

In Brief

This article describes the recent development of a diabetes-specific patient portal that is linked to an existing electronic medical record system. The portal was designed to provide patients with a secure means of electronic access to preventive health care reminders, information concerning their medications and health histories, educational materials, and self-management resources concerning diabetes-related risks. The authors briefly describe their work on the portal to date and discuss future directions for their research.

The Diabetes Patient Portal: Patient Perspectives on Structure and Delivery

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Although the use of computer technology has evolved from a workplace convenience to a mainstay in casual communication, it has lagged behind in patient-physician communication. Today, people make travel plans, carry out banking transactions, talk with business associates, and conduct many other personal interactions by computer via the Internet.¹ In the case of health care applications, however, concerns about privacy and patient safety have hindered the efforts of health care providers to pursue methods of electronic communication with patients.² The accidental disclosure of patient information to a third party or the failure of patients to access electronic messages on a timely basis could increase a provider's liability exposure. However, these problems can be prevented through patient education and the effective use of the electronic medical record (EMR) to provide a secure link not only between providers and their colleagues but also between providers and their patients.

A true EMR combines functions related to charting histories, ordering tests, and reporting results into a comprehensive patient record that allows multiple providers and practices to access the most up-to-date patient information and provide more appropriate care in outpatient and inpatient settings. Yet according to an Institute of Medicine report titled "Key

Capabilities of an Electronic Health Record System,"³ these functions of an EMR are insufficient because they fail to incorporate patients in the process.

As a chronic disease, diabetes requires the active participation of individuals with diabetes in their own management.^{4,5} Diabetes self-management education (DSME) is a crucial component in empowering people with diabetes to engage in self-management, and the literature widely supports its effectiveness.^{4,6,7} The most effective means of delivering DSME remains controversial.⁸ *Healthy People 2010* set as a goal to increase the number of people reached by DSME from 40% in 1998 to 60% in 2010.⁹ However, optimal programs to achieve this target are unknown.

Within this context, the University of Pittsburgh Medical Center (UPMC) sought to develop a secure diabetes-specific patient portal that would provide patients with access to preventive health care reminders, appropriate information concerning their medications and health histories, educational materials, and self-management resources on diabetes-related risks, including obesity, hypertension, and cardiac disease. To ensure that the portal would meet the needs of patients, UPMC staff involved in the project conducted focus groups in which a sample of diabetic patients

were involved in demonstrations, discussions, and evaluations of the proposed portal features. This article briefly describes work on the portal to date and future directions for research.

Structure of the Portal

The UPMC patient portal, known as UPMC HealthTrak, combines the communications power of an integrated EMR portal with customized features aimed at enhancing diabetes self-management. Because different UPMC outpatient offices involved in the project use EMRs from two different vendors, UPMC HealthTrak was constructed to seamlessly interact with both vendors' products.

UPMC HealthTrak allows patients to schedule appointments through the portal and to confirm dates and times of previously scheduled appointments, whether arranged through the portal, by telephone, or in person. Patients can also submit questions or reply to queries from physicians or other health team members at any time and not only during regular business hours.

Similarly, physicians, other providers, and staff can review patient questions and respond to patients directly, without having to worry about leaving telephone messages if patients are unavailable. In addition, patients can access their personal health information, such as laboratory test results that have been reviewed and released by their physician, medication lists, and medical history. After reviewing the information, they can print it out and share it with consulting providers, thereby avoiding the problem of having these providers prescribe medications without complete knowledge of the current drug regimen and other relevant data. If patients find that information on the portal is incorrect or incomplete, they can bring the problem to the immediate attention of their provider or the provider's practice (Table 1).

Additionally, UPMC HealthTrak includes several tools that were specifically designed to encourage lifestyle management goals of patients with diabetes and to prevent comorbid conditions. One customized tool is the daily logbook, which provides a central place for patients to keep track of exercise, BMI, and blood glucose levels. Another tool is a graphing function that illustrates past and current levels of hemoglobin A_{1c} (A1C), cholesterol, and blood pressure checked

during office visits. By monitoring changes in these measures of diabetes-related health risks, patients are better able to improve their self-management of diabetes.

Because the majority of patients with diabetes seen in the outpatient adult primary care setting have type 2 rather than type 1 diabetes, UPMC staff customized the portal to emphasize lifestyle modifications rather than insulin regimens and to encourage patients to set their own goals for health improvement. Emphasizing incremental health improvements in addition to providing "ideal goals" was considered crucial because many patients will not view the ideal goals as immediately achievable. With regard to weight, for example, UPMC providers give patients recommendations for exercise, give them a pedometer to help track the number of steps they walk each day, and encourage them to record the information. The portal presents each patient's data in terms of BMI and includes a chart of underweight, healthy, overweight, and obese values specific to the patient's height. The portal encourages patients to think about weight in terms of health instead of appearance and to track the results of exercise and other lifestyle changes on a daily basis.

Information about diabetes is provided on the site itself or via links to external resources. Information regarding a range of topics, including A1C, diet, and exercise, is provided on each page through a tab for frequently asked questions (FAQs). There are also links to UPMC infor-

mation about disease management and to other external sources of information.

Preliminary Testing and Assessment of the Portal

With permission from the quality improvement committee of UPMC and the University of Pittsburgh, the portal team recruited patients with diabetes to participate in five focus group sessions in which the patients discussed various diabetes-related topics, saw demonstrations of how the proposed diabetes patient portal would function, and completed questionnaires about the portal's usefulness and value.

Participants and procedures

Potential participants learned about the focus groups from either a poster or a diabetes nurse educator in a physician's office. To be eligible for the study, individuals were required to have a diagnosis of diabetes, to be over the age of 21 years, and to speak English. The project recruited a total of 21 participants from three primary care practices. The mean age was 53.4 years. Of the participants, 10 (48%) were men, 14 (67%) were white or European American, 15 (71%) had more than a high school education, 13 (62%) owned a computer, and 15 (71%) regularly used the Internet. Focus groups were conducted before wide-scale deployment of the portal, and thus participants were primarily not portal users.

A trained focus group facilitator conducted the focus group sessions between August and November 2004. The groups met in a central location during the evenings, and child care was provided. The discussion included six main topics: living with diabetes, resources used to help manage diabetes, views about patient-physician communication, views about a diabetes patient portal, feedback about features that would be useful to include in the portal, and paying for access to the portal. The sessions were audiotaped, and qualitative analyses of the transcripts will be published when they are available.

At the conclusion of the sessions, the participants completed a demographic questionnaire and a brief survey with three main tasks. The first task was to review a list of 15 features that might be provided by a diabetes-related portal and to rate each feature on a three-point Likert scale (not at all

Table 1. Original UPMC HealthTrak Features

Secure Messaging

- Request prescription refills
- Request medical advice
- Schedule appointments
- Request corrections to information (i.e., address)

View Medical Record Information

- Histories
- Medications
- Allergies
- Problem list
- Selected test results

Self-Management Tools

- Blood glucose log
- Weight and activity tracking
- Stress management

useful, somewhat useful, or very useful). The second task was to determine the total “worth” of a portal that included all of these features and to ascribe some monetary value for having 1 month of access to the portal. The third task was to allocate the worth across four entities that might be expected to subsidize portal maintenance (worth to the health system, to health insurers, to employers, and to portal users).

Each patient received \$25 and a parking voucher for participating in the study.

Usefulness of the portal features

The majority of participants ($\geq 60\%$) considered each of the 15 listed portal features to be at least “somewhat useful.” At the top of the list of features ranked as “very useful” (Table 2) were tools to assist in self-management, including a personal log for recording daily blood glucose levels (rated as very useful by 86%), a calculator to estimate average glucose control (86%), links to educational websites (71%), links to a diabetes newsletter (67%), an electronic scheduling system (67%), and an electronic reminder system (67%). Also highly rated (at 62% each) were secure communication with the health care team, links to other community-based resources, and general opportunities to develop interest groups with other patients.

Value of the portal

Although most participants rated the features of the portal as useful, only 17 participants answered a question about how much 1 month of access to the portal was worth. Of these 17 participants, 9 listed a value of \$0 (nothing), 5 assigned low values (\$5–25), 1 said \$250, 1 said \$500, and 1 said \$10,000. It is unclear whether the responses represented a true assessment of the portal’s worth, a misunderstanding of the question, or simply an example of patients saying what they thought researchers wanted to hear.

An analysis of odds ratios (ORs) showed that patients were more likely to assign a positive value to the portal if they were male, were not white, and had received a diagnosis of diabetes within the last 5 years (Table 3). Although our sample was small and the ORs were not significant, they point to some interesting trends to examine in the future, and they sug-

gest that the portal may be a niche service appealing only to specific subgroups of patients.

Subsidization of the portal

Given the values reported above, it was not surprising to find that only two participants supported a user’s fee to help maintain the portal.

Discussion

The UPMC diabetes patient portal was designed to enhance patient-provider communication and to allow patients to take a greater role in their own efforts to manage diabetes and prevent associated diseases. The portal allows patients to access their health information in a secure central

location and to make printouts that are easily portable to other locations.

It also enables them to initiate communication with their provider’s office outside of usual business hours. Using asynchronous communication, they can carefully compose questions and contemplate answers. They do not have to respond in the moment of live dialogue but instead can relate portions of the message to earlier messages, chart notes, or test results. This has the potential to decrease demands on providers’ time while at the same time creating more educated and participatory patients. This will be evaluated as the project goes forward.

Because the development of a web-based support tool such as the

Table 2. Percentage of the 21 Participants Who Rated Potential Portal Features as Very Useful

Portal Feature	Rated as Very Useful (%)
• Personal log to record daily blood glucose levels and graph fasting blood glucose for the past 6 months	86
• Calculator that uses daily blood glucose log to estimate diabetes control for the past 3 months	86
• Links to educational websites about diabetes	71
• Electronic newsletter that includes frequently asked questions, diabetes-friendly recipes, and community events of interest	67
• Online scheduling system that allows users to arrange routine appointments on the computer	67
• Electronic reminder system that confirms upcoming provider appointments or notifies users when a new appointment needs to be scheduled	67
• E-mail access to health care team that allows users to send (nonemergent) questions directly to them and receive responses within 1 business day	62
• Links to community resources for physical activity and meal-planning information	62
• Opportunities to form interest groups (e.g., walking groups, meal clubs)	62
• Access to an online personal trainer who can provide tips on increasing daily activity levels or developing exercise programs	57
• Access to individual nutrition and meal planners	57
• Opportunities to talk with other patients with similar concerns or interests (such as preparing meals the whole family will enjoy or what to do if you have gestational diabetes)	57
• Class schedules for sessions on healthy cooking	43
• Electronic bulletin boards that allow users to ask questions, post tips, and read suggestions and helpful hints from other patients	38
• Chat rooms that allow patients to share information with one another in real time	38

Table 3. ORs for Assigning a Positive Monetary Worth to the Portal*

Participant Characteristic	OR	95% CI
Male sex	5.8	(0.7–48.9)
Age < 50 years	1.2	(0.2–8.8)
Nonwhite race	2.1	(0.3–17.6)
High school education or less	0.5	(0.1–6.9)
Diagnosed with diabetes < 5 years ago	6.0	(0.7–49.8)

*The OR represents the likelihood that a participant with the characteristic listed in the table versus a participant without the characteristic listed would assign a positive value to the portal. For example, male participants are 5.8 times more likely than female participants to assign a positive monetary value to the portal.

diabetes portal requires funds for site maintenance and improvement, health care systems must consider ways to offset the costs. On the one hand, the focus group sessions revealed that patients with diabetes were enthusiastic about the self-management features and other features incorporated in the portal. On the other hand, they showed that patients were generally opposed to having portal users subsidize the costs of maintaining the portal.

There are several reasons that may account for these attitudes toward user fees. First, the group discussions may have influenced the participants' attitudes. For example, in one of the focus group sessions, a participant pointed out that if the portal succeeds in helping patients manage their diabetes, it may decrease the number of diabetes-related hospitalizations and thereby prove to be a cost-saving measure for the health system. At the end of the same session, only one participant in the group thought that a user fee might be acceptable. Second, the participants' responses may merely reflect their "preferred price" (the price they would volunteer to pay). Determining their "reservation price" (the price they would actually be willing to pay) will require the exploration of revealed preferences rather than stated preferences. Third, participants had only a brief introduction to the portal and were not active users. It is possible that after patients use the portal regularly, they will come to view it as more valuable, as has occurred with other technological advances, such as cell phones, which were initially considered to be luxuries and but are now regarded by many to be necessities.

Project staff used a small, purposeful sample of patients with diverse opinions regarding the diabetes patient portal. Further work is needed to improve the generalizability of these results and to address other questions raised by the study. They are currently conducting focus group sessions with active users to understand which of the portal features are perceived as being the most useful to patients. Additionally, they are auditing portal use to determine which features are most often used. They suspect that routine portal users will be more willing to assign a monetary value to a system they are actually using than to a system that is purely hypothetical or has merely been demonstrated to them.

Future work will also address the impact of the portal on quantitative outcomes. These include the impact on physiological measures such as A1C, as well as process measures such as office staff time. Additionally, researchers will evaluate the total cost implications of such a system.

A disease-specific or condition-specific portal is not likely to satisfy the needs of all targeted patients, and it is important to examine more closely the subgroups for which the portal will provide the greatest value. Health systems must decide whether their goal is to provide a general, convenient service for a large group of patients who are likely to use it only if the fee is minimal or whether to provide a niche service to a smaller group of patients who have a greater need for information (such as newly diagnosed patients) or a greater desire for rapid communication with their providers and are willing to contribute to the costs of the service.

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