TELEMEDICINE AND e-HEALTH
Volume 13, Number 5, 2007

DOI: 10.1089/tmj.2006.0089

Original Research

Exploring Challenges and Potentials of Personal Health Records in Diabetes Self-Management: Implementation and Initial Assessment

RACHEL HESS, M.D., M.Sc.,[1,2] CINDY L. BRYCE, Ph.D.,[1,2,3] SUZANNE PAONE, M.B.A.,[4,5]
GARY FISCHER, M.D.,[1,2] KATHLEEN M. McTIGUE, M.D., M.S., M.P.H.,[1,2]
ELLEN OLSHANSKY, D.N.Sc., F.A.A.N.,[6] SUSAN ZICKMUND, Ph.D.,[2,7]
KATHARINE FITZGERALD, M.I.D., M.P.H.,[1,2]
and LINDA SIMINERIO, R.N., Ph.D., C.D.E.[1,8,9]

ABSTRACT

The University of Pittsburgh Medical Center (UPMC) has implemented a personal health record grounded in the Chronic Care Model, UPMC HealthTrak, to assist patients with diabetes self-management. UPMC HealthTrak is based in the physician office and connects the patient, physician, and electronic medical record (EMR). Its functionalities include secure, electronic communication with the physician's office, along with preventive healthcare reminders, and disease-specific tools and information. In this paper, we describe challenges to office-based implementation of and initial patient reaction to the technology in the context of diabetes care. UPMC has deployed a secure Web-based patient portal, UPMC HealthTrak. We implemented UPMC HealthTrak in the ambulatory setting and assessed its impact on patient–practice communication. We conducted 10 90-minute focus groups (five pre- and five postimplementation) to assess patient reaction to UPMC HealthTrak. Focus groups were analyzed using grounded theory techniques. During the period September 2004–January 2007, there was no significant change in number of patient encounters or telephone calls received in our office, but the number of HealthTrak messages increased. Our 39 pre- and postimplementation focus group participants felt that the system would enhance communication with the office, and that the reminder system would be helpful. They also liked having access to

[1]Department of Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania.
[2]Center for Research on Health Care, University of Pittsburgh, Pittsburgh, Pennsylvania.
[3]Department of Health Policy and Management, Graduate School of Public Health, University of Pittsburgh, Pittsburgh, Pennsylvania.
[4]University of Phoenix, Health Administration, Phoenix, Arizona.
[5]Information Services Department, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.
[6]Program in Nursing Sciences, University of California, Irvine, California.
[7]Center for Health Equity Research and Promotions, VA Pittsburgh Healthcare System, Pittsburgh, Pennsylvania.
[8]University of Pittsburgh Diabetes Institute, Pittsburgh, Pennsylvania.
[9]Department of Health and Community Systems, University of Pittsburgh School of Nursing, Pittsburgh, Pennsylvania.

laboratory tests remotely. They were frustrated when tests were not released and messages not answered. A Web-based patient portal can be integrated into a clinical office, although patients may not quickly change communication patterns. Patients are responsive to technology. Future work should focus on diabetes-related outcomes assessment and intensifying interventions.

INTRODUCTION

DIABETES CARE is a national priority for health systems, as poor care can result in increased morbidity, mortality, and overall costs. Recently, care models such as the Chronic Care Model (CCM) that support enhancing patients' disease self-management have demonstrated positive outcomes.[1] The CCM emphasizes the need for: (1) clinical information systems that provide disease-specific patient registries; (2) computer-based decision support for practitioners; (3) development of healthcare system and community change to facilitate longitudinal care; and (4) programs to support patients' effective self-management. In short, the CCM calls for radical changes in the way that healthcare is delivered to patients who live daily with chronic disease.

In its 2003 report, *Key Capabilities of an Electronic Health Record System*, the Institute of Medicine (IOM) states that an optimal electronic medical records EMR should be characterized by several salient features: longitudinal collection of information; immediate access to information for authorized users; provision of knowledge and decision support to enhance quality, safety, and efficiency of patient care; and support of efficient processes for healthcare delivery.[2] The IOM further describes two critical building blocks of the EMR—the practitioner-maintained portion and the Personal Health Record (PHR)[2]—which allows patients to record and access medical record information and to communicate with their physician practice.

This IOM goal is slowly becoming a reality. While traditional EMR approaches to chronic disease management are limited by a physician-centered focus (they provide information and decision support only to providers and do not facilitate patient self-management), health portals open the EMR to the patient through the PHR. The increasingly available technology in the home allows the patients easy access to this information.[3]

The University of Pittsburgh Medical Center (UPMC) is committed to the principles of CCM and has demonstrated the effectiveness of the model in improving diabetes outcomes using evidence-based practices, enhancing access to clinical information with electronic record keeping, and supporting systems improvement projects through continuous quality improvement initiatives and randomized controlled trials.[4,5] UPMC maintains an active program to support patient diabetes self-management using diabetes nurse educators and pharmacists working in conjunction with physician practices to encourage and teach diabetes self-management.[4–7] This report focuses on an addition to UPMC's ongoing efforts in the fourth component of the CCM: to support patient self-management. By providing Web-based tools to the patient that are linked to the electronic medical record systems (EMR) used by their health care providers,[8] we aim to further integrate the patient into the disease management process.

Our prior work during the development of this portal suggests that features of a portal most valued by patients would include tracking blood glucose, information about diabetes, and communication with the office practice.[8] In this paper we describe our integration of multiple electronic systems into one patient portal to provide access to the PHR and tools to supplement our current self-management efforts, describe the integration of the system into the outpatient office workflow, and discuss patient's initial reaction to the portal.

UPMC HealthTrak

Providers (including our Diabetes Nurse Educators) at UPMC have access to two commer-

cial EMR systems (Cerner's Powerchart Office and Epic's Hyperspace) that allow the exchange of information between clinical settings (e.g., emergency departments, inpatient facilities, outpatient practices). The EMR that each provider uses depends on the location of his or her practice and contain medical information, such as clinical notes, radiology reports, and laboratory tests. They facilitate communication within offices and between providers who use the same EMR, and also permit documentation of telephone and written communication. Traditionally, EMRs have been centered at the point of care and primarily used by providers, not patients.

At UPMC, we have developed an interoperable technology approach using standard tools that overcomes system limitations and expands chronic care services, while leveraging current investments in information technology to link vendor-based PHRs with other self-management tools. The end result is UPMC HealthTrak, a portal that allows all patients to access disparate resources from the same Web interface. Additionally, the overarching HealthTrak structure also allows patients to view and schedule appointments.

UPMC HealthTrak links patients seamlessly to tools provided by the various EMR vendors, allowing patients to view information from their own EMR (including test results, medication and problem lists, and health reminders) in a PHR and to communicate electronically with their health care providers in a secure manner. Through this application, patients can also access self-management tools developed by UPMC, such as weight and activity logs to encourage healthy lifestyles and a stress scale with links to stress reduction information[8] as well as vendor-specific tools, such as blood glucose tracking. When patients use blood glucose tracking features, their values are automatically sent to their provider (including diabetes nurse educator) at specified intervals. Alert values (both high and low) are also automatically transmitted to the provider. These features enhance the provider involvement in day-to-day management. The site is designed so that third-party clinical, research, or information tools can be used while still maintaining the technical integrity of the secure EMR–PHR environment. This gives the patient the informational and motivational tools to assist with self-management of chronic disease.

MATERIALS AND METHODS

UPMC implementation

We implemented UPMC HealthTrak in three primary care practices in the UPMC health system. The practices (an academic general internal medicine practice, a community-based general internal medicine practice, and an academic family medicine practice) used two different EMR systems.

The most challenging provider-side aspect of integration is the integration of the secure patient messaging feature into the workflow of the practice. This integration is a critical factor to success; if communication fails, patients may not use other features. To ensure adoption of this new communication tool, we attempted to triage messages to the right recipient as per the usual office workflow.

To demonstrate the integration of electronic messaging into office workflow, we focus on the workflow of the University of Pittsburgh Physicians General Internal Medicine (UPP–GIM), a large academic internal medicine practice. UPP–GIM has 30 attending physicians and 32 residents. Attending physicians see patients between 1 and 8 half-days per week, while residents see patients 1 half-day per week. There are approximately 25,000 patient visits per year and 12,000 phone calls per month.

Prior to the use of electronic messaging, patient calls were routed to different staff members depending on the nature of the call. When patients called the office, they had the option of leaving a message for a prescription refill or speaking to the phone receptionist. The receptionist made appointments or transferred calls as needed. Calls were routed to the referral specialist, the health educator who helped manage patients with chronic medical problems (particularly diabetes), or one of four clinical-care teams, each with a nurse and secretary to support a specific group of residents and attending physicians. The appropriate staff person processed the call, typed a message into the

EMR, and, if necessary, routed the message to the physician for comment.

One weakness inherent in this system was that when a patient calls with a problem requiring input from the physician, the nurse needed to take a message with a plan of calling the patient back. Naturally, patients were often not at the phone when the office tries to call back, and so "phone tag" could go on, sometimes for days. Another concern was that office staff must type the patient's message into the EMR so that it was conveyed to the physician. This raised the risk of inaccurate transcription, resulting in erroneous advice or necessitating further contact to deliver an appropriate response. Finally, if there was a large volume of phone calls at a given time, patients may have to wait for long periods of time before a staff-person could answer their call.

Electronic messaging mirrors the phone flow, but also addresses the above problems. Depending on the type of message that the patient sends, the message is routed to the appropriate support staff (receptionist, referral specialist, nurse educator, or clinical-care team) and filed directly into the staff person's "in basket" in the EMR. Because office staff members always use this record, no one is required to go to a separate program or Web site to interact with the patient. Requests for medical advice are routed to the appropriate clinical-care team and reviewed by a nurse to make sure that they do not involve an urgent matter. The nurse either responds or forwards the message to the physician, who can respond directly to the patient. The messaging program instructs patients not to send urgent messages in this manner, and notifies them to expect a response within 2 business days. Patient-entered blood glucose values are automatically transmitted to the practice and provider at determined intervals to facilitate involvement in management between office visits. Additional automatic, real-time transmission of high or low alert values also occurs to notify the physician or nurse educator of a problem. All communication to and from patients is saved to the patients' electronic chart.

By mirroring the current office workflow and integrating electronic messaging into the EMR, the system ensures that messages are directed to the right person, are a part of the normal office flow, and become a permanent record in the EMR. Asynchronous communication is convenient for the patient and the physician, but other more direct means of communication (through a telephone call or an office visit) are available when appropriate. We describe the number of patients seen in UPP–GIM per month, number of messages sent, and number of phone calls received since the initial UPP–GIM implementation in September of 2004.

Focus group methods

As part of our formal evaluation, we focused on patients' reactions to UPMC HealthTrak and e-health in general. To gauge patients' reactions to and requirements of UPMC HealthTrak we conducted 90-minute focus groups, both before the release of UPMC HealthTrak to learn from potential users what features might be useful to them, and after the release to learn about the experiences of registered users. Participants included any patient with diabetes from the three UPMC HealthTrak pilot practices (an academic internal medicine group, an academic family medicine group, and a community internal medicine group) and represented a diverse patient population. We recruited prerelease participants with posters placed in participating practices and Diabetes Nurse Educators in those practices. Postrelease participants were recruited through a mass email sent to all UPMC HealthTrak users as well as advertising on the UPMC HealthTrak Web site. In the prerelease focus groups, patients from any of the practices could participate in any of the five focus groups. Because of subtle differences in features of UPMC HealthTrak specific to the EMR employed by the physician practice, participants in the postrelease focus groups were segregated according to physician practice.

Topics discussed during the focus groups included living with diabetes, desired information about diabetes, current sources of information about diabetes, doctor–patient communication, reaction to the portal, and views on paying for the portal. Participants had an opportunity to discuss these topics in gen-

eral along with the positive and negative aspects of the portal. In the prerelease focus groups, participants had 30 minutes during the session to explore UPMC HealthTrak, followed by a discussion about their impressions of it. During the focus groups, the moderator had access to the portal if questions arose that necessitated referencing the program.

A single moderator facilitated all focus groups, a note taker was present, and all groups were audiotaped and transcribed verbatim. Six of the authors (Hess, Fischer, McTigue, Bryce, Olshansky, and Fitzgerald) participated in the initial coding of the preimplementation focus groups. An additional author (Zickmund) also participated in the coding of the postimplementation focus groups. We used grounded theory methodology to analyze transcripts.[9,10] Using this technique, themes emerge during the coding process that are grounded in the data. As part of the analysis, we routinely compared themes between participants and groups to inform our understanding of how the themes related to the overarching constructs and theory. We present overarching themes as they emerge in the pre- and postimplementation focus groups and provide exemplar quotations as they relate to the theme.

RESULTS

Office integration and implementation

Since the September 2004 deployment of UPMC HealthTrak in UPP–GIM, we have tracked the number of office phone calls received and HealthTrak messages received. Figure 1 shows the number of phone calls and HealthTrak messages per patient per month, as well as the number of patients seen in the UPP–GIM office during the month. There is no change in number of patients seen per month or in the number of phone calls received. The number of HealthTrak messages is increasing; however, this increase is not moderating the telephone call volume.

Patient reactions

We conducted five preimplementation focus groups with 21 participants and five postimplementation focus groups with 18 participants. Characteristics of participants are presented in Table 1.

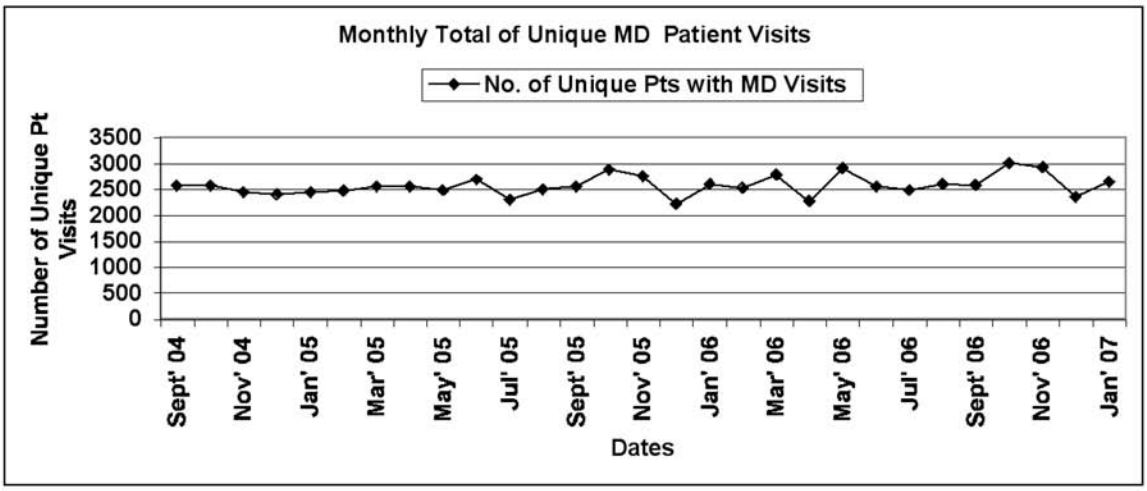
In the prerelease focus groups, participants felt that this system would enhance communication with the physician's office. They felt it would be most useful for obtaining laboratory results and communicating with the office to improve chronic disease management. For instance, one participant who already tracked his blood sugars electronically noted the usefulness of being able to e-mail blood sugar results so that his provider or diabetes educator could adjust medications during the interval between office visits. Patients also felt that it would assist with communication for providers who were not in the office every day.

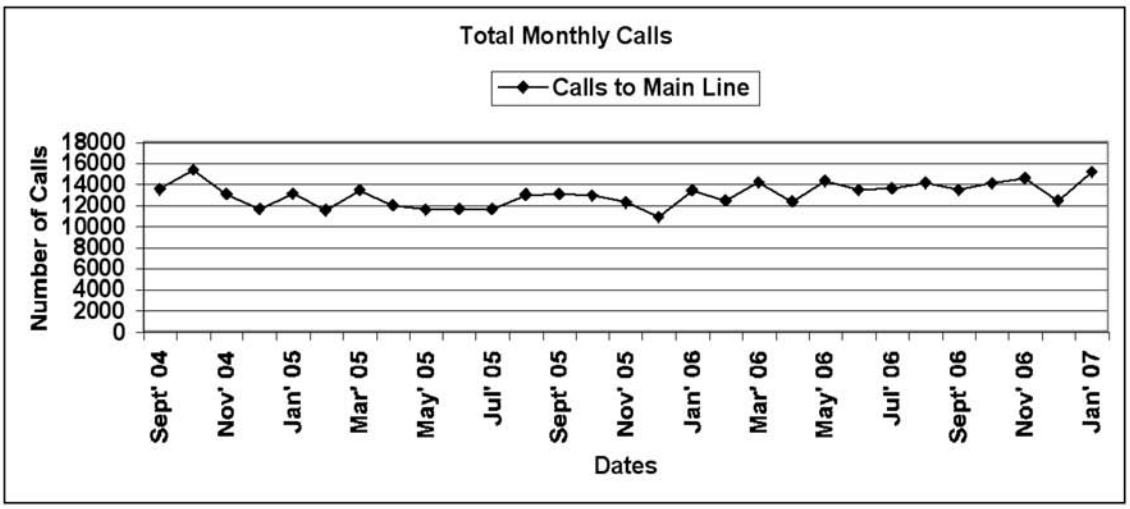
These participants found centralized information to be useful. Many of them consulted multiple sources to educate themselves about diabetes and diabetes self-management. Trusted information, endorsed by their physicians, was important and valuable.

Participants also commented that they were busy; they occasionally forgot appointments and did not always receive phone messages. The ability to receive appointment reminders and test results electronically suited their busy schedules. Participants felt that these features could improve their overall health, and result in fewer missed appointments.

In the postrelease focus groups, frequent users of UPMC HealthTrak felt that the portal provided them with a sense of empowerment. It allowed them access to medical records, such as laboratory tests, and gave them the ability to schedule and cancel appointments at their convenience. People used UPMC HealthTrak to manage their health between physician visits in consultation with their providers. Additionally, it allowed people to understand how lifestyle choices impact health. One participant remarked, "Some of the things that I can do something about . . . I do . . . prior to my next visit. And I think it helps me out that way, especially helping me out with cholesterol. Because I reduced mine, you know, way down from where it was."

However, patients also identified inefficiencies that included missing lab results (the system requires physicians to manually release re-





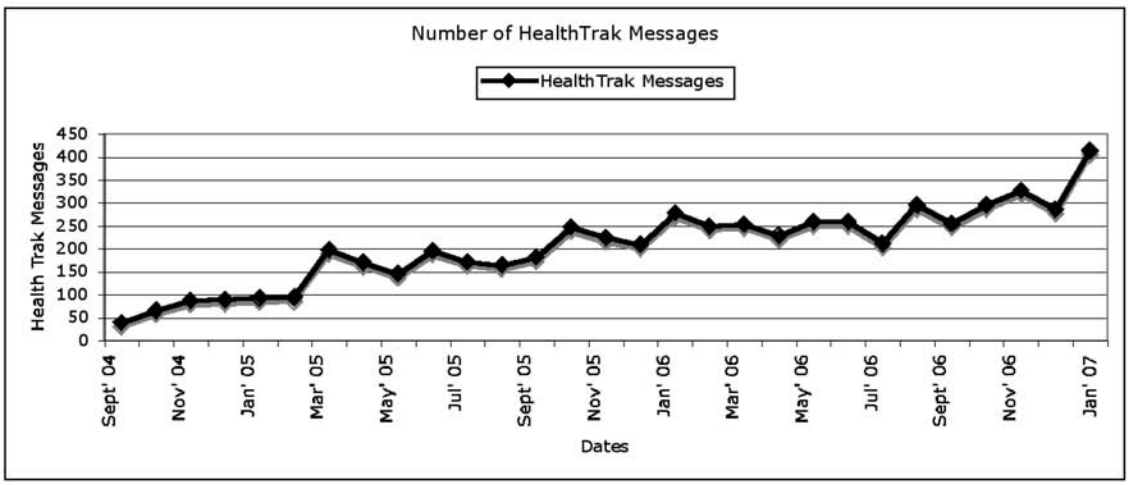


FIG. 1. Office contact volume in University of Pittsburgh Physicians General Internal Medicine. **Panel 1** shows the number of unique patient visits each month between September 2004 and January 2007. **Panel 2** shows the number of phone calls received by the office during the same period. **Panel 3** shows the number of HealthTrak messages during the same period.

Table 1. Characteristics of the 39 Study Participants[a]

Characteristic	Total sample (n = 39)	Preimplementation group (n = 21)	Postimplementation group (n = 18)
Male gender (%)	20 (51)	10 (48)	10 (56)
Mean age in years (SD)	54 (12)	53 (13)	55 (11)
Nonwhite race/ethnicity (%)	11 (28)	7 (33)	4 (22)
Highest level of education (%)			
High school graduate	7 (18)	6 (29)	1 (6)
Some college	12 (31)	7 (33)	5 (28)
College graduate	6 (15)	2 (10)	4 (22)
Postgraduate degree	14 (36)	6 (29)	8 (44)
Mean years since diagnosis of diabetes (SD)	10.2 (9)	9.7 (9)	10.8 (9)
Mean months on HealthTrak (SD)	N/A	N/A	8.1 (8)

Preimplementation participants did not have access to HealthTrak. All postimplementation participants, by definition, had access.

[a]N/A indicates not applicable.

sults for patient review), inaccurate information, and slow responses from the physician and/or nurse. Additionally, at the time of the focus groups, X-ray reports were not available on UPMC HealthTrak. This was frustrating to focus group participants. Finally, patients reported several barriers to use, including lost or unknown user names and passwords, and some patients were unaware of the features of UPMC HealthTrak that they said (after learning about them in the focus group) they would have found useful, like glucose tracking. Patients also expressed expectations of being able to contact all of their physicians, not just their primary care physician, which requires coordination and integration beyond this initial pilot effort.

DISCUSSION

Today's technological environment can facilitate proven core scientific principles of effective chronic disease management, such as the CCM, related to both primary and secondary prevention. The underlying principle of an interoperable technology framework is crucial to enabling chronic disease management in a cost-effective and scalable manner. The PHR provides an ideal environment to further link the patient to the physician office and involve him or her in more active disease self-management.

UPMC HealthTrak specifically has the potential to improve chronic disease management by enhancing patient self-management. The ability to view portions of the EMR, such as the problem list and the medication list, help to ensure that patients are aware of important aspects of their own diseases. Links to information about diabetes and other diseases allows patients to explore issues of concern to them. Glucose, blood pressure, and activity logs support patients in their efforts to comply with treatment plans that involve self-monitoring, and the integration of glucose and blood pressure logs with the EMR allow the care team to review these results and make therapeutic changes.

The feature of UPMC HealthTrak that has the potential to strengthen provider/patient relationships, but which also may cause the most resistance from providers, is secure electronic messaging. In our focus groups, secure, electronic communication was one of the features most valued by patients. This communication link is critical to effective patient self-management, and overcoming provider resistance is crucial. Secure, electronic communication between physician offices and patients promises many benefits.[11] Patients can initiate communication with the office at any time, even when the office is closed. They can complete simple administrative tasks, like scheduling appointments or requesting prescription renewals, without waiting to speak with staff. More substantive matters can be addressed though asynchronous, two-way communication, eliminating the need to "catch the doctor." If questions asked through secure messages are an-

swered by the physician, then electronic messaging can enhance the doctor–patient relationship and avoid the need for a third party (such as a nurse) to relay messages over the phone. Additionally, patient-entered blood glucose values can be automatically transmitted at routine intervals with alert values sent in real time to facilitate closer patient monitoring between office visits. Finally, all messaging is recorded with fidelity in the EMR.

There are features to enhance provider workflow as well. Requests for medication renewals and physician referrals can be structured so that patients provide all necessary information to process the requests, in contrast to voice mail messages from patients that often omit important information. Secure messaging may also increase office efficiency, because scheduling staff to handle electronic messaging throughout the day is more predictable than handling the minute-to-minute variation in phone call volume. Finally, secure electronic messaging allows physicians to communicate normal or slightly abnormal results to patients efficiently. ? Although physicians have expressed concern that patients will make inappropriate demands through electronic messages,[12] they always have the discretion to call the patient or request that the patient make an appointment if a matter requires more direct communication. Concern that physicians will be overwhelmed with electronic messages has not been observed by us or others.[11]

Integration into the office practice is realistic and achievable, but care must be taken to minimize deviation from usual flow, especially before systems are valued and engrained. Initially, phone call volume does not change, which may be frustrating to staff and minimize interest in learning a new means of communication. In fact, messaging may represent an additional means of communication as opposed to an alternative to telephone communication for patients.

Patients report that they value alternative means of communication with their physician practices and express comfort with technology. However, they also experience frustration when expectations go unmet. This can lead them to abandon potentially beneficial technologies. Features that were most valued were communication and tracking tools. HealthTrak users less frequently discussed educational resources, suggesting that simply placing resources within an environment is inadequate to stimulate patient use. Overcoming these barriers, both at the practice and patient level, is necessary to fully implement a patient-centered CCM that takes full advantage of technology innovations to improve diabetes self-management. More complete understanding of these barriers and techniques to overcome them is the focus of our current research. We are evaluating the impact of UPMC HealthTrak on compliance with diabetes screening tests (e.g., retinal and foot exams) and diabetes-related outcomes (e.g., hemoglobin A1C and lipid profiles). We are also developing an interactive portal-based lifestyle management tool to make intensive lifestyle interventions accessible to larger numbers of people.

ACKNOWLEDGMENTS

This research was partially sponsored by funding from the United States Air Force administered by the U.S. Army Medical Research Acquisition Activity, Fort Detrick, MD, Award Number W81XWH-04-2-0030. Dr. Hess has grant support from the National Institutes of Health, Department of Health and Human Services, through the National Institute on Aging AG024254. Dr. McTigue has grant support from the National Institutes of Health, Department of Health and Human Services, through the National Institute of Diabetes and Digestive and Kidney Diseases DK067192. Dr. Zickmund is supported by the Veterans Administration Health Services Research & Development Merit Review Entry, Program Career Development Award and Grant Number UL1 RR024153 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. This work was partially presented at the 2005 American Telemedicine Association National Meeting.

REFERENCES

1. Wagner EH, Sandhu N, Newton KM, McCulloch DK, Ramsey SD, Grothaus LC. Effect of improved glycemic control on health care costs and utilization. *JAMA*. **2001;**285:182–189.
2. Tang PC. *Key Capabilities of an Electronic Health Record System*. Washington, DC: Institute of Medicine of the National Academies, **2003.**
3. Millard R, Fintak P. Use of the Internet by patients with chronic illness. *Dis Manage Health Outcomes*. **2002;**10:187–194.
4. Siminerio LM, Piatt GA, Emerson S, Ruppert K, Saul M, Solano F, Stewart A, Zgibor JC. Deploying the chronic care model to implement and sustain diabetes self-management training programs. *Diabetes Educ*. **2006;**32:253–260.
5. Piatt GA, Orchard TJ, Emerson S, Simmons D, Songer TJ, Brooks MM, Korytkowski M, Siminerio LM, Ahmad U, Zgibor JC. Translating the chronic care model into the community: Results from a randomized controlled trial of a multifaceted diabetes care intervention. *Diabetes Care* **2006;**29:811–817.
6. Zgibor JC, Rao H, Wesche-Thobaben J, Gallagher N, McWilliams J, Korytkowski MT. Improving the quality of diabetes care in primary care practice. *J Healthcare Qual* **2004;**26:14–21.
7. Siminerio LM, Piatt G, Zgibor JC. Implementing the chronic care model for improvements in diabetes care and education in a rural primary care practice. *Diabetes Educ* **2005;**31:225–234.
8. Hess R, Bryce CL, McTigue K, et al. The Diabetes patient portal: Patient perspectives on structure and delivery. *Diabetes Spectrum* **2006;**19:106–110.
9. Glaser BG, Strauss AL. *The Discovery of Grounded Theory; Strategies for Qualitative Research*. Chicago: Aldine Pub. Co., **1967.**
10. Strauss AL, Corbin JM. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd ed. Thousand Oaks: CA: Sage Publications, **1998.**
11. Liederman EM, Morefield CS. Web messaging: A new tool for patient–physician communication. *J Am Med Inform Assoc* **2003;**10:260–270.
12. Delbanco T, Sands DZ. Electrons in flight—e-mail between doctors and patients. *N Engl J Med* **2004;**350: 1705–1707.

Address reprint requests to:
Rachel Hess, M.D., MSc.
Center for Research on Health Care
230 McKee Place, Suite 600
Pittsburgh, PA 15213

E-mail: hessr@upmc.edu