

## A Patient-Controlled Journal for an Electronic Medical Record: Issues and Challenges

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### Abstract

*Partners Healthcare System, Boston, MA, has developed a patient Web portal that features a patient-controlled electronic "journal" to allow patients to interact with their physician's electronic medical record. Patients can view and respond to health reminders, critique electronic chart information maintained by their doctor's office, enter additional clinical information, and prepare information summaries before an office visit. Creating shared information resources to support a collaborative care model required analysis of the business, architectural, and workflow requirements of the patient-controlled clinical portal and the physician-controlled electronic medical record system. In this paper we describe the challenges in aligning the two systems and serving the different user groups. Coupling the Patient Gateway system, serving over 8700 patients of 90 physicians as of September, 2003, with the Longitudinal Medical Record system, serving over 4000 physicians, has required a clear definition of user goals and workflow, well-defined interfaces, and careful consideration of system assumptions to succeed.*

### Keywords:

Patient computing, electronic communication, medical records systems, computerized

### Introduction

Interest in electronic patient-physician communication<sup>1</sup> and patients-as-contributors to their own medical record<sup>2</sup> have accelerated as health care organizations focus their efforts to improve the quality and delivery of care with technology.

Over the past ten years, Partners Healthcare, a large integrated delivery system in Boston, MA, USA, with millions of patients,

thousands of physicians, and multiple institutions and groups offering primary care and specialty care services in many settings (inpatient, outpatient, home care, rehabilitation care, etc.), has continued to invest in clinical information systems to improve quality of care. In 1999 Partners began a patient computing project, Patient Gateway, that went live in February 2002 and currently (as of September, 2003) serves over 8700 patients of 10 primary care practices with over 90 physicians. This report focuses on some key issues and challenges that resulted when the Patient Gateway "Journal" for patients was coupled with an electronic medical record (EMR) maintained by the patient's physician.

### Methods

#### Longitudinal Medical Record (LMR)

The LMR is an ambulatory-care electronic medical record system used by physicians and other clinical staff in the outpatient setting for documentation of medical care, including: patient problems, procedures, medications, allergies, health maintenance topics, and encounter notes. The LMR is also used to write prescriptions and to communicate with other providers.

#### Patient Gateway (PG)

Patient Gateway offers secure electronic communication between patients and physicians, as well as request forms, health and disease information, practice information, and other features. The application is entirely Web-based and incorporates services such as prescription renewal, appointment, and referral authorization requests. These are transmitted securely to authorized physicians and practice staff and stored permanently in Partners' clinical information systems. Physicians and staff can communicate directly with patients, can exchange messages with each other, and can place copies of messages into the electronic chart if desired.

#### Project scope

Three key requirements for the patient portal were initially identified and led to the decision to build rather than buy this system. The requirements were: (1) providing patients with a single portal across all Partners institutions and departments, (2) leverag-

1. Ferguson T. Online patient-helpers and physicians working together: a new partnership for high quality care. *BMJ* 2000; 321: 1129-1132.

2. Wald JS, Rind D, Safran C, Kowaloff H, Barker R, Slack WV. Patient entries in the electronic record: an interactive interview used in primary care. *Proc Annu Symp Comput Appl Med Care* 1995; 147-51.

ing Partners' clinical systems infrastructure and electronic medical record systems, and (3) responding to new opportunities and demands at Partners, which places a high value on innovation and adaptation as new opportunities and new demands emerge.

The scope of the initial pilot, intended primarily as a proof of concept, was to offer patients and practices a set of basic functions that would include: (1) secure form-based requests for prescriptions, appointments, and referral authorizations, (2) secure Web messaging (as an alternative to email), (3) medication and allergy list displays from the LMR, (4) licensed health information from Healthwise®, Inc., and (5) practice administrative information such as directions, insurances taken, staff listings, etc.

Once the proof of concept phase was completed (after three practices and 1000 patients were using the Patient Gateway portal), the patient "Journal" functionality was added as part of a large grant-funded initiative to study quality of care and patient portals. The Journal permits patients to view and respond to specific LMR information relating to their family history, health maintenance items, medications, and diabetes care (if appropriate).

The patient who has completed a Journal may send it to the physician's office in preparation for a visit or save it privately.

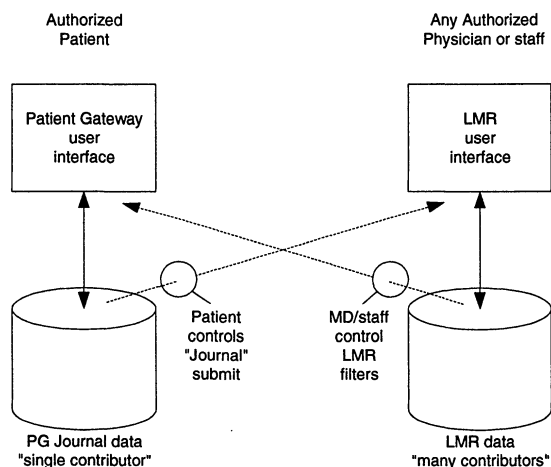


Figure 1 - Logical Patient Gateway and LMR interfaces

### Conceptual model

The conceptual model for the Journal (Figure 1) corresponds to the "integrated health system" model for Personal Health Records suggested in the Connecting For Health initiative<sup>1</sup>, in which EMR data is used to pre-populate the personal health record. Rules for cross-system viewing of clinical data are as follows: (1) Patient Gateway users may always see the most current abstracted LMR data available and released to Patient Gateway; (2) LMR users may always see Journal information if it has been "submitted" by the patient for review in the LMR.

In this model, the state of information shared between systems is formalized. Patients have the option to update their Journal without sharing the information if they wish. Specific abstracted health topics including relevant LMR info are presented to each patient based on system settings.

## Results

### Practice adoption

Patient and physician/staff interest in using Patient Gateway has been strong. Whereas 1000 patients enrolled in Patient Gateway in the first 12 months, that increased to 1000 patients per month in the second year, driven by practice marketing efforts and the addition of one new practice site per month.

Practices adopting Patient Gateway differed in both the actual system usage by patients, and in their expectations of how it would be used.

For example, one practice ("G" in Table 1) that already used email for a high volume of direct online communications between patients and their physician established a new policy requiring use of Patient Gateway instead. Large numbers of patients switched to the new system, alleviating physicians of routine messages that were handled by administrative staff. Some enthusiastic practices used telephone answering machine messages to advertise their use of Patient Gateway while patients were waiting "on hold", as well as direct mailings, exam room posters, and staff reminders encouraging patients to use Patient Gateway.

In contrast, other practices did not wholeheartedly encourage patients to use Patient Gateway for fear that too many patient messages would ensue. These cautious adopters offered some, but not all, request forms to patients. They discouraged patient use of freeform messaging by removing the practice mailbox called "Message desk" from view.

Characteristics and usage data for ten practices using Patient Gateway are presented in Table 1 to illustrate the variation among practices. Practices varied in their physician count (4 to 19); Patient Gateway accounts (201 to 2646), account-holder age (39 to 50 years) and gender (48% to 97% female).

They also varied in new accounts per week (6 to 56), messages per week per 100 accounts (3 to 13), and in the messaging services (Practice "desks") offered to patients (two to four).

There were no consistent statistical trends for the descriptive information seen in Table 1.

### Functional issues

#### Data storage

Keeping PG Journal data separate from LMR patient data was necessary for several reasons. First, patient data must be validated before it can be captured usefully in the medical record. Second, continuous patient access to the Journal might be hampered if physician or staff review was required to complete a Journal entry. These issues were addressed when a logically separate data store was created.

1. Markle Foundation, Connecting for health (2003). The personal health working group: final report, July 1, 2003.

Table 1: Characteristics of 10 practices using Patient Gateway

\*\*1 = Message desk, 2 = Medication desk, 3 = Referral desk, 4 = Appointment desk

Practice	Urban/ Suburban	Accounts	Active accounts	Mean age	% Female	Wks since live	Practice MDs	Patient Message/week	MSG/week /100 accts	Practice Desks**	New accts/wk
A	S	567	392	48	69	80.4	4	32.7	8.33	1234	10
B	U	2646	1811	50.3	50	79.9	19	57.7	3.18	-23-	27
C	U	1130	775	45	48	65.7	8	33.3	4.3	1234	14
D	U	201	97	48	60	25.4	3	5.33	5.5	-234	12
E	S	300	177	43	73	23.9	5	8.67	4.9	1234	7
F	S	430	255	50	61	23.7	11	15	5.88	-234	6
G	U	1800	1011	39	67	22.4	4	93	9.2	1234	44
H	U	278	136	49	78	14.9	15	17.3	12.7	-23-	11
I	U	426	198	45	95	14.7	8	16.7	8.42	-234	16
J	U	937	367	45	97	10.9	18	48	13.1	-234	56
ALL		8715	5219				95	328			203

### Decision support

Patient feedback and reminders for due or overdue health maintenance or diabetes items (e.g. pap smear, or HbA1c) are provided in the Journal based on un-validated patient entries, but are kept separate from the LMR decision support available for physicians and staff. Careful attention to word choices and context was needed since the patient lacks the professional training to weigh recommendations found in typical decision support messages offered to physicians.

In general, patient feedback was geared towards identifying self-care next steps or ways to obtain more information. For example, patients are advised to schedule a test colonoscopy if it is overdue, or may be asked to consider an appointment to discuss familial risk factors identified from their Journal responses. Since Journal information may be in error, and since it is not always known if Journal information will be new to the physician, care is taken in providing feedback to patients.

### Abstracted chart information

It was important to allow selective presentation of LMR data to the patient to create focus on specific areas (safety, health maintenance, risk identification, disease management) and to reduce the risk of sharing information electronically that required explanation or support. Whereas the typical LMR user is expected to have broad data access and to synthesize the information they find, the patient is directed to information and explanations (feedback) that have been tailored for easy understanding, in many cases.

### Architectural issues

#### Account architecture

The requirement for "single portal access" across Partners implied that a single patient login would permit access to multiple

physicians, departments, and services across institutions. Early in the pilot the focus was narrowed - to link a patient account to a single practice. With growing demand for Patient Gateway to be used in specialty care and ancillary departments (e.g. radiology), a "multi-practice" design has become critical.

Early requirements work identified the advantages to requiring each account to be identified with a patient in the enterprise master patient index (EMPI) at Partners. This was also limiting, since many community practices do not yet require use of the EMPI when they register new patients, and because many family and friends of the patient who would benefit from access to Patient Gateway would be similarly without an EMPI. For security purposes we continue to require that each Patient Gateway user must be registered in the EMPI, and anticipate that will continue.

#### Messaging architecture

The initial secure messaging system design utilized a single architecture for viewing, writing, and managing patient and staff messages. But patients and practice staff have different workflow constraints. LMR users require a tight coupling between clinical messaging systems and their clinical documentation systems, whereas patients have fewer workflow requirements but broader platforms that must be supported. As a result, the original architecture is being modified to accommodate the divergent user needs of patients and practice staff.

A common concern among physicians was the introduction of "yet another messaging system". Since physicians had corporate email, private email, LMR messaging, and now Patient Gateway messaging (in addition to pagers, mobile phones, office phones, etc.), defining interfaces with existing electronic messaging systems and a plan for converging systems where possible was necessary and became an important focus for some practices that were heavily reliant on electronic messaging in their workflow.

### ***Terminology for patient entries***

Since the Journal topics being deployed to patients require them to critique their medication list, note overdue diabetes and health maintenance items, and respond to feedback about meeting clinical “targets” such as weight goals, diabetes goals, etc., there was little need to develop an approach to patient terminology for those areas.

In the family history Journal a physician-led team developed data structures for the electronic medical record and mirrored those in the Journal form used by patients. In this example, efforts to identify and use standard terminologies, where possible, are important.

## **Discussion**

### **Physician fears**

Whereas physicians and staff thought a patient portal could reduce the hassle of telephone overuse and believed there were opportunities for time savings and load balancing of work through the introduction of asynchronous messaging, they also feared that their time would be under greater demand if phone access continues for patients and the new Web access added additional message volume. Physicians also worried that workflow would be disrupted by another messaging tool unless it was carefully coordinated.

Some felt that unless their time was reimbursed for Web visits and online communication, they would not favor online communication with patients.

These fears diminished with experience using Patient Gateway. Physicians found that 90% of patient messages never reached them since they were administrative in nature. Built in message notifications were adequate to safeguard against missed messages. Acceleration in the recruitment of both practices and patients to use Patient Gateway is an indirect indicator of reduced fears, but identifying and addressing physician concerns will continue to be a challenge.

### **Patient needs**

Patient Gateway currently meets some but not all of the needs that patients have articulated. Test results were not offered initially due to lack of policies in this area and concern about how to ensure abnormal test results were delivered in the right context and with the appropriate level of support. This issue is still being addressed, though selected test results are made available in the patient Journal.

### **Patient support**

Password distribution and password recovery have been significant challenges with growing use of the Patient Gateway system, requiring 0.5 to 1.0 FTE of support analyst time over the past 12 months. Simple enhancements such as automated password recovery tools were high-priority enhancements that have helped to keep the support burden manageable. The need to plan for continued support and focused enhancements to make the system usable is felt to be critical to the success of this project.

## **Security**

Terms of Use and a Patient Gateway Privacy Policy have been required of all patients who enroll in Patient Gateway to reduce the risk of unauthorized use, to strengthen the account management process; and to educate users on do's and don'ts of health information use. These were approved by institutional leadership and counsel, and continue to require adjustments as policies are updated.

### **Patient data policies**

With the creation of a new patient-controlled data store distinct from the chart data in the LMR, we needed policies and procedures for how the data is managed, how long it is maintained, who has access rights, and what happens if a patient closes their account. Journal data is managed similarly to LMR data in terms of security and integrity protections, auditing of access, persistence and backup.

Since electronic communication directly with a patient does not involve the sharing of confidential information among HIPAA (health insurance portability and accountability act) covered entities, there are no additional regulations governing Patient Gateway as a result of the HIPAA legislation.

### **Coordination with other systems and projects**

The third key requirement, flexibility to innovate, has proven essential in this project. The LMR is being deployed at an accelerated pace at Partners over the next five years. Several large “simplification” projects are underway to improve the patient’s “front end” experience registering for a visit, scheduling a visit, and completing administrative activities that have been time-consuming and frustrating in the past. Multi-site health content is being deployed for patients using the Web. Pilots to assess the feasibility for reimbursable Web visits are underway among health plans and could result in revenue opportunities for users of a patient portal.

Each of these projects and activities has a touch-point with Patient Gateway and offers an opportunity to leverage the Patient Gateway infrastructure, and to be leveraged as a new or enhanced “service” for patients using the portal.

### **Future course**

As Patient Gateway enters the coming year the demand for additional practices (adding specialty care to primary care), larger numbers of patients, and new types of information, administrative, and communication services is anticipated to continue.

Financing the patient portal is uncertain. Without clear industry-accepted return-on-investment data, initial funding of this project relied on internal IS (information system) department seed funds. With the successful demonstration of the proof-of-concept, additional seed funds were added and grant support was obtained to expand to 12 practices and 15,000 patients.

Substantial infrastructure development and team learning has taken place, positioning the product for use as a production system by sites and departments who will pay for it. With continued evaluation of the system we hope to demonstrate its role in cost savings, time savings, quality, and perhaps new revenue.

## Conclusions

The design and use of a patient-controlled Journal as part of an innovative Patient Gateway system at Partners has been accomplished through attention to change management among the pilot practices, support of patients, a focus on architectural and functional priorities, and a combination of internal and external sources of financial support.

The variation in use of Patient Gateway among 10 primary care practices suggests that the software must be flexible enough to accommodate baseline practices at each site, and that individual physicians and staff may tailor their use to suit their workflow and communication styles with patients and one another.

While there are qualitative and indirect signs that Patient Gateway provides value to its users, hard quantitative data has not been obtained. One area of particular importance is whether practice worries about time-consuming free-text messages from patients are justified or not.

As new Patient Gateway functions are created and piloted, the need to reexamine policies, architecture, standards, and workflow will continue.

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