longer than 20 minutes. During the sessions, subjects carried out a total of 2098 actions (shown in Table 3). 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 can be seen from Table 3, the most frequently used function was data review (accounting for 87% of all accesses to PatCIS. This consisted mostly of review of laboratory results. Patients also selected a variety of reports to obtain details, including radiology, cardiology, and pathology.

The data entry functions were used sparingly: vital signs were entered 34 times and diabetes information was entered 39 times. These data were also rarely reviewed.

Educational functions, which provide passive links to other Web sites were used 53 times. Advice functions, which use data taken from the patient's record as input to active guideline programs, were used 6 only times (Cholesterol 5 times and Mammography 1 time).

In summary, the features most used by patients were review of laboratory results and reports, while data entry, educational links and advice were used far less frequently.

Further details of the logging component of the evaluation can be found in reference [12].

Phone Interviews

Phone interviews were conducted with patients using PatCIS and with their physicians. The objective of the interviews was to obtain information about how useful subjects perceive PatCIS to be, what features they like or don't like and how they perceive their use of the system has affected their relationship with providers and decision making. In addition, interview probes were designed to help provide insight into why users displayed particular patterns of usage.

The results indicate that subjects, both the patients and physicians, felt that use of PatCIS made their interactions much more effective by improving the level of communication between patient and physician, as well as improving the patient's understanding of his/her condition. For example, one subject indicated that he closely followed his lab values at home (using PatCIS) and was able to discuss his condition at a more detailed level during doctor-patient interviews, helping him to better understand and manage his condition:

“You know I look for trends in my medical data and if I see something, there is a trend, I can contact the doctor to see what's going on, what we can do, change meds or whatever... Well, the advantages, the most important advantages is that you are kept abreast of your health conditions. Uh, and here is a matter of individuals, where you have to be realistic, and you say there is a problem is coming up and you are alert to it, and if you can't do anything about it, so be it. Nothing is really hidden from you. For example, I recently took some CAT scans and I am going into to surgery to remove one of my kidneys and I can review my report, you know what my report says.”

A second subject, who accessed the system predominantly to view his laboratory data on his wife's condition, described his use of PatCIS in the following way:

“Primarily I do it to check the labs, and then to correspond with her nephrologist as a result of that over the email. Occasionally if there is something I don't understand I click on the, you know there is a way I can link back to information, about particular drugs she is taking...Extremely useful, and I will tell you why. Prior to having access to that, most of my interaction with her physicians and her support staff was trying to get information, you know, how did she do today. Now I can get the information directly and the quality of the communication, I think the communication with her physician is much more efficient now, because we already what the labs are, and the conversation is what should we do, should we take more of this, less of that. Uh, do you want to see us, you know, that sort of thing. So it makes for much more efficient communication, we don't spend a lot of time trying to figure out what happened. Communication is more like OK, what do we do about it. So I find that saves time and I'm sure on the flip side of it they must like it too, for the same reasons”

When asked if use of PatCIS had affected decisions that were made, the response from this subject was the following:

“I wouldn't say it changes the nature of the decisions, because ultimately we are relying on professionals to tell us what to do. But number one I think it creates an environment where you get to decisions much more quickly. For instance if I get the information at 4 o'clock, she's a kidney transplant patient, if I see her creatinine jumped up significantly, I'm right in

touch, almost immediately with her physician. Uh, I sense that in another environment days may have gone by - we now get to it much more quickly. The second thing, we have access to more information, and all the information, not just selected items, we have a greater understanding of what's going on when the treatment is suggested to us, that is very helpful”

Regarding perceived changes in doctor-patient interaction, this subject went on to state that: “All the 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 actions, so to me its much more efficient than the old way”

This perception of the system as providing a mechanism for improving the patient’s awareness of day-to-day trends and thereby improving the level of communication during the limited time available during doctor-patient interviews was also mirrored by the comments of the physicians interviewed so far. For example, one physician when asked if he was aware of his patients using PatCIS stated the following: “Oh yes, all of the time, because they email me their concerns about labs... they do contact me all the time about labs”. This same physician also indicated that the level of questions asked by patients appeared to be raised since they had already had a chance to view their data before the doctor-patient interview.

When asked about the effects of use of PatCIS on patient understanding and changes in communication, both physicians indicated that use of the system could give patients more control of their condition and foster the level of communication. For example, one of the physicians interviewed stated the following:

“Well I think that it fosters communication, its another way of communicating. Right now most of the communication takes place during the a ten or fifteen minute visit and if I throw a lot of information at the patient about their condition or what I want them to do, or that sort of thing, its very hard for them to absorb all that, so I think it gives them a chance to go back and look at things again and a chance to read 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 I think.”

From the interviews it was clear that some of the subjects (both patients and physicians) were not aware of all the features made available to them using PatCIS. For example, from the interviews the subjects contacted so far were not aware of the advice-giving capabilities of PatCIS and one of the subjects was not aware that medical data could be entered into the system. Likewise one of the physicians indicated a desire to have access to PatCIS himself so that he could check out its features and actually view the screens his patients were referring to (based on the interview, this request is being carried out). In general it would appear that a standardized training session on use of the system would be desirable and that lack of knowledge of system capabilities may be the reason for the differential use of system functions, as described above in the section on analysis of logging data. Other areas for improvement which emerged from the interviews included identification of difficulties encountered by one subject in viewing graphs, where in some cases graphs requested were apparently not produced. In addition, one subject stated he considered difficulties using links to educational resources (i.e. the links did not lead to the desired sites). We are currently looking into these usability issues. Regarding possible negative impact of being able to access their data, the only comment made by one subject was that seeing their data might in some cases prove to be disconcerting particularly if a report or lab value was misinterpreted (i.e. leading to unnecessary concern). However, in the study to date, no subjects actually reported actually having experienced this.

Appendix F contains the probes used in the structured interviews with both patients and physicians, while **Appendix G** contains transcriptions of the actual interviews. The tables below (**tables 4-7**) provide both the probes used for conducting the interviews and a summary of answers to key questions during the interviews.

Table 4: Structured Probes Used for Interviews with Patient Users of PatCIS

Background Questions: I. when did you first login to PatCIS? II. How often have you been using PatCIS? III. Where do you use PatCIS from?
General Usage Questions: I. What do you use PatCIS for? II. Which features do you find most useful? Least useful? III. Have you had any problems in using PatCIS? IV. In general, how useful have you found PatCIS? V. Do you find the information you want? VI. How easy is PatCIS to learn? VII. Do you have any suggestions for improving PatCIS?
Questions regarding Effects on Health Care: 1. Do you feel that using PatCIS has changed the way you view health or illness? I. Has using PatCIS changed the way you make decisions? II. Has use of PatCIS changed your interaction with your health care provider? III. What do you think are the advantages of being able to access your health records? IV. Do you think there are any disadvantages? V. How does PatCIS fit into your daily activity? VI. What is your overall impression of PatCIS? VII. Do you have any suggestions for improving PatCIS?

Table 5: Structured Probes used for Interviews with Physicians

Background Questions: I. What do you know about PatCIS? II. How many patients of yours use PatCIS? III. Did the patients discuss their records with you?
Questions Regarding Effects of Use of PatCIS: I. Did your patient provide you with any feedback about use of PatCIS? II. Did you have any concerns about your patient using PatCIS? III. How do you think PatCIS could affect patients' understanding of health or illness? IV. Do you use a computerized patient record system?
Questions regarding Effects on Health Care: I. Has use of PatCIS affected any decisions you or your patient have made regarding the patient's health or health care? II. Has use of PatCIS changed in any way your interaction with your patient? III. What do you think are the advantages and disadvantages to you of having your patients access their own health information using PatCIS? What do you see as the potential role of information technologies for helping you care for and interact with patients?

Table 6: Summary of Interviews with Patients

Probe	Patient 1 (SK)	Patient 2(DK)	Patient 3 (GL)	Patient 4 (LV)	Patient 5 (PM)
Length of time using PatCIS	A year	Over a year	Several months	Several months	Over a year
Functions Used	- review of data (labs) - data entry (occasionally)	- review of data and trends - access to educational material (occasionally)	- review of data (labs)	- review of data (labs)	- review of data (labs)
Features found most useful	- graphing of results	timely presentation of labs graphs	- review of data	- review of data	- review of data
Usability problems	- graphs not displaying consistently	system initially slow problems accessing outside sources	- problem with accessing all reports	None reported	- problems with getting blood tests results presented in different ways
Understandable?	Yes	Yes	Yes	Yes	Yes
Usefulness?	“very useful for looking for trends in data”	“extremely useful”	“I think it is an excellent thing”	“I thought it was quite useful”	“Its very good for what I wish to do”
Ease of Learning?	Very easy	“Very simple for me”	“I picked it up fairly quickly”	“quite easy once I figured out the password process”	“fairly easy”
Changes to health care?	“improved, absolutely”	“can take a more active role than otherwise” “communication is less in way of getting information and more in discussing treatment options”	improved communication with physician about blood glucose levels - “if anything comes up can call your doctor right away”	- not significant (did not use frequently) – “I would think it is probably more useful for somebody who is monitoring a medical condition routinely”	- changed behavior because can get the blood test when its needed
Advantages	ability to keep abreast of health conditions helps you make decisions	access to information improved communication with physician	- can bring information to attention of physician	- gives ability to check data later (doctor’s visit too short and may forget)	- can get hold of whatever medical information needed
Disadvantages	- none	- information could potentially be anxiety provoking	- not having access to all reports available and updated	- not having access to all data wanted	- none
Overall Impressions	“excellent program”	“very positive”		“I am very impressed, clearly a step in the right direction”	“I think it is very good”
Suggestions for improvement?	Ability to see meds	- improved access to educational links	- greater access to all reports desired	- none	- none

Table 7: Summary of Interviews with Physicians

Probe	Physician 1 (JC)	Physician 2 (R)	Physician 3 AM)
Aware of patient using?	Rarely	Yes (5 patients), “all the time -- email me with concerns about their labs”	Yes
Did patient have problems using?	- initial problem accessing	- no	- no
Changes to health care?	- if patients follow their labs can get a better idea of how responding to therapy (can find out immediately) - fosters communication during doctor-patient interview - gives patient more ownership	- helped patients understand their illness - they are in control - increases level of efficiency - don't need to call patients, contact now through email regarding changes patients observe	- gives sense of control to patient - better patient understanding of illness
Do you use a CPR system?	Yes – WebCIS	Yes - WebCIS	Yes – WebCIS
Advantages?	-gives patients ownership and helps with compliance	- better patient understanding	- helps patients keep track about their condition so less dependent on doctor visits
Disadvantages?	- possibility for provoking anxiety or confusion with some patients	- none	- for some neurotic patients might lead to anxiety (potentially)

In summary, findings emerging from the interviews are the following:

- Both patients and physicians interviewed felt that use of PatCIS had improved the level and content of communication (both during actual doctor-patient interviews and using subsequent electronic communication (i.e. emailing)
- Patients indicated that review of their own data was a very useful function and allowed them to keep up-to-date on their condition and provide them with information about their condition which they could follow-up with their physician regarding interpretation and implications for treatment/therapy
- Low usage of certain PatCIS functions (as indicated in the section about on study of logging of use of system functions) may be due to lack of subject knowledge about PatCIS functionality, indicative of need for further training to subjects to introduce them to system features

- Subjects high usage of review functions (as discussed in the section above on results from automated logging) are consistent with the interview data which indicated that subjects found that access to review of their own data was a very useful capability
- Usability issues related to presentation of graphs and linkage to outside sites were raised and are being examined

I. Video-based Usability Testing

For a selected subset of subjects, cognitive usability testing methods we have developed were employed in the final phase of the evaluation. This involved asking subjects to interact with PatCIS to perform typical tasks (e.g. data entry or review, access of information). Subjects were asked to "think aloud" while doing so, and complete video recording were made remotely of computer screens as well as audio recording of their verbalizations. Using computer aided methods for video analysis we have developed, problems encountered by patients while they interact with the system are being identified (see [9] for methodological details).

DISCUSSION AND CONCLUSIONS

In designing our evaluation we adopted a multi-method approach in order to assess a variety of related questions (ranging from assessment of user expectations to analysis of specific interface problems). Methods, involving evaluation from a distance, have a number of distinct advantages, including the ease in creating and administering evaluation instruments via the web [10,11]. However, previous work in assessing use of systems by physicians and patients [3,9] has indicated that questionnaires alone may need to be supplemented by other techniques, such as interviews with patients (which can be conducted via telephone communication), and use of in-depth usability testing methods, with at least a few subjects. In this way, the limitations of any one method can be offset by the advantages of another. For example, questionnaires may tell us what users think they may be doing while interacting with a system, however automatically logged data of user interactions may provide more detail on what they actually do (which is often not the same [6]).

To date all interactions with the system have been logged, all baseline questionnaires collected as well as the emailed usability questionnaires. Phone interviews were also conducted with users as well as in-depth usability testing sessions carried out with a few of the patient subjects.

In summary, results to date indicate the following:

- Baseline data indicated that subjects (patients) using the system generally had a high level of education (post-secondary) and had been computer users for at least several years
- Log file data indicate that certain functions of the system were used more frequently, in particular, review of their own patient data. Other features, such as the educational links and advice function were used less often by patients
- Usability questionnaire data indicate that the system was usable and that information presented was perceived to be understandable by users. Need for improvement in system error messages and occasional problems with connectivity were cited by some subjects

- Phone interview data indicate that both patients and physicians felt that use of the system had improved the level of communication between patient and doctor. In particular, by allowing patients to view their own laboratory data, the discussion during the actual doctor-patient exchange was found to more efficiently focus on issues related to decisions regarding treatment and management.
- Low usage of certain PatCIS functions may be due to lack of subject knowledge about PatCIS advanced functionality, indicative of need for further training to more fully familiarize patients with system features.
- No adverse effects of use of the system were reported by either the participating patients or physicians.

In conclusion, it appears that the PatCIS architecture appears to be an appropriate framework for giving patients access to health information. It has been our experience that a multi-method approach to evaluation (including a number of data collection methods ranging from automated logging of user interactions to telephone interviews) has been useful in helping us to understand patterns of usage as well as subjects' perceptions regarding use of the system over time. Positive benefits of patient access include perceived improvements in doctor-patient communication, based on greater access to their own data. No apparent adverse effects of use of the system were reported during the duration of the study.

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APPENDIX A – Baseline Questions (Presented to Subjects on first login to PatCIS)

Welcome to PatCIS! Thank you for agreeing to participate. In order to better understand our users, we ask that you take a few moments to answer the following questions:

Recruitment/Background Questionnaire

A. Demographic Questions

1. Check off the category which indicates how old you are

0-19 years

20-39 years

40-64 years

65+ years

2. Check the box that indicates your sex

Male

Female

3. Which of the following choices best describes who you live with?

Alone

Family

Extended Family

Friends

Significant Other

4. Are you an employee of the Columbia-Presbyterian Health Center?

Yes

No

5. Check off the following that best describes the highest level of education you have achieved

Elementary School

High School

Technical School

College (Arts)

College (Science)

University Bachelor Degree (Arts)

University Bachelor Degree (Science)

Professional Degree (e.g. lawyer, doctor)

Postgraduate Arts Degree (MA or PhD)

Postgraduate Science Degree (MS or PhD)

6. Did you immigrate to the United States?

Yes

No

B. Computer Background Questions

7. How often do you use a computer?

Several times every day">Several times every day

Once a day

Several times a week

Once a month or less often

Never

8. When did you first started using computers?

In the past six months

In the past year

In the past last two year

More than two years ago

9. Check off all the computer systems which you currently use

IBM compatible

Macintosh

Mainframe computer

Other

10. Check off all the computer operating systems which you currently use

Windows

DOS

Macintosh

UNIX

Other

11. Do you have a computer at home that you use?

Yes

No

12. Check off all those types of computer programs which you use or have used

Word Processing

EMAIL

World Wide Web/Internet

File or Database Management Systems

Spreadsheets

Computer Games

Programming Languages

13. Check off how often you use the World Wide Web

Several times every day

Once a day

Several times a week

Once a month or less often

14. Do you have easy access to the World Wide Web?

Yes

No

15. Where do you access the World Wide Web from?

Home

Work

Other location

16. Have you ever used the World Wide Web to get information about health?

Yes

No

C. Health Related Questions

17. Check which health areas you would be interested in getting health information about

Diabetes

Lung Disease (including asthma)

Health/Disease Management

Cholesterol Management

Bone and Joint Diseases

Hypertension

Other

18. Check off all the sources that you have used to obtain information about health or illness

Talking to doctors

Talking to other health professional

Pamphlet

Books

World Wide Web

CD-ROM

Community Health Centers

19. How often do you visit your doctor?

Once or more each month

Every three months

Every six months

Once a year

Less often than once a year

20. How much time do you usually spend with your doctor per visit?

Less than 10 minutes

10-15 minutes

16-29 minutes

30-60 minutes

longer than 1 hour

21. Do you receive your health care at the Columbia-Presbyterian Health Center?

Yes

No

22. Is your doctor affiliated with the Columbia-Presbyterian Health Center?

Yes

No

Not sure

23. How often do you phone your doctor or other health professional with questions?

Once or more a week
Once or more a month
Every few months
Once a year
Never

24. Do you ever communicate with your doctor using a computer (e.g. by email)?
Yes
No

25. Check any of the following health professionals you see in addition to your primary doctor
Family doctor
Internist
Endocrinologist
Cardiologist
Pulmonologist
Gastroenterologist
Ophthalmologist
Gynecologist
Podiatrist
Nurse
Dietitian
Alternative health care providers (e.g. chiropractor or acupuncturist)
Other
None

D. Scales (on perceptions and willingness to participate)

Comment on the following statements:

27. Allowing patients to use the World Wide Web on a regular basis to enter and access their own health data, and receive advice will change how their health care is managed
Definitely agree
Agree
Unsure
Disagree
Definitely Disagree

28. Using computers and the World Wide Web will improve patients' interaction and communication with health care professionals
Definitely agree
Agree
Unsure
Disagree
Definitely Disagree

29. My current interaction and communication with my health care professionals is good
Definitely agree
Agree
Unsure
Disagree

Definitely Disagree

30. My doctor and health care professionals provide me with the best treatments and medications that are available

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

31. I feel comfortable using computers

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

32. I am a sophisticated computer user

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

33. I am willing to review my own health information using the World Wide Web

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

34. I am willing to receive and use health advice provided using the World Wide Web

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

35. I am willing to enter my own health data into my patient record using the World Wide Web

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

36. I am willing to use the World Wide Web to obtain educational information about health

Definitely agree

Agree

Unsure

Disagree

Definitely Disagree

E. General Comments

37. What do you think would be the advantages or disadvantages of using the World Wide Web to provide you with advice and information about your health and allow you to enter and review your health data ?

38. What kind of health information or help would you like to receive using the World Wide Web?

39. Is there anything else you would like to add regarding your health, general health issues or use of computers?

APPENDIX B – Summary of Responses to Key Questions on Baseline Questionnaire by Subjects

Question	S1 (battler)	S2 (sek9002)	S3 (kwp9001)	S4 (clg9003)	S5 (cag9007)	S6 (pam9011)	S7 (dgl9001)
Age (q1)	40-64	> 65	40-64			> 65	40-64
Sex (q2)	F	M		F		M	M
Education (q5)	Tech. school	B.S.	College-Arts	High School	B.A.	Post-grad Science degree	Post-grad Arts degree
Computer use (q7)	Every day	Every day	Every day	Every day	Every day		Every day
Years of computer use (q8)	> 2 years	> 2 years	> 2 years	> 2 years	> 2 years	> 2 years	> 2 years
Conditions interested in (q17)	Diabetes Cholesterol Hypertension	Diabetes Bone+Joint Hypertension	Hypertension Kidney transplant	Health/disease management esrd, transplant	Diabetes Hypertension	Health/Diseas e Management	Diabetes Health/ Disease Management
WWW will change health care (q27)	Agree	Definitely Agree	Definitely Agree	Agree	Agree	Agree	Disagree
WWW will improve communication (q28)	Agree	Definitely Agree	Definitely Agree	Definitely Agree	Definitely Agree	Definitely Agree	Agree
Expected advantages (q 37)	Access to information doctor may have forgotten to tell you	Keep informed of latest tech. And information will improve understanding	Would like to hear directly from doctor before take advice	Timely availability of test results Better knowledge of condition and changes	Improve access to doctors and response time Allow patient more control	Have health information available Able to get INR without bothering doctor's assistant	Great idea
Information wanted (q 38)	- Side effects of meds and interactions	- Best methods to control diabetes and testing sugars	- Updates in transplant management - access to records	- test results - general information	Had a kidney transplant and wants info on issues, meds	Info for my age e.g. prostate cancer	New research results and marketing

APPENDIX C – Data Collected from Baseline Questions for each user (note – answer numbers correspond to the questions given in APPENDIX A)

Baseline Questionnaire - User 1

----- Forwarded message -----
Date: Fri, 30 Apr 1999 19:43:07 GMT
From: Netscape http server - sen <http>
To: ciminoj

Userid: battler Date: Fri Apr 30 19:43:06 1999
Host: 156.111.223.120 Question# up to: 5
ANSW1 40-64
ANSW2 Female
ANSW3 Alone
ANSW4 Yes
ANSW5 Technical School
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 Mainframe computer
ANSW10 Windows
ANSW11 No
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 Computer Games
ANSW13 Several times a week
ANSW14 Yes
ANSW15 Work
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Cholesterol Management
ANSW17 Hypertension
ANSW18 Talking to doctors
ANSW18 World Wide Web
ANSW19 Once or more each month
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Every few months
ANSW24 No
ANSW25 Family doctor
ANSW25 Ophthalmologist
ANSW25 Gynecologist
ANSW25 Other
ANSW27 Agree
ANSW28 Definitely agree
ANSW29 Definitely agree
ANSW30 Definitely agree
ANSW31 Definitely agree
ANSW32 Definitely agree
ANSW33 Agree
ANSW34 Agree

ANSW35 Unsure

ANSW36 Agree

ANSW37 advantage:possible information your doctor may have forgotten to give you .

ANSW38 i'd like to know the side affects of medication i'm administered . how the medicines interact with other medication. allergies .

ANSW39 i can't think of anything at the moment .

--- end ---

Baseline Questionnaire - User 2

Subject #2!

----- Forwarded message -----

Date: Sat, 29 May 1999 02:48:33 GMT
From: Netscape http server - sen <http>
To: ciminoj

Userid: sek9002 Date: Sat May 29 02:48:31 1999

Host: ABD0E110.ipt.aol.com Question# up to: 5

ANSW1 >65

ANSW2 Male

ANSW3 Alone

ANSW4 No

ANSW5 BS

ANSW6 No

ANSW7 Several times every day

ANSW8 More than two years ago

ANSW9 IBM compatible

ANSW9 Other

ANSW10 Windows

ANSW11 Yes

ANSW12 Word Processing

ANSW12 EMAIL

ANSW12 World Wide Web/Internet

ANSW12 Spreadsheets

ANSW12 Programming Languages

ANSW13 Several times every day

ANSW14 Yes

ANSW15 Home

ANSW16 Yes

ANSW17 Diabetes

ANSW17 Bone and Joint Diseases

ANSW17 Hypertension

ANSW17.1 cardiology, nephritis, and organ transplant (kidney)

ANSW18 Talking to doctors

ANSW18 Books

ANSW18 World Wide Web

ANSW19 Once or more each month

ANSW20 Less than 10 minutes

ANSW21 Yes

ANSW22 Yes

ANSW23 Once or more a month

ANSW24 Yes

ANSW25 Internist

ANSW25 Cardiologist

ANSW27 Definitely agree

ANSW28 Definitely agree

ANSW29 Definitely agree

ANSW30 Definitely agree

ANSW31 Definitely agree

ANSW32 Agree

ANSW33 Unsure

ANSW34 Agree

ANSW35 Agree

ANSW36 Agree

ANSW37 Keep me informed of the latest technology. This information will enable me to best understand the treatment I am receiving to treat my medical problems.

ANSW38 Best methods to control my diabetes, and any new methods of testing blood sugar without using finger sticks

ANSW39 Main concern now is getting my software to be Y2K compliant.

--- end ---

Baseline Questionnaire - User 3

----- Forwarded message -----
Date: Thu, 3 Jun 1999 05:33:32 GMT
From: Netscape http server - sen <http>
To: ciminoj

Userid: kwp9001 Date: Thu Jun 3 05:33:30 1999
Host: 98CA895F.ipt.aol.com Question# up to: 5
ANSW1 40-64
ANSW3 Alone
ANSW4 No
ANSW5 CA
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW9 Macintosh
ANSW10 Windows
ANSW10 Macintosh
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 File or Database Management Systems
ANSW12 Spreadsheets
ANSW13 Once a day
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Hypertension
ANSW17.1 kidney transplant
ANSW18 Talking to doctors
ANSW18 Talking to other health professional
ANSW18 World Wide Web
ANSW18 Community Health Centers
ANSW19 Once or more each month
ANSW20 10-15 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Once or more a month
ANSW24 Yes
ANSW25 Ophthalmologist
ANSW27 Definitely agree
ANSW28 Definitely agree
ANSW29 Agree
ANSW30 Agree
ANSW31 Definitely agree
ANSW32 Definitely agree
ANSW33 Definitely agree
ANSW34 Unsure

ANSW35 Definitely agree

ANSW36 Definitely agree

ANSW37 for some reason, I would still like to hear directly from my doctor before I took any advice.

ANSW38 updates in transplant management, my own records

--- end ---

Baseline Questionnaire - User 4

----- Forwarded message -----
Date: Fri, 6 Aug 1999 17:20:23 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: clg9003 Date: Fri Aug 6 17:20:21 1999
Host: ABD539EF.ipt.aol.com Question# up to:
ANSW1 ANSW36
ANSW2 ANSW37
ANSW3 ANSW38
ANSW4 ANSW39
ANSW5 High School
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW10 DOS
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 File or Database Management Systems
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW13 Several times every day
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Health/Disease Management
ANSW17.1 esrd, transplant
ANSW18 Talking to doctors
ANSW18 Talking to other health professional
ANSW18 Pamphlet
ANSW18 Books
ANSW18 World Wide Web
ANSW18 CD-ROM
ANSW19 Once or more each month
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Once or more a month
ANSW24 Yes
ANSW25 Family doctor
ANSW25 Gynecologist
ANSW25 Nurse
ANSW25 Other
ANSW26 nephrologist
ANSW27 Agree
ANSW28 Definitely agree

ANSW29 Definitely agree
ANSW30 Definitely agree
ANSW31 Agree
ANSW32 Agree
ANSW33 Definitely agree
ANSW34 Definitely agree
ANSW35 Definitely agree
ANSW36 Definitely agree
ANSW37 timely availability of test results, amore thorough knowledge of
condition and changes
ANSW38 test results, general information
ANSW39 no
--- end ---

Baseline Questionnaire - User 5

----- Forwarded message -----
Date: Tue, 21 Sep 1999 22:04:19 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: cag9007 Date: Tue Sep 21 22:04:17 1999
Host: spider-tk05.proxy.aol.com Question# up to:
ANSW1 ANSW38
ANSW2 ANSW39
ANSW3 Family
ANSW4 No
ANSW5 BA
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 File or Database Management Systems
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW13 Several times every day
ANSW14 Yes
ANSW15 Home
ANSW15 Work
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Hypertension
ANSW17.1 kidney transplatation
ANSW18 Talking to doctors
ANSW18 Talking to other health professional
ANSW18 Pamphlet
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Once or more each month
ANSW20 16-29 minutes
ANSW21 No
ANSW22 No
ANSW23 Every few months
ANSW24 No
ANSW25 Gynecologist
ANSW25 Other
ANSW26 nephrologist
ANSW27 Agree
ANSW28 Definitely agree
ANSW29 Definitely agree

ANSW30 Definitely agree

ANSW31 Definitely agree

ANSW32 Definitely agree

ANSW33 Definitely agree

ANSW34 Definitely agree

ANSW35 Definitely agree

ANSW36 Definitely agree

ANSW37 I believe it would improve access to doctors, improve response time, be convenient for both the doctor and patient and allow the patient to have better control over their own body/health

ANSW38 I would like to receive new information on conditions I have, new medications both in the development stage and after approval. I would also like to see test results.

ANSW39 I had a very successful kidney transplant 2 months ago and consequently am very focused on issues, medications, etc. relating to that subject.

--- end ---

Baseline Questionnaire - User 6

----- Forwarded message -----
Date: Fri, 10 Dec 1999 14:54:06 -0500
From: Netscape http server - sen <http>
To: ciminoj

Userid: pam9011 Date: Fri Dec 10 14:54:04 1999
Host: vanryzin.cpmc.columbia.edu Question# up to:
ANSW1 >65
ANSW2 Male
ANSW3 Family
ANSW4 Yes
ANSW5 PSD
ANSW6 No
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW9 Macintosh
ANSW9 Mainframe computer
ANSW10 Windows
ANSW10 Macintosh
ANSW10 UNIX
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW13 Several times a week
ANSW14 Yes
ANSW15 Home
ANSW15 Work
ANSW16 Yes
ANSW17 Health/Disease Management
ANSW18 Talking to doctors
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Every three months
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Every few months
ANSW24 No
ANSW25 Cardiologist
ANSW27 Agree
ANSW28 Definitely agree
ANSW29 Agree
ANSW30 Agree
ANSW31 Agree
ANSW32 Unsure
ANSW33 Definitely agree
ANSW34 Definitely agree

ANSW35 Definitely agree

ANSW36 Definitely agree

ANSW37 I would have health information readily available. I would also be able to get my INR etc without bothering the physicians assistant.

ANSW38 Whatever, for my age. e.g. prostate cancer

ANSW39 No

--- end ---

Baseline Questionnaire - User 7

----- Forwarded message -----
Date: Tue, 1 Aug 2000 15:03:15 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: dgl9001 Date: Tue Aug 1 15:03:14 2000
Host: adsl-138-89-33-142.nnj.adsl.bellatlantic.net Question# up to:
ANSW1 40-64
ANSW2 Male
ANSW3 Alone
ANSW4 No
ANSW5 PAD
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 File or Database Management Systems
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Health/Disease Management
ANSW17 Hypertension
ANSW17.1 renal disease, transplant, immunosuppressives, etc.
ANSW18 Talking to doctors
ANSW18 Talking to other health professional
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Once or more each month
ANSW20 10-15 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Once or more a week
ANSW24 Yes
ANSW25 Other
ANSW26 Orthopedic surgeon, vitreo-retinal specialist, infectious disease,
orthopedic surgeon, nephrologist
ANSW27 Disagree
ANSW28 Agree
ANSW29 Definitely agree
ANSW30 Disagree
ANSW31 Agree

ANSW32 Agree
ANSW33 Definitely agree
ANSW34 Agree
ANSW35 Agree
ANSW36 Agree
ANSW37 great idea.
ANSW38 new research results, and marketing.
ANSW39 no.
--- end ---

Baseline Questionnaire - User 8

Date: Thu, 24 Aug 2000 07:45:35 -0400 (Eastern Daylight Time)
From: James Cimino <ciminoj@flux.cpmc.columbia.edu>
Subject: Forwarded mail....
X-X-Sender: ciminoj@flux.cpmc.columbia.edu
To: Andre Kushniruk <kushniruk@med.mcgill.ca>,
Vimla Patel <patel@hebb.psych.mcgill.ca>

A late addition to PatCIS...

----- Forwarded message -----

Date: Wed, 23 Aug 2000 16:33:15 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: ras9014 Date: Wed Aug 23 16:33:14 2000

Host: AC9C5409.ipt.aol.com Question# up to:

ANSW1 ANSW38
ANSW2 ANSW39
ANSW3 Family
ANSW4 No
ANSW5 CA
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW13 Several times a week
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Lung Disease (including asthma)
ANSW17 Health/Disease Management
ANSW17 Cholesterol Management
ANSW17 Hypertension
ANSW18 Talking to doctors
ANSW18 Talking to other health professional
ANSW18 Pamphlet
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Once or more each month
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Once or more a month

ANSW24 Yes

ANSW25 Cardiologist

ANSW25 Ophthalmologist

ANSW25 Alternative health care providers (e.g. chiropractor or acupuncturist)

ANSW27 Agree

ANSW28 Definitely agree

ANSW29 Definitely agree

ANSW30 Definitely agree

ANSW31 Definitely agree

ANSW32 Definitely agree

ANSW33 Definitely agree

ANSW34 Definitely agree

ANSW35 Definitely agree

ANSW36 Definitely agree

ANSW37 Advantages: I can see my test results immediately without having to wait for a phone call or without me having to call my doctor. I can keep better track of the information to chart how I'm doing. I don't know of any disadvantages.

ANSW38 If my test results are not good, I would like to receive information relating to how to improve them. If I am scheduled for some sort of treatment, I would like to know more about that treatment, side effects and how it is done, before I get there.

ANSW39 Being a heart/double lung transplant recipient, I want to be kept abreast of any changes or new advances in the medication that I must take now. I was taking propulcid and only found out from the newspaper that it was being recalled and taken off the market. I hope to find this information out way in advance of that.

Baseline Questionnaire - User 9

Userid: lav9002 Date: Fri Jul 7 15:10:39 2000
Host: vcb0500206344.cpmc.columbia.edu Question# up to:
ANSW1 40-64
ANSW2 Male
ANSW3 Family
ANSW4 Yes
ANSW5 PAD
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 File or Database Management Systems
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW13 Several times every day
ANSW14 Yes
ANSW15 Home
ANSW15 Work
ANSW16 Yes
ANSW17 Cholesterol Management
ANSW17 Hypertension
ANSW18 Talking to doctors
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Every three months
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Every few months
ANSW24 No
ANSW27 Definitely agree
ANSW28 Definitely agree
ANSW29 Definitely agree
ANSW30 Definitely agree
ANSW31 Definitely agree
ANSW32 Definitely agree
ANSW33 Definitely agree
ANSW34 Agree
ANSW35 Definitely agree
ANSW36 Agree
--- end ---

Baseline Questionnaire – User 10

----- Forwarded message -----

Date: Fri, 15 Sep 2000 08:35:21 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: DGL9001 Date: Fri Sep 15 08:35:21 2000
Host: adsl-138-89-37-82.nnj.adsl.bellatlantic.net Question# up to:
ANSW1 40-64
ANSW2 Male
ANSW3 Alone
ANSW4 No
ANSW5 PAD
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW13 Once a day
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Hypertension
--- end ---

Baseline Questionnaire – User 11

----- Forwarded message -----

Date: Tue, 10 Oct 2000 16:14:06 -0400
From: Netscape http server - sen <http>
To: ciminoj

Userid: SEK9002 Date: Tue Oct 10 16:14:04 2000
Host: dialup-63.210.222.5.NewYork1.Level3.net Question# up to:
ANSW1 >65
ANSW2 Male
ANSW3 Alone
ANSW4 No
ANSW5 BS
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 Spreadsheets
ANSW12 Computer Games
ANSW12 Programming Languages
ANSW13 Several times every day
ANSW14 Yes
ANSW15 Home
ANSW16 Yes
ANSW17 Diabetes
ANSW17 Hypertension
ANSW17.1 Kidney disease
ANSW18 Talking to doctors
ANSW18 World Wide Web
ANSW19 Every three months
ANSW20 Less than 10 minutes
ANSW21 Yes
ANSW22 Yes
ANSW23 Every few months
ANSW24 Yes
ANSW25 Internist
ANSW25 Cardiologist
ANSW27 Definitely agree
ANSW28 Definitely agree
ANSW29 Definitely agree
ANSW30 Definitely agree
ANSW31 Definitely agree
ANSW32 Agree
ANSW33 Definitely agree
ANSW34 Agree

ANSW35 Definitely agree

ANSW36 Definitely agree

ANSW37 Advantage is to gain assurance that I am receiving good treatment
for my
illness.

ANSW38 Clinical data, research work being done in various areas. and
information
on medications.

ANSW39 A record of my prescriptions

--- end ---

Baseline Questionnaire – User 12

----- Forwarded message -----

Date: Thu, 30 Nov 2000 15:20:29 -0600 (Central Standard Time)
From: James Cimino <ciminoj@flux.cpmc.columbia.edu>
To: Andre Kushniruk <andrek@pascal.math.yorku.ca>, Vimla Patel <patel@hebb.psych.mcgill.ca>
Subject: Forwarded mail....

A late enrollee...

----- Forwarded message -----

Date: Thu, 30 Nov 2000 00:16:01 -0500
From: Netscape http server - sen <http>
To: ciminoj

Userid: gwc9002 Date: Thu Nov 30 00:16:00 2000
Host: 24-164-135-218.nyc.rr.com Question# up to:
ANSW1 40-64
ANSW2 Male
ANSW3 Family
ANSW4 No
ANSW5 PD
ANSW6 No
ANSW7 Several times every day
ANSW8 More than two years ago
ANSW9 IBM compatible
ANSW10 Windows
ANSW11 Yes
ANSW12 Word Processing
ANSW12 EMAIL
ANSW12 World Wide Web/Internet
ANSW12 Spreadsheets
ANSW13 Several times every day
ANSW14 Yes
ANSW15 Home
ANSW15 Work
ANSW16 Yes
ANSW17 Health/Disease Management
ANSW18 Talking to doctors
ANSW18 Pamphlet
ANSW18 Books
ANSW18 World Wide Web
ANSW19 Every six months
ANSW20 16-29 minutes
ANSW21 Yes
ANSW22 Not sure
ANSW23 Every few months
ANSW24 Yes
ANSW25 Internist
ANSW25 Ophthalmologist

ANSW25 Other
ANSW26 persoanl trainer
ANSW27 Agree
ANSW28 Agree
ANSW29 Agree
ANSW30 Definitely agree
ANSW31 Definitely agree
ANSW32 Definitely agree
ANSW33 Definitely agree
ANSW34 Unsure
ANSW35 Definitely agree
ANSW36 Agree
ANSW37 Feeling I can get the information when I want to know it, rather
than wait to ask and be told.
ANSW38 Access to my test results
Alerts re drug interaction or side-effects

APPENDIX D – Usability Probes (emailed to subjects)

WE ARE CONDUCTING AN EVALUATION OF PATCIS AND WOULD APPRECIATE YOUR HELP

PLEASE FILL IN THE APPROPRIATE ANSWERS

1. How often do you use PatCIS?

- a. every day
- b. several times a week
- c. once a month or less
- d. less than once a month
- e. never

Answer:

2. For what purposes do you use PatCIS?

[enter as many as applicable]

- a. to see my own patient data
- b. to enter my own data
- c. for educational purposes
- d. to get specific medical advice
- e. other

Answer:

PLEASE COMMENT ON THE FOLLOWING STATEMENTS:

3. I find PatCIS useful.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

4. I am willing to ENTER my own health data into my patient record using the World Wide Web.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

5. I am willing to REVIEW my own health information using the World Wide Web.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

6. My doctor and other health care professionals provide me with the best treatments and medications that are available.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

7. Use of PatCIS has improved my interaction and communication with health care professionals.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

8. Use of PatCIS has improved my understanding of health and illness.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer:

9. Use of PatCIS has changed how my health care is managed.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree

e. definitely disagree

Answer:

10. Have you had problems in using PatCIS?

Answer (please describe any problems):

11. Is there any other information would you like made available to you that you cannot access through PatCIS? If so, what is it?

Answer:

12. In general, are you able to find information you want using PatCIS?

Answer:

PLEASE SELECT FROM THE FOLLOWING SCALES AND ENTER ANY COMMENTS YOU MAY HAVE

For any feature of PatCIS below which you have not used, please enter NA (Not Applicable)

13. Text on the computer screen

Hard to read		Easy to read
1	2 3 4	5 6 7

Answer:

Comments? :

14. Graphs and tables

Easy to understand		Hard to understand
1	2 3 4 5	6 7 NA

Answer:

Comments? :

15. Sequence of screens

Confusing Clear
1 2 3 4 5 6 7

Answer:

Comments? :

16. Are the help/information buttons useful?

Not at all Very useful
1 2 3 4 5 6 7 NA

Answer:

Comments? :

17. Use of medical terms throughout the system

Inconsistent Consistent
1 2 3 4 5 6 7

Answer:

Comments? :

18. Medical information provided

Confusing Clear
1 2 3 4 5 6 7

Answer:

Comments? :

19. Specific medical advice

Confusing Clear
1 2 3 4 5 6 7

Answer:

Comments? :

20. Error messages

Unhelpful Helpful
1 2 3 4 5 6 7

Answer:

Comments? :

21. Learning to use PatCIS is

Difficult Easy
1 2 3 4 5 6 7

Answer:

Comments? :

22. Can tasks be performed in a straight-forward manner?

Never Always
1 2 3 4 5 6 7

Answer:

Comments? :

23. Links to other sites:

Not useful Extremely useful
1 2 3 4 5 6 7

Answer:

Comments? :

24. System speed:

Too slow Fast enough
1 2 3 4 5 6 7

Answer:

Comments? :

25. How reliable is PatCIS?

Very unreliable Very reliable
1 2 3 4 5 6 7

Answer:

Comments? :

26. What is your overall impression of PatCIS and do you have any suggestions for improving it? :

APPENDIX E – User Responses to Usability Questionnaire (see Appendix D for the corresponding questions)

Usability Questionnaire – User 1 (D.G.)

----- Forwarded message -----

Date: Fri, 11 Feb 2000 20:08:41 EST

From: Plectical@aol.com

To: ciminoj@flux.cpmc.columbia.edu

Subject: Re: PatCIS Questionnaire

1. c

2. a, c

3. a

4. a

5. a

6. a

7. a

8. a

9. a

10. Occassionally,,, it is very difficult to access paticis,,,typically in early evening

11, no

12. yes

13 7

14. 1

15 4

16. 4

17. 5

18. 5

19. n/a

20 4

21. 7

22. 6

23. 4

24 2

25. 7

Patcis makes it much easier to actively participate in my wife's medical care by allowing me to closely monitor her lab results. It also allows me to more intelligently interact with her doctors.

Usability Questionnaire - User 2

----- Forwarded message -----

Date: Mon, 14 Feb 2000 14:22:00 -0500 (EST)
From: Paul Meier <meier@neyman.stat.columbia.edu>
To: James Cimino <ciminoj@flux.cpmc.columbia.edu>
Cc: jjc7@columbia.edu
Subject: Re: PatCIS Questionnaire

>
> PatCIS USer Survey
>
> 1. How often do you use PatCIS?
>
> a. every day
> X> b. several times a week
> c. once a month or less
> d. less than once a month
> e. never
>
> Answer:
>
>
> 2. For what purposes do you use PatCIS?
> [enter as many as applicable]
>
> X a. to see my own patient data
> b. to enter my own data
> c. for educational purposes
> d. to get specific medical advice
> e. other
>
> Answer:
>
>
> PLEASE COMMENT ON THE FOLLOWING STATEMENTS:
>
> 3. I find PatCIS useful.
>
> a. definitely agree
> xb. agree
> c. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> 4. I am willing to ENTER my own health data into my patient record using the
> World Wide Web.
>

> a. definitely agree
> b. agree
> xc. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> 5. I am willing to REVIEW my own health information using the World Wide Web.
>
> a. definitely agree
>x b. agree
> c. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> 6. My doctor and other health care professionals provide me with the best treatments and medications that are available.
>
> a. definitely agree
>x b. agree
> c. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> 7. Use of PatCIS has improved my interaction and communication with health care professionals.
>
> a. definitely agree
>x b. agree
> c. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> 8. Use of PatCIS has improved my understanding of health and illness.
>
> a. definitely agree
> b. agree
> c. unsure
>x d. disagree
> e. definitely disagree
>

> Answer:
>
>
> 9. Use of PatCIS has changed how my health care is managed.
>
> a. definitely agree
> b. agree
> xc. unsure
> d. disagree
> e. definitely disagree
>
> Answer:
>
>
> *****
>
> 10. Have you had problems in using PatCIS?
>
> Answer (please describe any problems):
>
>
>
> 11. Is there any other information would you like made available to you that
you
>
> cannot access through PatCIS? If so, what is it?
>
> Answer:
>
>
> 12. In general, are you able to find information you want using PatCIS?
>
> Answer: yes
>
>
> *****
>
> PLEASE SELECT FROM THE FOLLOWING SCALES AND ENTER ANY COMMENTS YOU MAY HAVE
>
> For any feature of PatCIS below which you have not used, please enter NA
(Not
> Applicable)
>
>
> 13. Text on the computer screen
>
> Hard to read Easy to read
> 1 2 3 4 5 x 6 7
>
> Answer:
>
> Comments? :
>
>

> 14. Graphs and tables
>
> Easy to understand Hard to understand
> x1 2 3 4 5 6 7 NA
>
> Answer:
>
> Comments? :
>
>
> 15. Sequence of screens
>
> Confusing Clear
> 1 x 2 3 4 5 6 7
>
> Answer:
>
> Comments? :
>
>
> 16. Are the help/information buttons useful?
>
> Not at all Very useful
> 1 x2 3 4 5 6 7 NA
>
> Answer: I have not used them
>
> Comments? :
>
>
> 17. Use of medical terms throughout the system
>
> Inconsistent Consistent
> 1 2 3 4 5 6 x 7
>
> Answer:
>
> Comments? :
>
>
> 18. Medical information provided
>
> Confusing Clear
> 1 2 3 4 5 6 7
>
> Answer: Did not use it
>
> Comments? :
>
>
> 19. Specific medical advice
>
> Confusing Clear
> 1 2 3 4 5 6 7

>
> Answer:
>
> Comments? :
>
>
> 20. Error messages
>
> Unhelpful Helpful
> 1 x 2 3 4 5 6 7
>
> Answer:
>
> Comments? :
>
>
> 21. Learning to use PatCIS is
>
> Difficult Easy
> 1 2 x3 4 5 6 7
>
> Answer:
>
> Comments? : I get some confusion on my system (egI am
not able to print)

>
>
>
> 22. Can tasks be performed in a straight-forward manner?
>
> Never Always
> 1 2 3 4 5 x 6 7
>
> Answer:
>
> Comments? :
>
>
>
> 23. Links to other sites:
>
> Not useful Extremely useful
> 1 2 3 4 5 6 7
>
> Answer:I have not done this
>
> Comments? :
>
>
> 24. System speed:
>
> Too slow Fast enough
> 1 2 3 4 5 6 x 7

>
> Answer:
>
> Comments? :
>
> 25. How reliable is PatCIS?
>
> Very unreliable Very reliable
> 1 2 3 4 5 x6 7
>
> Answer: I wanted to get the blood test early and it brought up the
day that I had it one year ago, strange!!
>
> Comments? :
>
>
> 26. What is your overall impression of PatCIS and do you have any
suggestions
> for improving it? :
>
> I find it very good for my purposes. By and large I have no idea to
improve it. However, I remain confused about getting it from a remote
computer.
>

Usability Questionnaire - User 3

As you saw from my note to this patient, he never used the system. It seems that he answered the questionnaire as if *that* was the application...

-- Jim

----- Forwarded message -----

Date: Tue, 29 Feb 2000 02:51:43 EST

From: Uamuam@aol.com

To: ciminoj@flux.cpmc.columbia.edu

Subject: Re: PatCIS Questionnaire (2nd Request)

In a message dated 2/28/2000 5:20:12 PM Eastern Standard Time, ciminoj@flux.cpmc.columbia.edu writes:

PatCIS User Survey

1. How often do you use PatCIS?

- a. every day
- b. several times a week
- c. once a month or less
- d. less than once a month
- e. never

Answer: E

2. For what purposes do you use PatCIS?

[enter as many as applicable]

- a. to see my own patient data
- b. to enter my own data
- c. for educational purposes
- d. to get specific medical advice
- e. other

Answer: A, C, D

PLEASE COMMENT ON THE FOLLOWING STATEMENTS:

3. I find PatCIS useful.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree

e. definitely disagree

Answer : B

4. I am willing to ENTER my own health data into my patient record using the World Wide Web.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: C

5. I am willing to REVIEW my own health information using the World Wide Web.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: B

6. My doctor and other health care professionals provide me with the best treatments and medications that are available.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: B

7. Use of PatCIS has improved my interaction and communication with health care professionals.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: C: (IT WOULD IF IT WASN'T SO LATE IN THE GAME)

8. Use of PatCIS has improved my understanding of health and illness.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: B (MORE SO IF I HAD ACCESS TO IT EARLIER)

9. Use of PatCIS has changed how my health care is managed.

- a. definitely agree
- b. agree
- c. unsure
- d. disagree
- e. definitely disagree

Answer: D

10. Have you had problems in using PatCIS?

Answer (please describe any problems): YES, FOR SOME REASON IT'S EASIER NOW. REACHING YOU WAS A PROBLEM.

11. Is there any other information would you like made available to you that you

cannot access through PatCIS? If so, what is it?

Answer: YES, JUST HOW EARLY DOES PROSTATE CANCER HAS TO BE CAUGHT BEFORE IT CAN BE REMEDIED?

12. In general, are you able to find information you want using PatCIS?

Answer: I HAVE NOT BEEN TRYING BECAUSE OF THE COMPLICATION IN USING PATCIS.

PLEASE SELECT FROM THE FOLLOWING SCALES AND ENTER ANY COMMENTS YOU MAY HAVE

For any feature of PatCIS below which you have not used, please enter NA (Not Applicable)

13. Text on the computer screen

Hard to read Easy to read
1 2 3 4 5 6 7

Answer: 6

Comments? : NONE

14. Graphs and tables

Easy to understand Hard to understand
1 2 3 4 5 6 7 NA

Answer: THIS FIRST REAL CONTACT, NO GRAPHS, OR TABLES IN THIS COMMUNIQUE.

Comments? :

15. Sequence of screens

Confusing Clear
1 2 3 4 5 6 7

Answer: 7

Comments? :

16. Are the help/information buttons useful?

Not at all Very useful
1 2 3 4 5 6 7 NA

Answer: N/A

Comments? :

17. Use of medical terms throughout the system

Inconsistent Consistent
1 2 3 4 5 6 7

Answer: SO FAR, SO GOOD

Comments? :

18. Medical information provided

Confusing Clear
1 2 3 4 5 6 7

Answer: 7 (I'M READING YOU LOUD AND CLEAR)

Comments? :

19. Specific medical advice

Confusing					Clear		
1	2	3	4	5	6	7	

Answer: NONE

Comments? :

20. Error messages

Unhelpful					Helpful		
1	2	3	4	5	6	7	

Answer: NONE

Comments? :

21. Learning to use PatCIS is

Difficult					Easy		
1	2	3	4	5	6	7	

Answer: IT WAS DIFFICULT UNTIL NOW, (7)

Comments? :

22. Can tasks be performed in a straight-forward manner?

Never					Always		
1	2	3	4	5	6	7	

Answer: I DON'T UNDERSTAND QUESTION, WHAT TASK?

Comments? :

23. Links to other sites:

Not useful					Extremely useful		
1	2	3	4	5	6	7	

Answer: NO LINKS

Comments? :

24. System speed:

Too slow Fast enough

1 2 3 4 5 6 7

Answer: NOT ENOUGH TIME COMMUNICATING TO KNOW

Comments? :

25. How reliable is PatCIS?

Very unreliable Very reliable

1 2 3 4 5 6 7

Answer: IF I KNEW THE BEAST (PATCIS) BETTER, PERHAPS IT WOULD BE TAMER (MORE RELIABLE)

Comments? :

26. What is your overall impression of PatCIS and do you have any suggestions

for improving it? : I FEEL AS THOUGH I AM IN A VERY UNIQUE POSITION, I KNOW WHAT MY PROBLEM(S) ARE, AND IT'S JUST A MATTER OF TIME. NO. NO SUGGESTIONS

Usability Questionnaire - User 4

Our biggest user...

----- Forwarded message -----

Date: Tue, 29 Feb 2000 16:57:53 EST
From: SKa8825213@aol.com
To: ciminoj@flux.cpmc.columbia.edu
Subject: Re: PatCIS Questionnaire (2nd Request)

- 1 c
- 2 a,c
- 3 a
- 4 b
- 5 a
- 6 a
- 7 a
- 8 a
- 9 a
- 10 Sending e-mail from the site.
- 11 no
- 12 yes
- 13 7
- 14 1
- 15 7
- 16 6
- 17 7
- 18 7
- 19 7
- 20 6
- 21 7
- 22 Getting data table of one test over a period of time requires going back and forth 2X. Same with the graph.
- 23 7
- 24 6
- 25 7
- 26 Overall program is excellent. Would be better if you could access it over internet explorer as that is what most people have. Could present a problem with people who have old machines with limited memory.

Usability Questionnaire - User 5

>
> PatCIS USer Survey
>
>1. How often do you use PatCIS?
>
>c. once a month or less
>
>2. For what purposes do you use PatCIS?
>[enter as many as applicable]
>
>a. to see my own patient data
>c. for educational purposes
>d. to get specific medical advice
>
>3. I find PatCIS useful.
>
>b. agree
>
>4. I am willing to ENTER my own health data into my patient record using the
>World Wide Web.
>
>b. agree
>
>5. I am willing to REVIEW my own health information using the World Wide Web.
>
>b. agree
>
>6. My doctor and other health care professionals provide me with the best
>treatments and medications that are available.
>
>a. definitely agree
>
>7. Use of PatCIS has improved my interaction and communication with health
>care
>professionals.
>
>a. definitely agree
>
>8. Use of PatCIS has improved my understanding of health and illness.
>
>a. definitely agree
>
>9. Use of PatCIS has changed how my health care is managed.
>
>a. definitely agree
>
>*****
>
>10. Have you had problems in using PatCIS?
>
>Answer (please describe any problems):
>

>NO
>
>
>11. Is there any other information would you like made available to you that
you
>cannot access through PatCIS? If so, what is it?
>
>Answer:
>
>No
>
>12. In general, are you able to find information you want using PatCIS?
>
>Answer:
>
>Yes
>
>*****
>
>PLEASE SELECT FROM THE FOLLOWING SCALES AND ENTER ANY COMMENTS YOU MAY HAVE
>
>For any feature of PatCIS below which you have not used, please enter NA (Not
>Applicable)
>
>
>13. Text on the computer screen
>
>Answer: 5
>
>Comments? : Pretty easy to read
>
>
>14. Graphs and tables
>
>Answer: 5
>
>Comments? : Easy
>
>
>15. Sequence of screens
>
>Answer: 7
>
>
>16. Are the help/information buttons useful?
>
>Answer: 7
>
>
>17. Use of medical terms throughout the system
>
>Answer: 7
>
>
>18. Medical information provided
>
>Answer: 7

>
>19. Specific medical advice
>
>Answer: 7
>
>20. Error messages
>
>Answer: 7
>
>21. Learning to use PatCIS is
>
>Answer: 6
>
>22. Can tasks be performed in a straight-forward manner?
>
>Answer: 7
>
>23. Links to other sites:
>
>Answer: NA
>
>24. System speed:
>
>Answer: 7
>
>25. How reliable is PatCIS?
>
>Answer: 7
>
>26. What is your overall impression of PatCIS and do you have any suggestions
>for improving it? :
>
>Excellent
>
>

APPENDIX F - Probes for Interviews with Patients and Physicians

Probes for Interviews with Patients:

I. Background

We are conducting an interview to assess your experience in using PatCIS, in order to improve the design of the system. Are you willing to participate?

- When did you first login to PatCIS?
- How often have you been using PatCIS since then?
- Where do you use PatCIS from (at home? when?)

II. General Usage

- What do you use PatCIS for? Why?
- Which features do you find most useful? Least useful? Why?
- Which features have you not tried and why? (could go through list of features and ask about each one - data entry, data review, education, obtain specific advice -- this way could see if didn't use was there a reason, e.g. not aware of feature)

III. Usability

- Have you had any problems in using PatCIS? e.g. in accessing information, finding what you want, **understanding** information presented etc. (if so describe)
- In general how useful have you found PatCIS?
- Is there information you like made available to you that you cannot access through PatCIS? If so, what is it?
- Do you find the information you want?
- How reliable do you find PatCIS? (also speed)
- How easy do you find PatCIS to learn?
- Do you have suggestions for improving PatCIS (e.g. function, user interface)?

IV. Effects on Health Care Interaction, Behaviours and Decision Making

- Do you feel that using PatCIS has changed the way you view health or illness, or any of your behaviours related to your health? (explain)
- Has using PatCIS changed the way you make decisions? If yes, how has it changed? (examples?)
- Has use of PatCIS changed in any way your interaction with your health care providers? (e.g. doctor, nurses etc.)
- What do you think are the advantages to you of being able to see and access your own health information using PatCIS? what are disadvantages?
- How does use of PatCIS fit into your daily activity?

V. Wrap-up

- What is your overall impression of PatCIS and do you have any suggestions for improving it?
- Are you willing to come in to the hospital and have your use of PatCIS observed?

Probes for Interviews with Physicians:

We are conducting a short interview to improve the design of PatCIS. We would really appreciate your feedback.

Are you willing to participate?

- What do you know about PatCIS (the Web-based patient clinical information system that one of your patients is using) (do you feel the explanation given to you was adequate – how much time?)
- Were you aware of your patient using PatCIS (i.e. did they discuss their use of the system)?
- Did the patient discuss his/her records with you?
- Did the patient understand his/her record?
- Did PatCIS help your patient understand his/her illness?
- Did the patient use the system to enter their own data? was this useful to you?
- Did your patient provide you with any feedback about use of PatCIS OR report any problems in interacting with PatCIS?
E.g. in understanding information presented by the system? (if so what were the problems)
- Did you have any concerns about your patient using PatCIS? (for (a) viewing their data, (b) entering data (c) for educational purposes (d) for obtaining advice on their condition (cycle through each one and probe)
- How do you think PatCIS could affect patients' understanding of the health and illness?
- Do you use a computerized patient record system? (e.g. WebCIS) What other computer systems do you use?

II. Effects on Health Care Interaction, Behaviours and Decision Making

- Has use of PatCIS affected any decisions you or your patient have made regarding the patient's health or health care?
- Has use of PatCIS changed in any way your interaction with your patient?
- What do you think are the advantages and disadvantages to you of having your patient be able to see and access their own health information using PatCIS?

III. Wrap-up

- What is your perception (impression) of use of these kinds of technologies by patients? What do you think about them?
- What do you see as the potential role of information technologies, such as computerized records) for helping you care for and interact with patients?

APPENDIX G – Transcripts of Interviews with Patients and Physicians

Subject – Patient SK

E - How long have you used PatCIS?

I think its been about, I think its been a good, almost a year?

E - And how often do you typically use PatCIS?

About once a month

E - And where is that from, your home?

Usually from my home, and its to check my, I do my bloods once a month, so just check the results, and if there is a problem I just call back the doctor

E - So to review your data, the information

Right

E - And what features do you find most useful?

I like the graphing function, when it works. Right now its not working

E - What happens when it doesn't work?

I get just a straight line

E - So sometimes it just shows a straight line, it doesn't show your values?

Right. But when it works, that's a great feature. Its shows how things are progressing for that particular test and uhm, also I go to several of the sites to review, medical problems, you know with health and stuff like that

E - Like the educational sites that are linked to it?

Yes

E - I see, OK,

I think one area that should be in there would be your medications, uh, what meds you are on, and the dose and how often you take it

E - That's not currently there?

Right

E - So its sounds like you use it for data review and educational purposes

Right

E - Do you do any, it has a data entry feature?

On occasion

E - To enter

Blood sugars, blood pressure, temperature

E - You mentioned one problem in looking at graphs, have you had any other problems in using PatCIS, accessing the information you want, or understanding the information presented?

None at all

E - So its pretty understandable

Oh yeah.

E - In general how useful have you found PatCIS?

Very useful. You know I look for trends in my medical data and if I see something, there is a trend, I can contact the doctor to see what's going on, what can we do, change meds or whatever. The areas I'm very interested in is the creatnin levels and that's and indication of how well your kidney is doing, so if you see the creatnin level going up

E - Is there any other information you would like to see available, that you can't see now?

No

E - How easy did you find it learn how to use the system

Like a duck to water!

E - So it was pretty intuitive

E - I guess you mention you sometimes discuss information you get with your doctor, like when your values change

Right. But also I use several doctors. In other words I have a nephrologist, I have a surgeon, and we also email back and forth. If there is a different doctor associated with Columbia I can get online with them and they can access the file to check it out

E - Do you think using PatCIS has changed the way you view your health or anything related to health, or your interaction with your physician?

I think its improved, absolutely

E - In general, what do you think are advantages of seeing your own health information, and might there be any disadvantages?

Well, the advantages, the most important advantages is that you are kept abreast of your health conditions. Uh, and here is a matter of individuals, where you have to be realistic, and you say there is a problem is coming up and you are alert to it, and if you can't do anything about it, so be it. Nothing is really hidden from you. For example, I recently took some Catscans and I am going into to surgery to remove one of my kidneys and I can review my report, you know what my report says. Lets say, I can read medical books, therefore I can understand data, understand reports, understand what they mean.

E - I suppose if you didn't have that background it might be more difficult?

Yes

E - And has it changed in any way the way you make decisions?

It definitely helps to make decisions

E - What is your overall impression of the system and do you have any suggestions for improving it?

I think its an excellent program, and I like using it. The only improvement I could see is that if it gives you your medical info, your meds, what meds you on. And that would be a big improvement

Subject – Patient DG

E - When did you first log on to PatCIS?

It must have been, my wife was transplanted the first time in March 99. And it must have been with 60-90 days following the transplant her nephrologist made me aware of it and I signed on

E - How many times per month have you used it since then?

Well it depends what's going on with my wife's treatment. There have been times when I logged on to it on a daily basis to check on her labs, when things are quiet, I would say two or three times per month would be the minimum and sometimes, its several times daily when she's been hospitalized.

E - And where do you use it from, home?

Actually I use it from both home and my office

E - What do you generally use it for?

Primarily I do it to check the labs, and then to correspond with her nephrologist as a result of that over the email. Occasionally if there is something I don't understand I click on the, you know there is a way I can link back to information, about particular drugs she is taking, or what creatinin means

E - OK, the educational information, the info buttons

Exaclty, I was reaching for the word but couldn't find it

E - There is also links to other sites, do you use those?

Very rarely but I have. I also use it not only to look at her current data, but trends over time, it has some nice graphs

E - Which features do you find most useful, you mentioned graphs and charts

Yes

E - Any others in particular?

Primarily, I mean the primary purpose is real-time, I mean as close to real-time information that I can get on the labs. I guess the next would be looking at trends

E - There is a data entry function, have you ever used that?

No

E - Have you had any problems in using the system, say in accessing information, finding what you want, or understanding information that may be presented?

Lets see, a couple of things on that. The system was very slow and I had trouble getting in, but it seems like in the last four or five months I haven't had that issue, so whatever was wrong in that sense has been remedied. I noticed that sometimes when I click on a link to an educational resource, the link doesn't work. It happens more often than not.

E - Like an outside source

I think so. For instance on the labs the creatinin, I'm just using an example, so I click on to that and it doesn't go anywhere, and that happens a lot

E - Would that be the info buttons, the help?

Yes

E - In general how useful have you found PatCIS?

Extremely useful, and I will tell you why. Prior to having access to that, most of my interaction with her physicians and her support staff was trying to get information, you know, how did she do today. Now I can get the information directly and the quality of the communication, I think the communication with her physician is much more efficient now, because we already what the labs are, and the conversation is what should we do, should we take more of this, less of that. Uh, do you want to see us, you know, that sort of thing. So it makes for much more efficient communication, we don't spend a lot of time trying to figure out what happened. Communication is more like OK, what do we do about it. So I find that saves time and I'm sure on the flip side of it they must like it too, for the same reasons

E - Is there any information you would like to see made available to you that isn't there now?

Not that I can think of, because anything I've been interested in getting a look at I've been able to get a look at. I've also used it, I'm sorry I mentioned labs, the other thing I've looked for is radiology. I've spent a fair amount of time when she was having trouble with her kidney and having ultrasounds and biopsies looking at those results too, which is very helpful because it helps me to ask questions, that sort of thing.

E - How easy did you find PatCIS to learn?

Very simple for me, fairly easy program to work with, for sure

E - Do you have any suggestions for improving PatCIS, the user interface or its functionality.

The only thing I would suggest, is more ease of use on the educational links. It just seems to be extremely difficult to get at the educational material

E - Like you were giving the example of clicking on it and nothing appears?

Yes, exactly. That would be my major suggestion for improvement

E - How about when it appears, is it understandable or useful?

Sometimes it is. Put it this way, sometimes its too simple, othertimes its too technical

E - So its hard to the exact right level of explanation you want?

Exactly. It would be helpful if it would be designed for a semi-intelligent layman

E - Maybe if they had levels, like easy, medium or technical

I think its a great program. And quite frankly, when we see local doctors, it drives me crazy, because I've been spoiled by my quick access, it drives me crazy when I've got to wait for somebody to tell me something

E - Have you discussed information obtained with your doctor?

Absolutely

E - Do you feel PatCIS has changed how you or wife view health?

One thing I think, the tendency with most people is to take a passive role in their medical treatment. And I think the result in terms of our behaviour, particularly my own is that I take a much more active role than I otherwise, than I did previously. And I think that a lot of that simply has to do with being able to get understandable information, uh you know, the more you know the better off you are and I think that it has made us both much more actively involved in her treatment

E - OK, like has it changed the way you make decisions?

I wouldn't say it changes the nature of the decisions, because ultimately we are relying on professionals to tell us what to do. But number one I think it creates an environment where you get to decisions much more quickly. For instance if I get the information at 4 oclock, she's a kidney transplant patient, if I see her creatanine jumped up significantly, I'm right in touch, almost immediately with her physician. Uh, I sense that in another environment days may have gone by - we now get to it much more quickly. The second thing, we have access to more information, and all the information, not just selected items, we have a greater understanding of what's going on when the treatment is suggested to us, that is very helpful

E - Has it changed your interaction with your health care provider?

Absolutely, in a very positive way. As I said first of all the 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 actions, so to me that's much more efficient than the old way

E - In general, what do you think the advantages of being able to see your data, or disadvantages

I think the advantages I discussed, which is access to information, timely, more timely solutions, uh I think that disadvantage, which I haven't experienced, but I think information can be very scary if you don't understand what it is you are looking at and there is the potential of a patient receiving information that is not understood and reacting to it in way that is not productive, like panic or ignoring it or what have you. I think information can be scary if its not placed in the correct context, so that's a risk, although that is not a risk that we have experienced

E - What is your overall impression of the system and do you have any suggestions for improving it?

My overall impression is very positive and the only suggestion I have would be some work on the technical aspects of having these links functioning more effectively

E - That was the example you gave about educational material

Correct, but overall I think its a good system. At least it served my purpose very well

Subject - Dr. R.

E - What do you know about PatCIS?

A few patients of mine who are using it

E - Have you ever seen it?

I haven't actually seen it

E - OK, but you've been told about it

Yes

E - OK, so how many patients do you have that have been using it?

Five

E - Were you aware of your patients using PatCIS, did they ever discuss use of the system with you?

Oh, yes, all the time, because they email me with their concerns about labs

E - That was one of my other questions, did they provide you with any feedback about the use of the system, or report any problems in interacting with it?

No, I think for the most part they were very satisfied. They do contact me all the time about labs

E - OK, is it about the meaning or interpretation of the labs?

They are saying if the labs have gone up or down

E - Were they able to understand their record?

They were

E - So it was a higher level interpretation of an up or down

They know pretty much what to expect, they know the outliers

E - And that might trigger them phoning you?

Exactly, so they often check it before I do

E - So in general would you say PatCIS helped your patients understand their illness?

Oh, tremendously

E - OK, I guess not just understand, but it sounds like it also helped them with monitoring it?

Yes

E - Did the patients use the system to actually enter their own data?

No, Is there an option for that?

E - There is a data entry option, if you want to enter blood glucose you could do that. There are some other options, there is the educational help

I saw the screen for one of my patients, how do I access it myself?

E - That is a good question, I can check for you

Because I want to see what it looks like from their end

E - That might be interesting

Because glucose levels would be very helpful for me

E - OK, that was another question I had, were you told much about PatCIS in terms of what it could do?

All I was told was that its a vehicle for providing access to patients

E - They didn't go over the functions with you?

I'd love to know

E - That might be good to know. Some features might not be used so much if patients and doctors are not aware of them...

Especially blood pressures and glucose, that would definitely help us

E - I'll get back to the designers on that. Did you have any concerns about your patients using PatCIS and viewing their data?

No

E - Or for educational purposes, there is also some other function for obtaining advice

I wasn't aware of it

E - So you generally didn't have any concerns about patients using PatCIS

Its a great idea

E - In general how do you think PatCIS could affect patients' understanding of health and illness?

Well for one thing, they are sort of in control, once they know what is going on. I think there is two answers to this question. One is that there is a second level of, to make sure nothing goes wrong. If they miss, a single lab in one day, I'll make sure they'll do it. Secondly, they get a much better understanding.

E - Do the come back with different or better questions

Oh yeah, all the time

E - Do you use a computerized patient record system, like WebCI?

I use my own

E - So its like a computer patient record

Its like a database

E - OK, and what other computer systems to you use?

I use Medline, I use PDR, a database

E - Do you think use of PatCIS has affected any decision you or your patient have made regarding the patient's health or health care

Uhm, not directly. It probably wouldn't change anything I normally do. But I think it just increases the level of efficiency

E - Has PatCIS changed in any way your interactions with your patients?

Yes, tremendously. I mean its really easy, now I contact through email, never call these patients

E - In general what do you think are the advantages and disadvantages of having your patients see their own health information?

Well I think there are no disadvantages

E - Advantages?

It gives a better understanding to patients and its much more efficient

E - What do you see as the potential role of information technology, like computerized patient records?

I think its the way to go.

Subject – Dr. J.C.

E - What do you know about PatCIS?

Oh, actually I know quite a bit.

E - Was it one patient that was using the system?

I actually had two patients

E - Were you aware of your patients using PatCIS, did they ever discuss the system use with you?

Oh, no

E - Never?

Well one of them came to me later and told me he had not been using it because he had trouble getting access to the system. He didn't tell me about his use of it, so I guess that counts, he told me he had not been using it

E - So that was due to a problem accessing the system, was he accessing it from home?

He didn't have a computer

E - So it was logistical, he didn't have a computer. OK, so I had some other questions, one was did you think the patient understand his/her record but I guess the patient didn't discuss it

That one no, the other patient I actually asked the patient about it and she told me she found it useful for looking at her labs

E - OK, she was using it to look at her labs. Do you think it helped her at all in understanding about her illness from what she told you?

I couldn't say one way or the other

E - OK, it was just simply to look at her labs. And did she or the other patient use it all to enter their data?

Not as far as I know

E - Yeah, I assume that if they use it to enter data it would be used in conjunction with you the doctor

Yes

E - OK, so that answers those questions about did the patient provide you with any feedback or discuss any problems in interacting. As far as you are concerned did you have any concerns, about your patient using PatCIS for the four functions, say (a) reviewing the data, (b) for entering the data, (c) for educational purposes, or for (c) obtaining advice

No

E - No, not in any of those?

No

E - How do you think PatCIS could affect your patients' understanding of health and illness?

Well I think that if they were following their cholesterol or blood sugar they would get a better idea of how they are responding to therapy, if they were being treated for you know, high cholesterol or diabetes. Uh, I think that if somebody had a test like a mamogram they would get a result sooner than if they waited for me to see it. I think patients worry, as I would worry about, test results. For the answers they can find out immediately rather than waiting for me to call them or for them to call me.

E - OK, so I guess to keep them more informed about their condition

Yes

E - What about the other components, say the advice or the educational?

Well I guess there is a lot of potential for that. I don't know how much they would use it. If they don't use it I mean I don't think it would benefit them

E - I guess we will look at the logs. Do you use a computerized patient record system?

Yes, WebCIS

E - Do you think use of PatCIS has affected any decisions you or your patient may have made regarding their health or health care?

No

E - Because you don't know?

I think that they just used it - I mean one patient didn't use it and one patient used it only a small amount

E - Do you think its changed in any way your interaction with the patient?

No

E - In general what do you think are the advantages of having your patient being able to see and use their own health information using systems like PatCIS? Advantages or disadvantages?

Advantages of patients using it?

E - Yes

Well as I said you know, being able to follow their own results I think gives them more ownership of those results and helps them you know maybe think about sticking to diet or medication so they can see the results themselves

E - As far as any particular disadvantages

Well I think that people may get scared or confused by the results. Uhm, they might read a report, not understand it and be concerned. Or they might also read it and not be concerned about something they should be concerned about because they misunderstand it. They might read a report

that says that they have cancer, but if they don't see the word cancer they might think that oh they don't have cancer and then not follow up on the results, things like that. That hasn't happened but there is potential for that.

E - OK, the last question - what do you see as the potential role of information technologies such as computerized patient records for helping you care for an interact with your patients?

Well I think that it fosters communication, its another way of communicating. Right now most of the communication takes place during the a ten or fifteen minute visit and if I throw a lot of information at the patient about their condition or what I want them to do, or that sort of thing, its very hard for them to absorb all that, so I think it gives them a chance to go back and look at things again and a chance to read 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 I think.

E - I see, to provide them extra information that you couldn't possibly get to talk to in the short time of the interview?

Even if I give it to them, they won't retain. I mean if I tell the patient 20 things in 10 minutes, they are not going to remember it all, even though they seem to understand it. But you know, human memory just isn't capable. And I write it down for them but this is another way for them to go and reinforce it

E - To augment that knowledge. Thanks!

Subject – Patient LV

E- When did you first log on to PatCIS?

Probably some time in the spring.

E - How often do you use PatCIS? How many times per month would you say?

I would say less than one. I used it initially to get familiar with it, and see how it worked. And it worked fine, all the instructions on how to use it were very clear. But since I don't really have any chronic medical problems, You know I don't get any lab tests every month or any of that sort of thing, I really have had no need to go back and look at it again.

E - Where did you use PatCIS? Was it from your home?

No it was actually from my office, up at Presby.

E - When you did use PatCIS, what did you use it for?

Just to see what results were there, to see what clinical data was actually in the system.

E - What features do you find most useful? Was that the only features you used really?

That was really the only thing I did. I mean you know I had the standard radiology exam and I had had a standard bloodwork thing, that just the company to get an annual physical and I was curious to see what it looked like.

E - O.K., so you didn't check out any of the education sites.

No.

E - Did you have problems using PatCIS?

No not really

E - In general how useful would you say PatCIS was?

I thought it was quite useful, I think it is probably more useful to somebody who is monitoring a medical condition routinely, for somebody like me who didn't get the physical once a year, and that's about it.

E - Was there any information that you wanted made available that you couldn't access through PatCIS?

Well, I think things like physician notes would be helpful, but I realize that at this point it is unlikely since the physician notes are written down on a piece of paper in his office.

E - How easy did you find PatCIS to learn?

Oh, quite easy, once I figured out the password process, then it was fine.

E - Do you happen to have any suggestions for improving PatCIS?

Not specifically No. I think it does what it claims to do.

E - if I asked you if you thought PatCIS has changed the way you view health or illness.....

I don't think so. Not to significant.

E – Did it change at all the way you interact with your doctor? Did you discuss PATCIS at all?

I think we had one conversation about it, and that's it and since I don't e-mail my doctor back and forth we don't have that kind of communication. And there is really no need for him to communicate with me, other than when I predictably go and see him.

E –What would you think are the advantages to you having access to your own health information using PatCIS?

Well I think its...typically the problem when the doctor gives you information during the visit, if you don't write it down then you will probably forget what it was, and this gives you the ability to go in check it later. Which is very helpful.

E - Do you think there are any disadvantages to PatCIS?

Only that it doesn't have as much data in it that you would like.

E - What is your overall impression of PatCIS?

I am very impressed. I think its clearly a step in the right direction.

Subject – Patient PM

E - When did you first log on to PatCIS?

About a year or two ago.

E - How often do you use PatCIS? How often per month would you say?

Well I use it basically when I have my blood tests, so that's two times per month.

E - Do you use it from home or from a different location?

Either one but mainly from the university.

E - What do you use it PatCIS for?

Blood test results.

E - Do use any of the other features?

Well honestly no.

E - Why would you say you don't use them?

Well I am busy, I should look at it but I don't in truth.

E - Have you had any problems using PatCIS?

No lets see, well once in a while I have a problem with the people who put the notices but not with PatCIS, I find that I didn't get yesterdays reading, but I get it the blood tests two different ways, one way I get it and the other way I don't, but I don't think that's a matter of PatCIS, that's got do do with the blood tests machines themselves.

E - Is there any information you would like made available to you, that you cant access through PatCIS?

I really don't think so, its very good for what I wish to do, but other than that no I don't have any desires.

E - How easy did you find PatCIS to learn?

Fairly easy, its fine you know I can't memorize the code numbers but I have them in my book, and look them up.

E - Do you have any suggestions for improving PATCIS?

Well I am somewhat annoyed at the what do you call it, the machine that turns over every minute, but that's O.K.

E - Do you feel that using PatCIS has changed the way you view health or illness, or any of your behaviours?

Uh well it has changed my behaviour because I wanted to get the blood test when I needed it, and now I can. But that's the only way it has changed my behaviour.

E - Has it changed the way you make decision's at all?
No

E - Has the use of PatCIS changed in the way you interact with your doctor? Have you spoken to him about it?

He is satisfied with this arrangement, and no I don't think I talk to him about it.

E - What do you think are the advantages to you being able to access your health information using PatCIS?

Although I use it for only one process, because I don't have any other ailments, its very good. It's very good indeed that I can get a hold of whatever medical information I need and that's satisfied me quite well.

E - Do you think there are any disadvantages to using PatCIS?

I don't think so.

E - What is your overall impression of PatCIS, do you have any suggestions for improving it?

No, I think it's very good. I have no suggestions for improving it.

Subject – Dr. AM

E - What do you know about PatCIS?

Other than what do I remember, relatively little I mean whatever Jim had said to me I looked at initially but I...I have been inactively involved with his care so I didn't retain very much.

E - So you are aware of your patient using PatCIS, they discussed it with you?
Oh yeah

E-Did your patient discuss his records with you at all?

You mean after he saw something on PatCIS did he get back to me?

E-Right

No, because the management for the results that he is looking at really is being given by somebody from outside of the system.

E - So you are not sure if he understood his records after seeing them on PatCIS?

No, I don't know what his comprehension. I know that you have discussed issues what constitutes a good and bad result. So I know that he is aware of that but he is basically the conduit to bring these to another physician.

E - Do you know if PatCIS helped him understand his illness?

I think it gave him a sense of control over things because he was horribly frustrated by the process of waiting for paper results and being faxed and things like that, so in a sense it gave him a sense of control of what was going on, a better understanding well I think I can only guess I don't know for certain.

E - Do you know if he used the system to enter his own data?

I think he uses it passively but I can't say for certain.

E - Do you have any concerns about your patients using PatCIS? Reviewing data or entering data?

In particular or all of my patients in general?

E- All of them

I think there are some of my patients that it probably that I think a lot of my patients would benefit, but I think there are distinct patients that I can think of that would be, that are somewhat neurotic and this would probably feed into their neurosis and being able to check their results all the time. But for the vast majority it would be helpful and for a handful it would be problematic.

Do you think it's a good idea for them to obtain advice on their condition through PatCIS?

Maybe I don't understand.

E- Well sometimes they can put in questions via e-mail or just a search of some sort and it puts them to a website that answers some questions.

Oh I suspect but I don't know that Dr. M. is using that, but I have a number of patients I think that are sophisticated enough other university professors here that would be find that terrific, and would clearly come back to me with information that they found or concerned with. Yeah I think that would work well.

E - Do you use a computerized patient record system?

In my office for the outpatient records?

E- Yes like WebCIS

I use WebCIS all the time.

E - Do you use any other computer systems?

Obviously to check labs I use webcis all the time and its terrific. I don't have an outpatient medical record system where I do my notes although all my notes are done on a word processor, its not being done on a sophisticated system. I do others there is a couple of sites that I use one site has all of the ICD9 codes on it and you can put in a search word to put in the appropriate code. That is very helpful, but nothing for everyday patient record keeping.

E - Has the use of PatCIS affected any decisions you or your patient have made regarding the patients health or health care?

No, because I am not doing the management of his comadin it hasn't for me but I know but it probably has either hastened, I am sure on several occasions it has hastened his call to his doctor to get an adjusted medication dose.

E - Has the use of PatCIS changed in any way your interaction with your patients?

What do you think are the advantages or disadvantages to you of having your patients being able to see and access their own health information using Patcis?

Clearly there are disease entities that require the patient to modify their diet or their medication intake. Like diabetes or lipid disorders which I think this would be very valuable because I think they could keep track and wouldn't be highly dependent on doctor visits. I think they would be more inclined to keep track and recognize the affect of indiscretions or interactions that may have affected their level. So I think for those patients it would be terrific.

E - What do you see is the potential role for information technology such as computer patients records for helping you care and interact with your patients?

Well I think it's a terrific role and I wish our institution was forever long working on the outpatient side of things.

Thank you very much for your time.

Subject – Patient GL

E - When did you first log on to PatCIS?

Oh I don't remember, I remember I had trouble logging on I would have to go onto the internet to see my first letter to Mr. C., I had trouble getting access at first because there was a special log-on name and there was an access code that was necessary and he could only send me that by mail, so I had to wait for that in the mail. It's only the past couple of months I think.

E - How often do you use Patcis you think? How many times per month?

Well I was having trouble at first and I was in the hospital from August 3rd through August 25th. I used it while I was at the hospital. And a little bit prior to before I was in the hospital as well.

E - Do you use it from home as well?

Yes both in the hospital and at home.

E - What did you use PatCIS for?

To get my bloodwork, and to get my reports and to get my medical records. I didn't enter any of my own personal data you know since if anybody had wanted it they could always request it to me and since I generally e-mail my doctor with all the information back and forth I saw no reason to enter it twice.

E - What features did you find most useful?

Just the lab work, nothing else. There wasn't anything else available. I many times can I read the disclaimer.

There wasn't much of anything else on there.

E- There is education stuff.

The educational stuff that I logged on to look at was not of a technical need that I have. I have had diabetes my whole life so what do I need to know about the treatment of diabetes? I have hypertension and I know about ace inhibitors and beta blockers ext..and how they function and calcium channel blocker and how they function in me, so don't need to know about that. I need to know about the medication. The experimental medication that I am taking. The imuno supressors, you know like prograf and cellsat. These are the key information things that I need to know and that I thought I had access to.

E - Have you had any problems in using Patcis?

Nothing other then the problems I mentioned to you this morning.

E- Could you re-iterate a tiny bit?

Yes, there is a problem with printing out medical information you know so I either have to if it doesn't print out right away I have to copy it from the screen. The second thing I have problems with is I can no longer access the apnew reports and discharge summaries of my recent hospitalizations nor can I get some of the reports from some of the technical exams that I have recently had. Like I recently had a electromyogram and the results weren't on there. There is very little information I can get out of my EKG's or anything cause they are not on there either.

E - How easy do you find PatCIS to learn?

I think it's well except for the first bit, I think I picked it up fairly quickly. Play with the keys you know it tells you which reports you can get, and you just click on them and then they show up then you scroll down, and you are all set.

E - Do you have any suggestions for improving PatCIS?

Yes! You can get a patient information system. You know I mean I think its really a travesty with the program that you can't access anything other then your lab work. I mean that's not what I was led to believe that was the intent of the program.

E - Do you feel using PatCIS has changed the way you view your health or illness, or any of your behaviors related to health in any way?

No, I just wanted to see the lab work last week from the preoperative testing, before I went in and to get a quick look at it trying to print it out and it wouldn't print out, and there were a couple of abnormalities on the lab work but nobody even mentioned anything to me at the hospital. You know before the operation, so I was a little disappointed at that.

E - Have you discussed information obtained with your doctor?

Oh yes it's kind of funny. When I call my doctor up I said How come you didn't tell me my blood glucose levels were high, and he told me he didn't access what's it called Medcis first.

E - What do you think the advantages are to you being able to access your own health information using Patcis?

So I don't have to bother any of the staff doctors mainly, but otherwise I have to make the calls and it's a heck of a lot cheaper for me to be able to get this information over the internet, and it would also be a lot cheaper for me you know rather than waiting for the hospital to send me the copies to process the insurance claims, I have to slip to a tax to Queens right away. That way I don't have bother the patient doing losses because certification if I don't for the in patient stays. It's necessary and that also a lot of doctors order a lot of tests and I see the bills that come to me from the mail you know from the hospital, I would like to see who ordered them and when. I would like to see who matched them up. Because some of the tests I didn't even know about.

E - Do you think there are any disadvantages to using PatCIS?

Oh no, I think it is an excellent thing and if anything comes up that you are aware of you can call your doctor right away. You know like I am amino suppressed and I am a diabetic, so I don't have normal responses to infection. Other then my bloodwork, if I have an elevated white count. Or an elevated creatnine, I would know that something is the matter right away. And I could bring it to his attention if he hadn't seen it yet already. Its kind of crucial to any transplant patient or anybody with a chronic disease because they would know what the test results should be, whether you should have been instructed as such and they should be notified right away. I am not saying the transplant department is bad in any way, but there highly notification of people is not the best. For example if I have a progress test done on a Tuesday O.K. and they are supposed to notify me what the level is or what the increase for my pro graph and fk are the same thing. Whether I should take more or less they are supposed to notify me right away, why do I have to find out sometimes a week later, I couldn't access it on the patcis system. I mean its something that can improve medical care and its certainly a disadvantage not to have that information right away. I mean soon as the lab work hits the computer I should be able to have it. And the lab work hits the computer very quickly. Also I am being treated at home by a therapist and what not. The EMG

results would have been very useful for the visiting nurses to have right away to stick in their chart. And I still don't have them. And then you should excuse me because I think Doctor McMurphy is probably one of the most wonderful doctors at Columbia but his secretary Betty, she won't give anything out over the phone. So I have absolutely nothing as far as the mg is concerned. But I already had the carpal tunnel surgery so that's a done deal.

E - Your doctor is Mr. M.?

No my doctor M., no he was the doctor who I had seen over the emg and the MRI I got the MRI results right away because I needed before my next visit to Columbia. I got those right away. And I was able to bring them over to Dr. McMurtry the next day when I went to visit him. So off the day I had the EMG he had both the results right away and he was able to advise me the next day on what the problem was what I should do.

So the doctor that you sometimes talk about Patcis would be Dr. Radkkrishnan?

Rada was the female goddess and Krishnan was the male god in Indian mythology. They were husband and wife. He is a pretty smart guy, that is why as soon as Patcis came available he wanted me to get on it.

E - Well I think its definitely beneficial to educated people such as yourself that can pretty much access it very easily and not get too

Well why are they limiting my access without not telling me about it?

E. I am not sure.