PATIENT-CENTERED HEALTH RECORD

LINKED TO A REFERRAL SERVICE

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Abstract

Objective: To develop a personal health record (PHR) that can be used in a number of electronic health care services and to evaluate its application in referral management.

Design: A web-based PHR that can be used by patients when requesting referrals was developed. In addition to the information that is usually stored in a PHR (e.g., medical history, medications and allergies), patients can store a record of their consultations. The PHR also includes a messaging system that can be structured into the workflow of referral management as well as allowing more general communications. An evaluation study was conducted with 43 patients.

Results: Twenty-seven patients completed a survey in which 85% of respondents were satisfied with the usability and 96% were satisfied with the overall online referral process. Clinicians were satisfied with the content of subjects' PHR and referral problem descriptions and found the information detailed enough to triage all cases. Both patients and providers reported their communications were enhanced by the system and found the messaging system convenient to use.

Conclusion: The PHR is beneficial in health care applications other than the emergency and travel cases in which it was initially promoted. When used as part of the referral process, a system based on the PHR can enhance patient-provider communications.

Index Terms: personal health record, referral, patient-centered care, World Wide Web, Internet, medical record

I. INTRODUCTION

One of the biggest challenges for patients today is capturing all of their health information in one place so that it will be accessible to them and to the providers with whom they wish to consult. As individuals move, travel, switch health insurance carriers and get their care from different providers, their medical records are distributed across multiple sites where they have received care. These records are generally not exchanged and updated unless the sites are part of a network of providers that share common information systems [1,2,3]. Past medical records are an important input in clinical decision-making, and without the consolidation of all relevant medical information, there is a substantial risk of medical errors, delays in diagnosis, and inefficient treatment. The personal health record (PHR), a Web-based patient-owned electronic medical record (EMR), was created to consolidate all of a patient's medical information in a single accessible, yet secure, location.

PHR systems developed in the late 1990s were targeted for patients who were traveling and needed health care and also in emergencies where patients were unconscious and not able to provide their health information. Typical information in these PHRs included patients' medical histories, insurance information, allergies, immunizations, medications, and past surgeries. Prior studies evaluating PHRs have been based on criteria for provider-owned EMRs, comparing features and examining the user interface [4,5]. Common features in EMRs, such as using ICD (International Classification of Diseases) codes to precisely identify diseases, could not be implemented easily in PHRs, where patients are responsible for data entry. The reliability of patient-entered data has also been questioned [4]. For example, in emergency care, it is important to have reliable information in the PHR if the patient is unable to respond to questions. However,

prior studies have not examined the actual content of patient-entered information in the PHR or its clinical utility in practice.

Travel and emergency care were early target applications of the PHR because they involve patients seeking care from new providers. An application of the PHR that has not been addressed in the past and which is also easier to evaluate clinically is referral management. A referral is a request initiated either by patients' health care providers or by patients themselves to see a specialist for a problem that is not being managed adequately by their current provider. It is usually for a diagnosis, treatment, surgery, or second opinion of a problem. For example, consider primary care physicians treating patients with osteoarthritis. If the patients have severely damaged joints, they may be referred to an orthopaedic surgeon for evaluation about whether they are good candidates for surgery. When patients initiate a referral on their own, it is called a self-referral. Self-referrals include patients who bypass their primary care physician to seek specialty care or are recommended by their primary care physician to seek consultation from a specialist on their own. As patient education continues to improve, patients are becoming increasingly knowledgeable about their health conditions and available treatment options. More patients are taking the initiative in starting the referral process by asking their primary care providers to initiate referrals [6,7] or seeking specialists on their own [8,9].

In current practice, telephone calls are used to initiate referrals. The information shared consists of a brief problem description, contact information, and insurance. If the first specialist contacted cannot see the patient, the same information needs to be supplied again to another specialist. Patients often need to obtain a copy of all prior medical records to bring to the visit as well. In [10] and [11], electronic referral systems linked with provider-owned EMRs were developed to address these isssues and increase the efficiency of the referral process. Using the

patient-owned PHR in the referral process, however, can be more generic and beneficial. The PHR contains medical records not only from a single provider but also potentially from over the lifetime of the patient. The flexibility of this model allows both the patient and the provider to initiate referrals electronically and for patients to maintain a permanent record of their consultations.

We have developed a PHR that includes not only information common in prior PHRs, but also detailed descriptions of patients' acute or ongoing problems. Using the information in the PHR, patients can request self-referrals for their specific problems. The PHR is linked to a web-based referral management system by which patients' referral requests are received and consultations with an appropriate specialist can be managed. The PHR also consists of a secure electronic messaging system that facilitates the referral process between patients and their specialists. A study was conducted to evaluate the usability of our system and the clinical utility of the PHR for requesting and managing self-referrals.

II. METHODS

We have developed a PHR, called the Personal Health Information Management System (PHIMS). PHIMS was designed with the goal of consolidating patients' records from present and future health information data sources in mind. The connections shown on the right side of Figure 1 are enabled, where data can be transferred from existing clinical information systems (EMRs, laboratory information systems, and picture archiving and communications systems) as well as from patients' portable sensors, such as glucometers. Patient education resources, shown as multimedia digital library, can also be linked from PHIMS to help explain data (e.g., the meaning of laboratory test results). Patients can share their data with their clinicians in both structured and unstructured ways. For instance, patients can simply open up read-only or read-

write views of their records to their primary care physicians during an annual checkup. Patients can also include all or a subset of their records as part of a structured request to see a specialist (i.e., a referral). In order to test this expanded concept of a PHR, we have developed a referral system, called the Facilitated Accurate Referral Management System (FARMS) that interfaces with PHIMS. The referral system was customized for patients seeking consultations with surgeons at the University of Washington Department of Orthopaedics and Sports Medicine's clinics. In this section, we describe the application functionality, design, and evaluation procedure.

A. Functional Overview

PHIMS is a web-based repository that contains patients' medical information, such as their general information (e.g., date of birth, address, emergency contact), insurance, primary care physician's contact information, family health history, past surgeries, allergies, medications, laboratory tests, and social history (e.g., occupation, number of people in the household, alcohol and tobacco consumption). Figure 2 shows a web page where patients can record their allergy information. The menu along the left side of the screen is used to navigate to the various categories in PHIMS. Patients can also document their acute and/or ongoing medical problems in PHIMS, and they can use this information to request a referral. The problem documentation consists of a description of the problem, how and when it started, whether it is getting better or worse, and interventions that have been tried and their effects. Figure 3 shows one of the web pages used to collect patients' problem information.

Figure 4 outlines the use of PHIMS in the referral process. Patients first need to create a user account in PHIMS before they can store their medical information. Patients can fill out PHIMS in any order they choose and over as many sessions as needed. Once a problem has been

documented, patients can choose to submit a referral request. In our current implementation, the types of problems patients can enter are restricted to the area of orthopaedics. Before submitting the request, FARMS automatically checks PHIMS to see if patients have filled in all the information required for a referral. This information includes documentation of the problem, contact information for the patient, contact information for his or her primary care physician, and insurance information. If any of this required data is missing, FARMS prompts patients to return to PHIMS and provide the missing data. Once the referral request is submitted, FARMS directs the request to an appropriate patient care coordinator (PCC) based on the information in PHIMS. For instance, a patient suffering from a prior sports-related injury that has resulted in chronic rotator cuff pain would be directed to a PCC who handles shoulder referrals. A PCC reviews patients' referrals and triages the referrals according to the type of problem, severity, geography, and other attributes. The PCC can send messages using PHIMS to ask patients for additional information and to schedule an appointment with a specialist, or he/she can forward the referral request to another PCC. In our current implementation, the PCC can also notify patients that the clinic cannot help them with their condition, and they should seek alternative treatment (e.g., physical therapy). However, the eventual goal would be to eliminate the need to send this type of message by expanding the network of providers connected to our system.

When appointments are scheduled, PCCs can use PHIMS to send messages to patients with the appointment time as well as directions to the clinic, parking information, and housing information for patients traveling from outside of the area. FARMS semi-automates this process by generating part of the appointment message but allowing the PCC to append additional reminders. The patients' view of an appointment message is shown in Figure 5. Once an appointment is scheduled, specialists can review patients' information in PHIMS. The goal is to

have more time during the visit to discuss the problem that prompted the referral by eliminating the time spent asking patients for the information that is already in PHIMS.

B. System Design

The architecture of the combined PHIMS and FARMS systems, shown in Figure 6, is a web application running on the Microsoft .NET platform, Internet Information Server (IIS), Windows 2000 Server, and Microsoft SQL Server 2000 (Microsoft Corporation, Redmond, WA). The .NET platform was chosen for its security features, automatic memory management, and rich web application framework library, ASP.NET. Our application is divided into 3 layers, as shown in the application server portion of Figure 6: user interface, components, and operating system. The .NET Common Language Runtime (CLR) provides an object-oriented runtime environment and operating system services. In the components layer, PHIMSLib is the foundation on which FARMS consisting of the FARMSLib library and a user interface is built. PHIMSLib contains objects that manage user accounts, messaging, auditing, and PHR data.

Messaging is an essential function that is managed by PHIMSLib. Since messages may contain protected health information, they are stored in the database instead of being sent as regular SMTP-based Internet e-mail. Using this scheme, we can ensure all communications are encrypted by restricting connections to our server to 128-bit SSL connections, and we can maintain an audit trail of message accesses. The messaging system is linked with users' regular e-mail accounts via reminder messages that are sent when a user receives a new secure message. The reminder simply informs users they have a new message and asks them to log into the PHIMS website to read it. Applications can either use the messaging system as-is or build on top of the basic features. In the case of FARMS, the message template feature was customized to aid PCCs. For example, there is a standard message for new patients with directions to the clinic and

a standard message that suggests patients look into alternative treatments. All messages are kept as part of the PHR and can contain additional data to indicate that they are part of a health care service, such as a referral request.

Also located in the components layer of the system, the FARMSLib library manages the referral process. A referral can be in one of the following states: in the process of being created by a patient, waiting for action by a PCC, referred, or directed to alternative treatment. FARMSLib manages these states to ensure consistency in the database and uses PHIMSLib to message patients when their referral state changes. FARMSLib is also responsible for assigning referral requests to PCCs. In this study, there are a small number of PCCs, so the routing process simply looks at the part of the body the referral concerns to direct the request (e.g., hip and knee requests go to PCC *A*, and shoulder and elbow requests go to PCC *B*). FARMSLib abstracts the referral routing process so that only a single component, the referral router within FARMSLib, needs to be replaced to accommodate more PCCs and clinics in the future.

The user interface layer is based on ASP.NET, a platform for web applications hosted by the .NET CLR. The user interface is divided into role-specific pages (system administrator, patient, patient care coordinator, and specialist) and common pages (messaging and account maintenance). The patient pages are further subdivided into basic PHR and referral request pages so that the basic PHR pages can be independently reused in other applications (e.g., monitoring patients with chronic disease). All pages are secured using ASP.NET's resource authorization and authentication mechanisms.

The system meets all HIPAA technical security requirements. Auditing and data authentication are handled by PHIMSLib and FARMSLib objects. These objects are protected by user-based authorization while the ASP.NET pages are protected by role-based authorization.

Patients are authenticated by ASP.NET, and providers are authenticated by Pubcookie, a university-wide web-based authentication system at the University of Washington [12]. Providers can log in and be authenticated in PHIMS, FARMS, and MINDscape [13], the University's web-based medical records system. Pubcookie also supports SecurID (RSA, Inc., Bedford, MA) hardware tokens, and PHIMS and FARMS can be configured to require providers to log in with their SecurID in addition to their user name and password.

C. Clinical Deployment

The system was deployed for a period of 6 months, during which subjects were recruited by two methods. During the first month, patients who called the Bone and Joint Center for an appointment with a shoulder or elbow specialist were informed about the study and asked if they would like to participate. During the remaining period, links to our recruiting and informed consent materials were placed on the University of Washington Department of Orthopaedics and Sports Medicine's patient education website. The links were placed at the end of articles authored by the specialists in the study and on the general shoulder and elbow surgery information page. Usage of the system was tracked during the study period, and subjects were asked to respond to a questionnaire two weeks after they submitted a referral request. After the study period, a view of the data without personally identifiable information was analyzed.

III. RESULTS

Over the study period, 43 subjects completed referral requests using the PHIMS and FARMS systems. The reasons for referral were for diagnosis (10), treatment (14), surgery (13), and second opinion (6). Two patient care coordinators (PCCs) managed the requests for consultations with 3 specialists. Three subjects were recruited during the first month when they

called for an appointment, and the remaining 40 subjects were recruited via the patient education website.

A. Patient Characteristics

Subjects' ages ranged from 22 to 67 years with an average age of 45.12 years old. Compared to the shoulder clinic's referral patient population over the last 9 years, the subjects were 6.67 years younger (Table 1). Thirty subjects were male and 13 where female, which is comparable with the clinic population. Figure 7 shows the distribution of the subjects' state of residency. Seventeen subjects resided outside the state of Washington. Those from outside the state of Washington were mostly from the western United States, although there was also one subject from Canada and one from Germany. Compared to the clinic population, our study attracted more patients from outside the western United States.

B. System Usage

The time taken to complete a referral request ranged from 9 minutes to 8 weeks with the distribution shown in Figure 8. Thirty-five of the 43 requests were completed within one and a half hours, and 39 were completed within one day.

Using the secure messaging component of the system, PCCs sent 136 messages to subjects, and subjects sent 88 messages to PCCs. PCCs responded to 71% of their messages and referral requests within 1 day, and 94% within 1 week. Figure 9 shows the referral requests submitted and messages sent by subjects and PCCs over time. Where multiple events occurred during a single day, the events are separated vertically in the figure.

C. Survey Response and Comments

Figure 10 shows the results of the user satisfaction survey obtained from 27 subjects after they submitted a referral request and had the opportunity to communicate with PCCs. The average responses to the survey questions are shown in numerical form, where 1 corresponds to strongly agreeing with the statement and 6 corresponds to strongly disagreeing with the statement. Eighty-five percent of the subjects were satisfied with the usability of the system with responses that were at least somewhat agreeing with statements 1 to 4 about the user interface. Ninety-six percent of subjects were satisfied with the overall system.

Subjects were also invited to provide additional comments on the survey. As with the survey questions, the comments can be categorized as pertaining to the system itself or to subjects' interactions with the clinic (i.e., customer service) as shown in Table 2. Of the positive comments, subjects liked the convenience of being able to asynchronously message the clinic, being able to fill out their information online at their own pace, and the customer service in general. Many subjects felt that the use of technology enhanced the level of service. Criticisms were directed at technical problems with the web user interface and some general customer service issues faced by the clinic (e.g., patients dissatisfied about not getting an appointment). Other service issues were related to problems with integrating the information collected online with the normal referral process. For example, patients in the first month were mailed paper versions of the forms they already completed online. Later on in the study, the process ran more smoothly as office procedures were modified to accommodate the online patients.

IV. DISCUSSION

Surgery is a major intervention in the health of a patient and is performed when less invasive options have been exhausted. Surgeons need to be confident that surgery can benefit the patient,

and patients need to feel reassured that surgery is the best course of action. A complete medical history should be available to reduce the chance that something potentially health endangering may be overlooked. Within the confines of a 20-minute clinic visit, surgeons need to find out about the patient's health problem, find out relevant details of the patient's medical history, discuss the surgical procedure with the patient, and still allow the patient to ask questions. The UW Department of Orthopaedics and Sports Medicine patient education website in conjunction with PHIMS can address some of these tasks before the visit. Patients can learn about the surgery on the patient education website and the surgeon can learn all about a patient's health problems and medical history using PHIMS. Time is saved during the visit to discuss the important question of whether surgery is the best choice for the patient and if they are ready for surgery (e.g., are they willing to accept the risks of surgery, do they have realistic expectations for the results, do they have social support for post-surgical care and rehabilitation).

The effectiveness of the online patient education and PHR approach depends on several factors. Patients must be able and willing to establish a PHR over the Internet. To be able to use PHIMS, patients need to have some knowledge of computer usage and access to the Internet. Patients must also find PHIMS to be easy to use and convenient. Some patients may be averse to using technology to coordinate their health care. They may feel more comfortable speaking to their PCCs over the telephone and want a response from their PCCs immediately. The PHIMS and FARMS electronic systems need to fit into the workflow of the clinic so that PCCs will adopt the system. Finally, specialists need to find patient-entered information in the PHR useful in providing care for their patients. We have begun to investigate some of these issues in the present study. Overall, both patients and providers recognized the potential benefits of our system and welcomed the opportunity for enhanced communication and a higher quality visit.

A. Patient Acceptance

Forty-three patients enrolled in our study to use PHIMS to carry out their referral request. One of the specialists in our study had 25% of his referrals during the study period originate from our system. Without the research study and informed consent language attached to PHIMS, we expect a higher number of patients will use our system—there were 10 times more visitors to our study recruiting web page than patients who created a PHIMS account. These results indicate there are patients willing to use a PHR when they are given assurance that their PHR data will be useful to their health care provider. There is also evidence that PHIMS attracted a different set of patients than the usual clinic population. Compared to the clinic's referral patient population over the past 9 years, patients in our study were 6.67 years younger ($p=0.00918$). This population may be more actively using the Internet to seek health information, and many (66.6% of the study patients) may have a health insurance plan that allows them to freely choose a provider.

Once patients were in PHIMS, they were generally satisfied with the technical and human aspects of the referral process. Our patient survey results show that 96% of respondents were satisfied with their online referral experience. In terms of the technical aspects of our system, 85% of respondents were satisfied with its usability. Although some patients found the forms to be long, 17 of them spent the time to enter detailed information. Several patients also commented that they found the system convenient to use, and they felt they were able to provide a more complete health history than they would have been able to at their clinic visit.

B. Provider Acceptance

Both patients and providers found being able to communicate via the Internet desirable. As seen in Figure 9, usage of PHIMS and FARMS was regular while new referrals were in the system. The traffic pattern suggests patients and PCCs were comfortable using the system to

communicate with each other. An average of 5.2 messages were exchanged per patient. Since some patients were from outside the Pacific U.S. time zone, it may have been more convenient for them to use the messaging system than to call during business hours. All but 3 patients felt comfortable communicating with the PCC using the messaging system (question 7 in Figure 10) and found the response time acceptable (question 8 in Figure 10). One PCC felt that the messaging system addressed the problem of telephone tag, where each party cannot reach the other and both parties end up leaving a series of messages to return each other's call. Also contributing to PCCs' acceptance of the system was the workflow-oriented design of their interface, which allowed them to quickly prioritize patients and efficiently respond to each request.

Also on the provider side, specialists found PHIMS to be beneficial. One specialist reviewed all subjects' records in PHIMS and was satisfied with their completeness. Based on patients' documentation in PHIMS, there was sufficient information for triage in all cases. Normally, when new patients call the clinic to request an appointment, the PCCs extract information from them over the telephone and write down the important pieces. During the clinic visit, specialists continue the process of documenting patient information. Therefore, what is documented is a condensed and interpreted version of patients' words. While a specialist's written notes are important, they are his or her interpretation of a patient's problems and not what the patient says verbatim, hence some of the information and meaning are lost. For instance, some patients describe pain sensations very graphically. A condensed clinical description or pain rating scale would lose much of the information. Even though some patients in our study provided very detailed and lengthy entries, specialists felt it was important to have all the information rather than a condensed version. The lengthy descriptions could be skimmed quickly and read at a later

time if needed, such as after surgery when the specialist can reread the description and see the degree to which the patient's pre-surgical problems were resolved. It gives specialists a unique baseline assessment of patients' medical problems in their own words. Nowhere else is this type of information captured in as much detail for later comparison on the effectiveness of treatment.

C. Patient-Provider Communication

In our study, patients' PHIMS information was attached to the patient chart and read by the specialists before and/or during the visit. Two specialists commented that the availability of patient information in PHIMS before their appointment allowed them to spend more time talking with their patients about their concerns and also enabled them to probe more deeply into their conditions (e.g., 'I see you injured your shoulder in a fall; do you recall how you landed?'). Time is saved since the specialist can jump immediately to questions and clarifications instead of spending time to be briefed on the patient's history. One patient also commented that she perceived time was saved during the appointment due to her specialist having reviewed her data in the system beforehand. She was pleased to have more time to ask questions about her diagnosis and how to proceed. Hence, allowing patients to document their health in their own words can convey information that is useful in making treatment decisions and enhance communications between patients and providers.

D. Future Work

One of the goals of the PHR is to allow patients to share their records with providers of their choice. PHIMS allows patients to maintain a permanent record of their consultations that can be used for future clinical and hospital visits. One of the main barriers to this goal is agreeing upon and implementing universally recognized digital identifiers for patients and providers. In the

interim, patients in PHIMS can give access to their records to any provider affiliated with the University of Washington, which includes physicians in Washington, Wyoming, Alaska, Montana, and Idaho, who have user accounts in the University's systems. For other providers, patients can print out their records in PHIMS or alternatively, they can save their records as an XML file that can be e-mailed or stored in a portable device.

Even without the full implementation of universal identifiers, PHIMS has the potential to bring benefits to a range of health care applications. PHIMS and FARMS can be applied directly in settings other than orthopaedics to enable patients to request referrals and allow secure communications between patients and providers. However, it is also important to realize the potential long-term benefits of PHIMS when it is used after the consultation. For instance, PHIMS can be coupled with home biosensor instruments for home monitoring of chronic diseases, such as diabetes [14]. Another example is an extension of the surgery referral application. If the specialist recommends surgery, it will be useful to store the images and lab tests required for the surgery as well as the surgical notes after surgery in PHIMS. Follow-up after surgery can be carried out in part by home monitoring and this data can be added to PHIMS. For example, videos of shoulder range of motion after shoulder replacement surgery can keep a surgeon informed of his or her patient's progress between visits [15]. All of this information can be stored in PHIMS to give patients and the specialists of their choice a longitudinal view of their health.

To benefit fully from PHIMS, patients and providers need to be diligent in keeping the system updated. Surgery is often not the final stage in relieving a condition. Patients need to be followed up in rehabilitation. If the surgery was for arthritis, other joints will need to be monitored and notes on the effectiveness of the surgery will be useful if other joints need

replacement. Therefore, the need to update an ongoing condition in PHIMS is both necessary and recommended. It will be worthwhile to evaluate the long-term usage of the patient health record in the future.

V. Conclusion

We have used the personal health record in a common health care service that leverages the property that data in the personal health record are patient-entered. Results indicate that the system was well received by patients, clinic staff, and specialists. All parties involved found the system to be user friendly, convenient, and able to facilitate patient-provider communications. The system architecture was designed to be expandable to other settings and applications where it can enable higher quality care.

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TABLES

	Clinic Population†	Study Group‡	*z* test, *p-value*
Age (Mean (SD))	51.79 (16.79)	45.12 (12.12)	-2.605, 0.00918
Gender (No. (%) of subjects)			
Female	1296 (40.25)	13 (30.23)	1.34, 0.18
Male	1924 (59.75)	30 (69.77)	
Location (No. (%) of subjects)			
West	2691 (97.54)	38 (88.37)	0.004*
Other	68 (2.46)	5 (11.63)	

†*The age, gender, and location characteristics for the clinic population was based on data from 3258, 3220, and 2759 number of patients respectively.*
‡*The study group consists of 43 patients.*
**Normal approximation is not valid, therefore z-test is not used here. P-value is calculated based on exact binomial probabilities.*

Table 1. Comparison of patient demographic characteristics.

Topic	# of Comments
Convenience of messaging	3
Enhanced quality of service	8
Online forms preferred vs. paper forms	4
System-related service complaint	2
Other service complaint	3
Technical suggestions	4

Table 2. Patient survey comment topics.

FIGURES

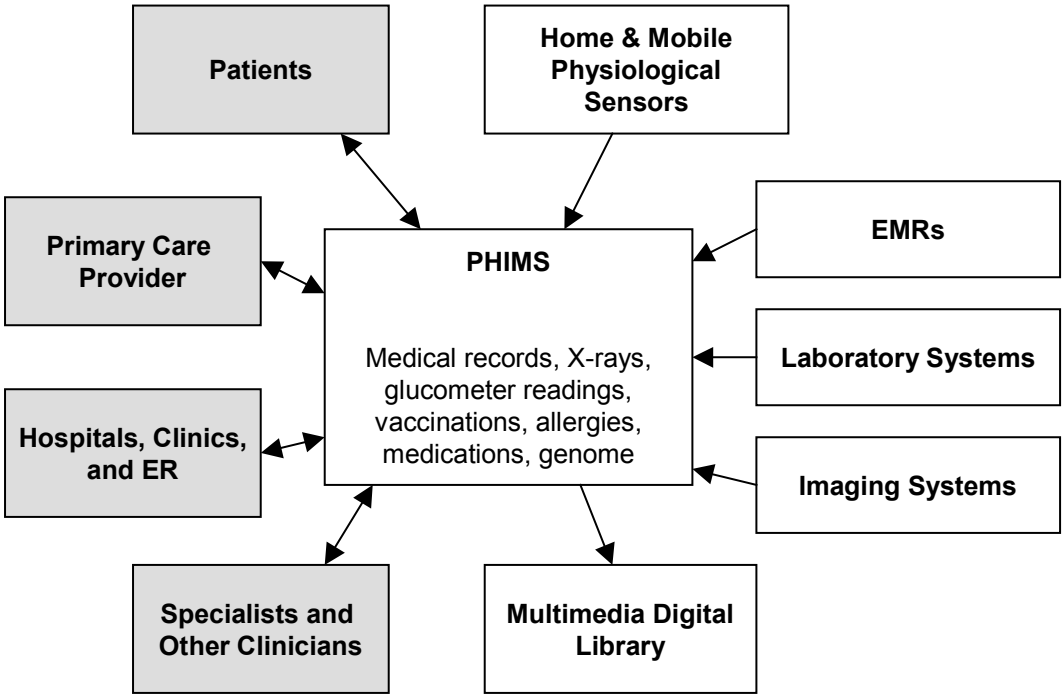

Figure 1. PHIMS connectivity.

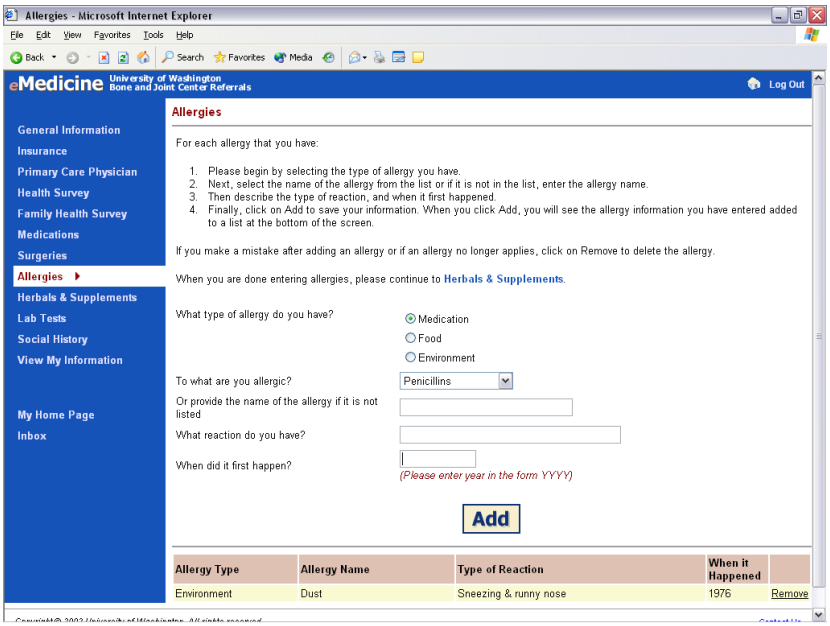

Figure 2. PHIMS allergies page.

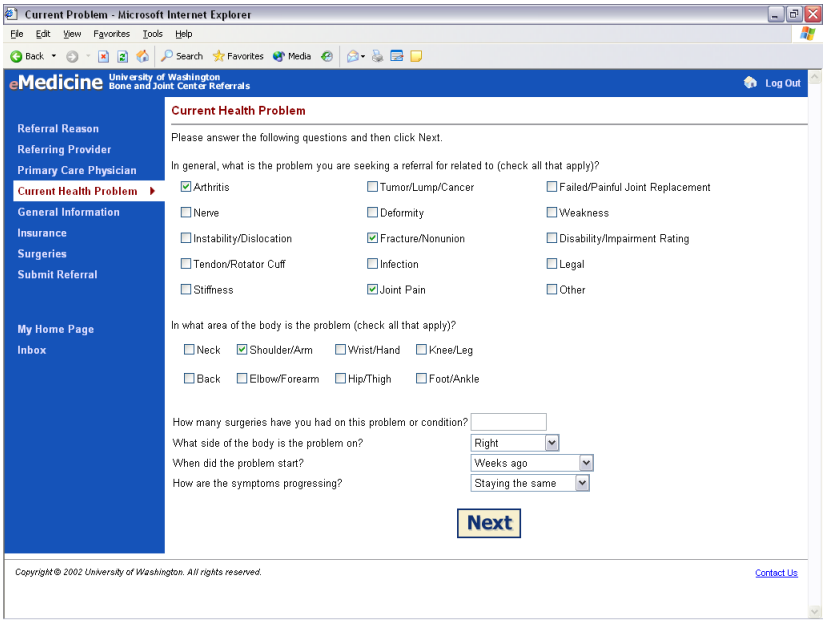

Figure 3. PHIMS health problem page.

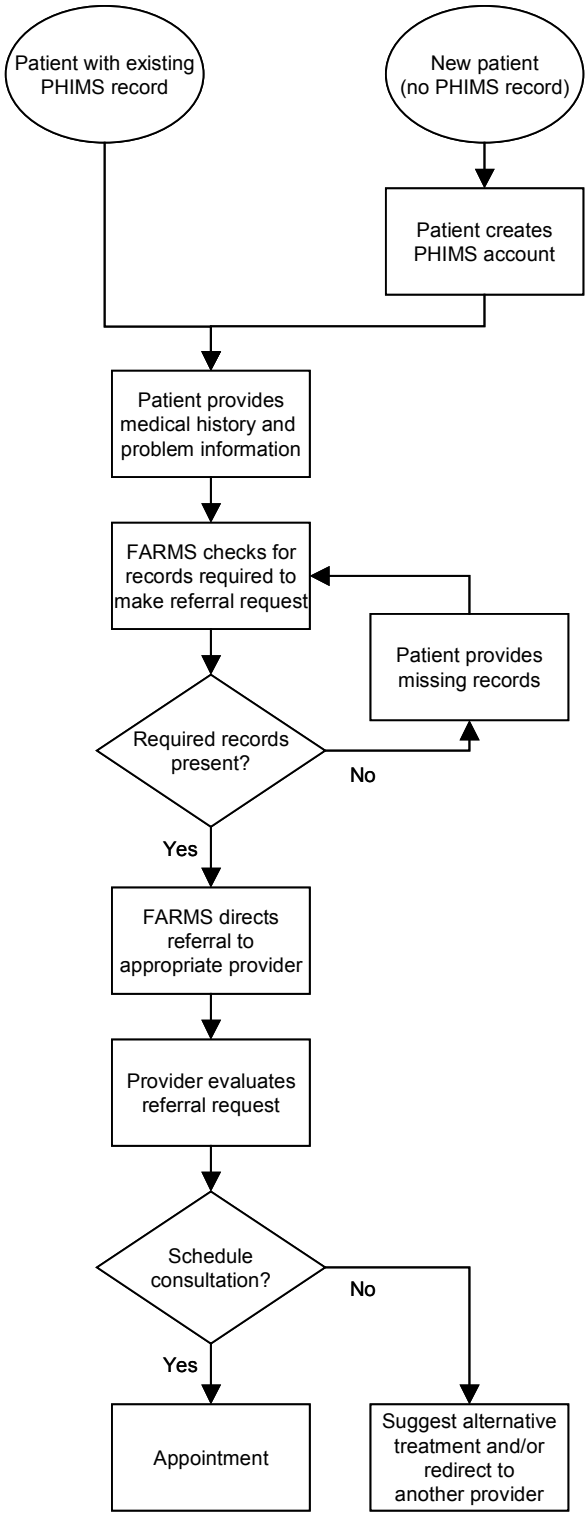

Figure 4. Use of PHIMS in the referral process.

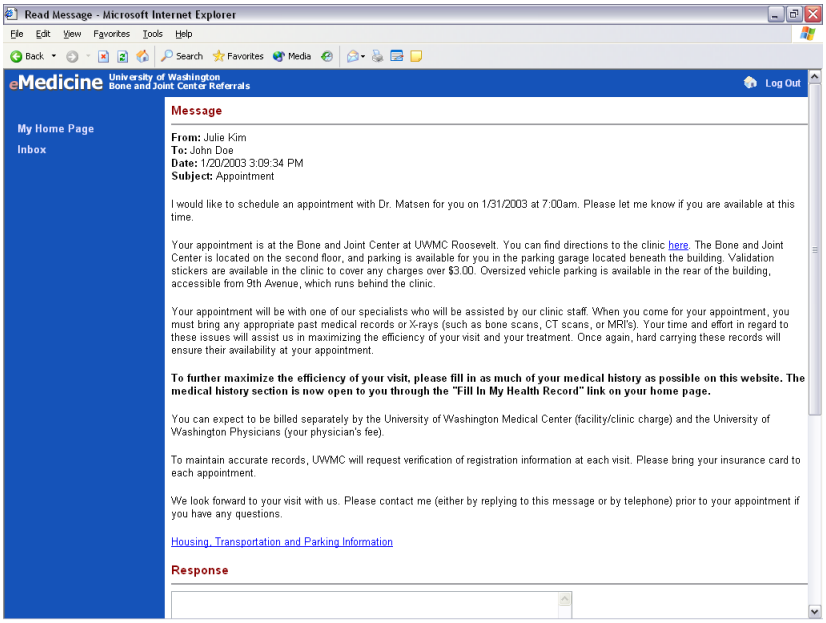

Figure 5. PHIMS message display.

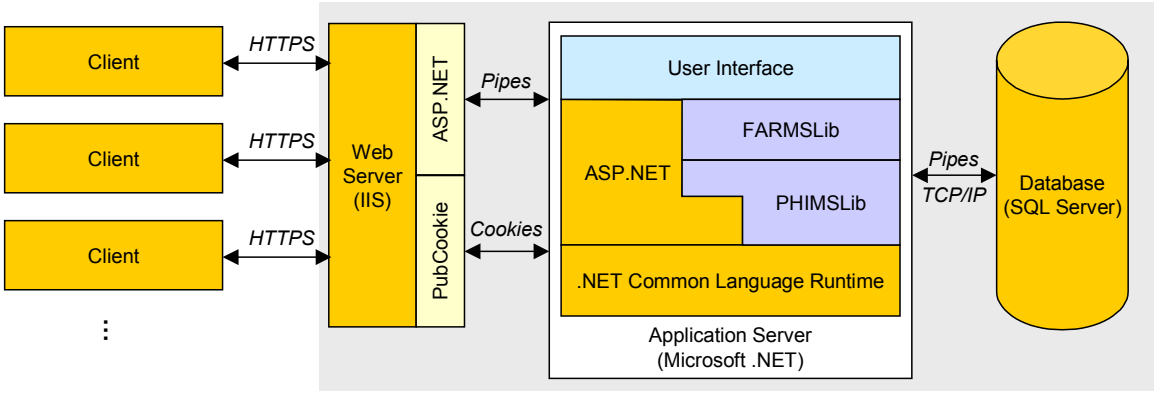

Figure 6. PHIMS and FARMS system architecture.

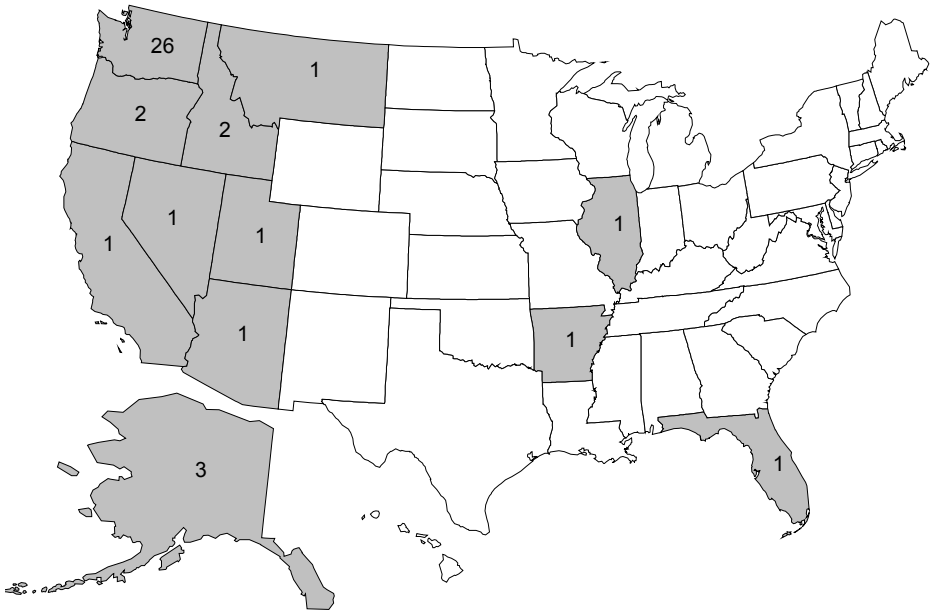

Figure 7. Subjects' state of residency.

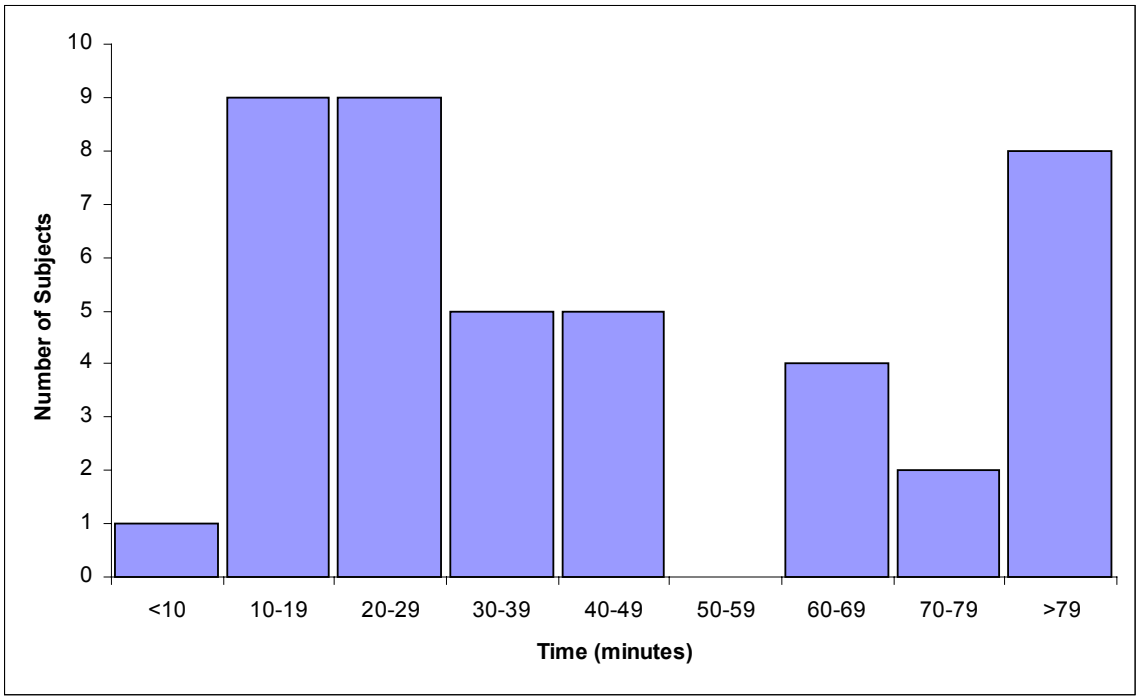

Figure 8. Referral completion time.

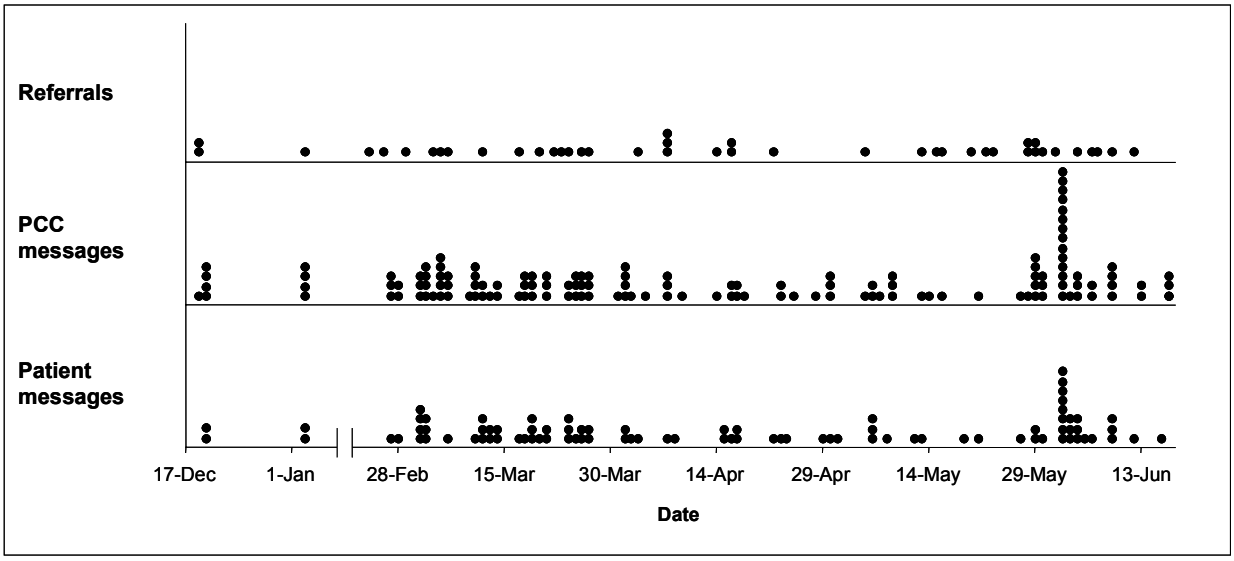

Figure 9. Referrals completed and messages sent.

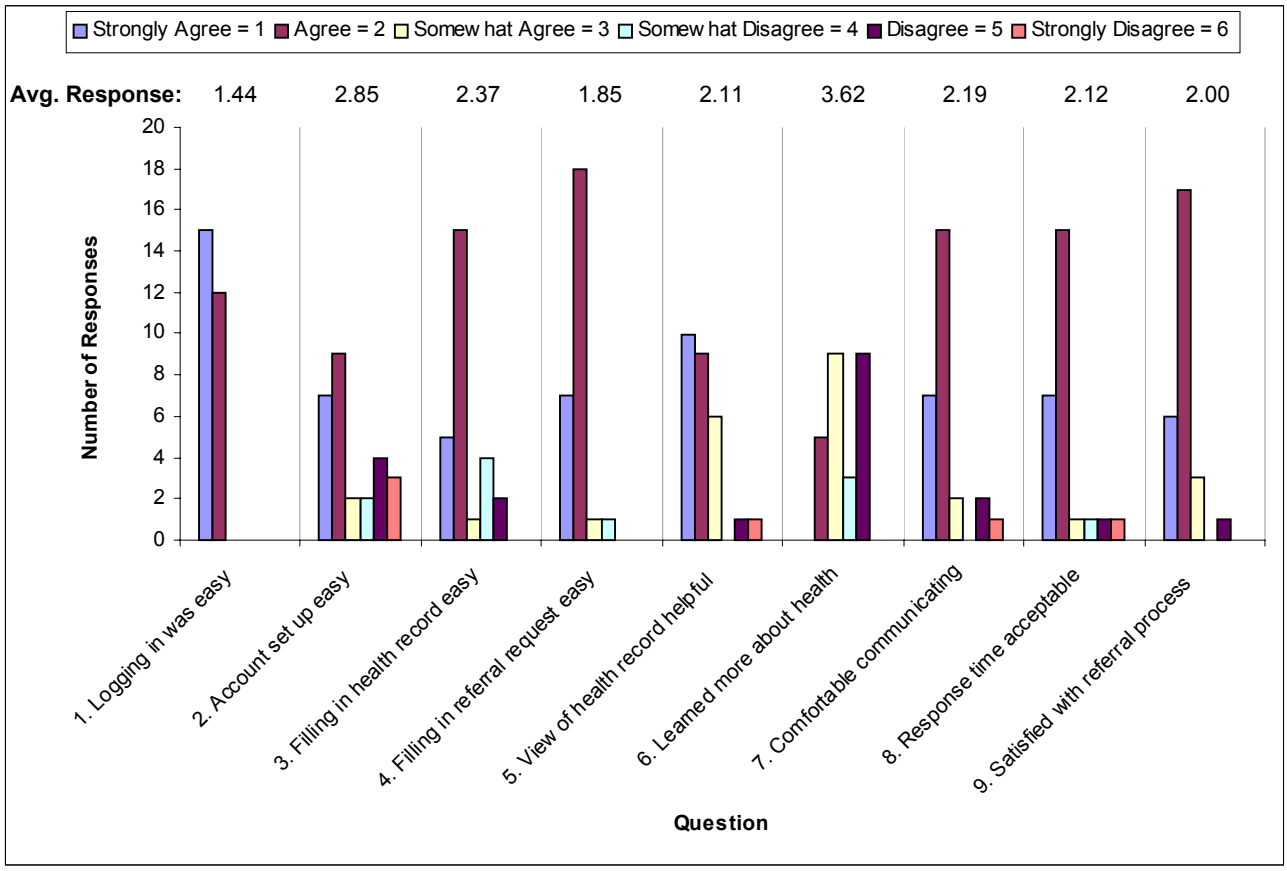

Figure 10. Distribution of survey responses.