

Project Title:	Patient-Centered Online Disease Management Using a Personal Health Record System
Principal Investigator:	Tang, Paul, M.D.
Organization:	Palo Alto Medical Foundation
Mechanism:	RFA: HS07-007: Ambulatory Safety and Quality Program: Enabling Patient-Centered Care through Health Information Technology (PCC)
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Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use

Summary: This study, approximately mid-way through its progress, expands on the project team’s prior work in developing a Personalized Health Care Program (PHCP) that actively supports a partnership between the patient and his/her multidisciplinary care management (CM) team using an online disease management (ODM) system. This CM team includes a nurse diabetes care coordinator, a clinical pharmacist, a nutritionist, and the patient’s physician(s). The ODM system is integrated with Epic Systems’ EpicCare (Epic version Spring 2007), a comprehensive, Certified Commission for Health Information Technology (CCHIT) certified electronic health record (EHR) system. Patients of the Palo Alto Medical Foundation (PAMF) have access to an integrated personal health record (PHR), PAMFOnline, which is a customized version of Epic Systems’ *MyChart* PHR. PAMFOnline provides patients with a health summary from their EHR (diagnoses, medications, allergies, lab test results with physician annotations, immunizations, and a health maintenance schedule); physician-endorsed information resources about health topics; the ability to request a prescription renewal or appointment; a list of pending appointments and lab orders; and private notes patients enter themselves, which are not visible to the clinical staff. In addition, patients can communicate electronically with their health care team.

The EMPOWER-D (Engaging and Motivating Patients Online With Enhanced Resources—for Diabetes) study applies the PHCP tools to support patients with type 2 diabetes. Using a specially designed wireless adaptor that attaches to their glucometer, patients can wirelessly upload their glucometer readings to their PHR from anywhere. When they log into PAMFOnline, they can view the information graphically and correlate their glucose trends with other information about their health behavior (e.g., diet, exercise, medication use). Working from a shared action plan developed specifically for each individual, the patient works with the CM team, primarily using online communication, to adjust their medications or make further lifestyle changes. Custom-tailored “nuggets” of patient education and advice are “dispensed” to a patient based on his/her specific clinical situation (e.g., responding to uploaded glucose readings, nutrition logs, test results, or patient questions). These “nuggets” can be personalized text, videos, graphs, or hyperlinks on topics such as hypoglycemia, controlling food portions, and exercise. The project team also provides a Diabetes Summary Report that consolidates all the relevant information pertaining to their diabetes in a single report. Importantly, the report correlates the patient’s specific action plan with their risk of major complications of diabetes (e.g., stroke, kidney failure, heart attack, blindness).

The project team is evaluating the ODM program for diabetes as compared to usual medical care in a two-arm randomized, controlled trial (RCT) at PAMF. To be included in the trial, patients must have inadequately controlled type 2 diabetes, defined as hemoglobin A1c (HbA1c) >7.5 percent, and be without severe complications. The primary hypothesis under evaluation is that patients in the intervention arm will have lower HbA1c at 12 months post-randomization than those receiving usual medical care. Secondary hypotheses are that, compared with usual medical care, the intervention will be associated with improved self-management practices (e.g., medication adherence, home monitoring of glucose and blood pressure, diet, and exercise); improved biologic measurements such as blood pressure and lipids; better processes of care (e.g., frequency of monitoring tests); lower cardiovascular risk; enhanced patient experience and satisfaction with care; and improved patient psychosocial well-being. These measures will be assessed in both groups by lab testing, EHR data extraction, and an online questionnaire at baseline, 6 months, and 12 months post-randomization.

Specific Aims

- Refine the PHCP platform with a particular focus on enhancing the customization capability of the ODM system and ensuring a seamless incorporation of ODM into the work flow of clinicians on the CM team and with the self-management process of patients. **(Achieved)**
- Evaluate the ODM program for diabetes, relative to usual medical care, in a two-arm RCT. **(Ongoing)**
- Disseminate results of the RCT in the scientific literature and deploy the PHCP program in PAMF and other ambulatory care settings for use with diabetes and other chronic conditions. **(Upcoming)**

2008 Activities: For the initial groundwork activities, the project team obtained institutional review board (IRB) approval of study protocols, materials and clearance to access EHRs; developed the Data and Safety Monitoring Board Charter, presentations, and paper-based materials for orienting PAMF clinicians to the study; and conducted presentations at several sites. The team enhanced the online intervention and conducted alpha and beta testing of two versions of the system with diabetic patients, making additional changes based on the patients' feedback.

The project team has begun recruitment and enrollment into the trial, but has experienced much slower enrollment than expected due to a diabetic population that is 40 percent better controlled than the national benchmark. In response, the project team modified the recruitment procedures and expanded the pool of potential participants to include another geographic location, the Santa Cruz Medical Clinic, which recently merged with the Palo Alto Medical Clinic.

Preliminary Impact and Findings: From beta tests, patients valued their relationship with the nurse diabetes care coordinator and the comprehensive patient-specific risk information in the Diabetes Summary Report, and found online messaging a convenient and efficient alternative to phone calls. Patients commented that starting with manual entry of glucometer and health behavior data provided valuable insights about changes in glucose readings in relation to their dietary intake and physical activity. Following the initial learning period, they valued the efficiency gained through wireless uploading of glucose readings, which makes it easier for them to continue measuring and uploading their readings on a sustained basis.

Selected Outputs

Goknar E. Innovative online diabetes management program will launch in May. *Healthcare Journal of Northern California*. December 2007.

Bohan S. Online diabetes care shows promise. Oakland Tribune. November 5, 2007. Available at: http://findarticles.com/p/articles/mi_qn4176/is_20071105/ai_n21089015/. Accessed June 2009.

Grantee's Most Recent Self-Reported Quarterly Status: The project has experienced an unanticipated challenge in finding enough diabetics who are not adequately controlled. The project team has expanded their geographic sites for recruitment and modified their recruitment procedures. The revised recruitment process has significantly increased the efficiency and yield of recruitment.

Milestones: Progress is mostly on track.

Budget: Somewhat under spent, approximately 5 to 20 percent.