

The Value of Personal Health Records for Chronic Disease Management: What Do We Know?

Mark Tenforde, MPH; Anil Jain, MD; John Hickner, MD, MSc

BACKGROUND AND OBJECTIVES: Electronic personal health records (PHRs) allow patients access to their medical records, self-management tools, and new avenues of communication with their health care providers. They will likely become a valuable component of the primary care Patient-centered Medical Home model. Primary care physicians, who manage the majority of chronic disease, will use PHRs to help patients manage their diabetes and other chronic diseases requiring continuity of care and enhanced information flow between patient and physician. In this brief report, we explore the evidence for the value of PHRs in chronic disease management.

METHODS: We used a comprehensive review of MEDLINE articles published in English between January 2000 and September 2010 on personal health records and related search terms.

RESULTS: Few published articles have described PHR programs designed for use in chronic disease management or PHR adoption and attitudes in the context of chronic disease management. Only three prospective randomized trials have evaluated the benefit of PHR use in chronic disease management, all in diabetes care. These trials showed small improvements in some but not all diabetes care measures. All three trials involved additional interventions, making it difficult to determine the influence of patient PHR use in improved outcomes.

CONCLUSIONS: The evidence remains sparse to support the value of PHR use for chronic disease management. With the current policy focus on meaningful use of electronic and personal health records, it is crucial to investigate and learn from new PHR products so as to maximize the clinical value of this tool.

(Fam Med 2011;43(5):351-4.)

The electronic personal health record (PHR) is “an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure, and confidential environment.”¹ At a

minimum, PHRs allow individuals to manually input health information onto a Web site where it can later be accessed as needed from the Internet. Advanced, interoperable PHRs can electronically transfer a patient’s clinical data from electronic health records (EHRs) of different hospitals,

pharmacies, health insurers, and other health care entities to the patient-controlled PHR. In addition to storage of and access to clinical data, many PHRs provide secure patient-clinician messaging, prescription request and renewal capabilities, access to high-quality educational material, and other features designed to promote patient self management and enhanced communication with health care professionals.

Patient adoption of personal health records has been sluggish. A 2009–2010 national survey estimated that only 7% of Americans reported having used a PHR.² This number will increase as more physicians use electronic health records that interface with patient PHRs. Patient access to PHRs will also be driven by the growth of the primary care Patient-centered Medical Home model.

Personal health records can be used for a variety of purposes but may hold the greatest potential clinical value in chronic disease management, which requires continuity of care and long-term follow-up. Family physicians and other primary care physicians, who provide most chronic disease care, have inadequate time during outpatient appointments to educate patients about the complexities of chronic disease management.³ The population of the United States

From the Medicine Institute, Cleveland Clinic, Cleveland, OH.

is aging, increasing the burden of chronic diseases, which challenges health care organizations to implement innovations for the efficient and effective care of these patients. There is also increasing demand from consumers to shift from a paternalistic model of medical care to a patient-centered model in which the patient is motivated and perhaps incentivized to be an active and informed member of the health care team. Because of the patient-centric nature of PHRs, they are ideally suited for advancing this paradigm change in health care.

We set out to explore the current evidence base for the value of personal health record use in chronic disease management.

Methods

We searched MEDLINE for the following terms (singular and plural): *PHR*, *personal health record*, *personal electronic health record*,

patient-held record, *patient portal*, *personally controlled health record*, *shared electronic medical record*, and *shared electronic health record*. The terms *health information technology*, *shared access*, and *electronic decision support* were also included in the search. Articles were limited to those published in English between January 1, 2000, and September 30, 2010.

Included articles mentioned chronic disease generally or a specific chronic disease(s) in the title and/or abstract and also described programs that fit the above definition of a PHR. Articles on paper-based personal health records were excluded, as were PHR perspective or editorial articles.

We were interested in PHRs that connected patients with health care providers to facilitate information exchange and communication (such as PHRs linked to provider EHRs). We therefore excluded articles on PHRs

with no patient health information input by a health care provider. Such a PHR might include an independent online site that allows individuals to manually enter and store their health-related information.

Results

Of 1,417 articles found, 10 dealt with PHR adoption and attitudes, six included descriptions of existing PHR programs focused on chronic disease management, three dealt with direct clinical outcomes, and two didn't fit into any of the above categories (Figure 1).

Of the three studies with direct clinical outcomes,⁴⁻⁶ all were randomized trials of adults with type 2 diabetes mellitus (DM) (Table 1). In addition to usual care received in primary care practices, patients in intervention groups received access to PHRs that interfaced with their providers' EHRs. Control group patients received either usual care or usual care and access to a PHR that only allowed them to update their family medical history and review non-DM-specific preventive services.⁴ As detailed in Table 1, the interventions resulted in some but variable improvements in diabetes-related process and outcome measures.

None of these studies were "pure" PHR studies. Patients in intervention groups all received other care tools in addition to PHR access, such as regular one-on-one communication with care managers or receipt of telephone and mail-based clinical information. This makes it difficult to determine the individual influence of PHR access on patient outcomes. Other limitations common to these and other health informatics studies include lack of patient blinding (possible Hawthorne effect) and problems with obtaining large sample sizes.⁷ All three studies also suffer from a potential lack of generalizability, in that patients in the studies likely differed from the general population in terms of factors like Internet access and health literacy.

Figure 1: Articles on Personal Health Records

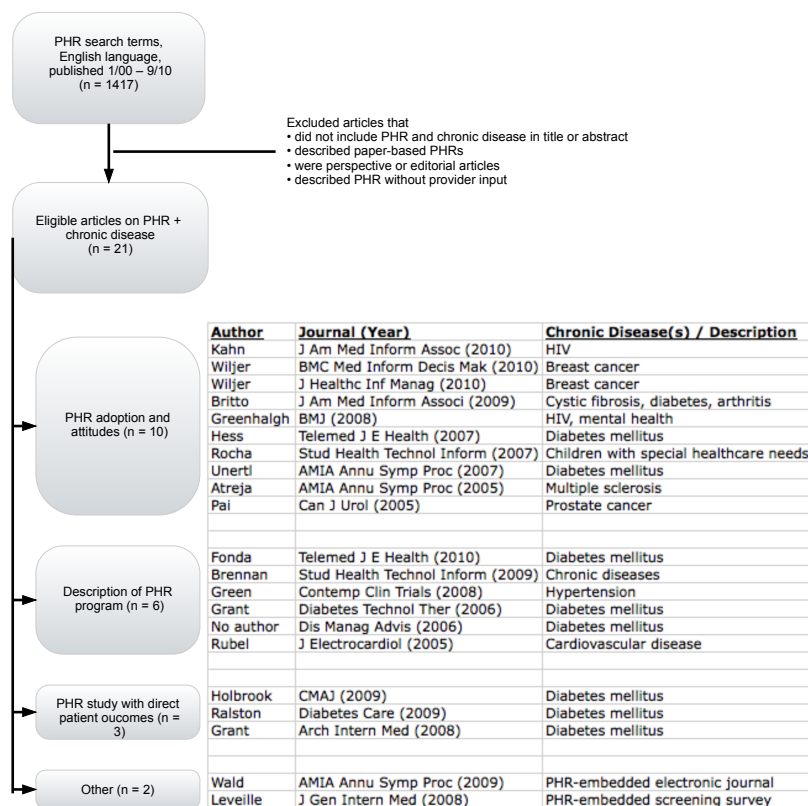


Table 1: Summary of Diabetes-related PHR Studies With Clinical Outcomes

| Authors | Journal (Year) | Sample Size | Intervention | Main Outcomes | Key Findings | Limitations |
|----------------|------------------------|-------------|---|---|---|---|
| Grant et al | Arch Intern Med (2008) | 244 | Access to DM-specific PHR + patient submission of electronic "Diabetes Care Plan" | Change in HbA1c, blood pressure, LDL cholesterol at 12 months; initiation or intensification of DM-related medications at first episode of care after Diabetes Care Plan submission | No difference in improvements in HbA1c, blood pressure, LDL cholesterol between groups; greater intensification of DM-related medications in PHR group versus control group (53% versus 15%, $P < .001$) | Small sample size and well-managed patients with DM limited ability to detect differences; medication intensification likely due to Diabetes Care Plan reducing barriers to medication adjustment |
| Ralston et al | Diabetes Care (2009) | 83 | Access to PHR + Web-based care management (including frequent contact and tailored advice from a care manager) | Change in HbA1c, total cholesterol, systolic and diastolic blood pressure at 12 months | HbA1c declined significantly in intervention compared to usual care group (change -0.7%, $P = .01$) after adjustment for age, sex, baseline HbA1c; mean changes in other outcomes did not differ between groups | HbA1c improvements likely due to care manager, not access to PHR; resources required for care manager intervention likely not available for many practices |
| Holbrook et al | CMAJ (2009) | 511 | Access to DM-specific PHR + telephone reminder system, mailing of diabetes care tracker, instruction to schedule additional visit with family physician | Change in composite scores based on attainment of diabetes-related process and clinical targets (13 variables total, including HbA1c, blood pressure, and cholesterol) at 6 months | Improvement in composite process and clinical scores in intervention group compared to usual care group; minimal differences between groups for individual measures (eg, HbA1c declined only 0.2% more in intervention than control group ($P = .029$)) | Can not determine relative influence of the PHR versus telephone and mail-based interventions; instruction to schedule additional appointment only in intervention group likely affected process scores ¹¹ |

DM—diabetes mellitus, HbA1c—hemoglobin A1c, LDL—low-density lipoprotein, PHR—electronic personal health record

Discussion

Despite the potential of PHR use to enhance chronic disease management and improve patient outcomes, the evidence to support the clinical value remains limited. Three randomized trials of patients with diabetes mellitus show some, albeit

inconsistent improvements in diabetes care in individuals given PHR access. All had study limitations that obscure a clear interpretation of their results.

This does not mean that clinicians should dismiss PHRs as ineffective tools. They provide one avenue for

strengthening relationships between patients and clinicians and of educating and potentially empowering patients in self-management. Further, studies in various settings, including the VA health care system and HIV care clinics, show that patients value their PHRs.^{8,9} The development of

next-generation PHR tools, funded by the Robert Wood Johnson Foundation¹⁰ and others, will offer more tailored, point-of-care patient support for those with diabetes and other chronic diseases. Further research is needed to evaluate and optimize the utility of new PHR programs in chronic disease management, either alone or in combination with other telemedicine interventions or care strategies.

ACKNOWLEDGMENTS: We thank Scott Endsley, MD, and Stasia Kahn, MD, for their manuscript review and suggestions.

CORRESPONDING AUTHOR: Address correspondence to Dr Hickner, Medicine Institute, Cleveland Clinic, 9500 Euclid Avenue, G10, Cleveland, OH 44195. 216-445-8915 Fax: 216-636-0046. hicknej@ccf.org.

References

1. Connecting for health. The Personal Health Working Group final report. July 1, 2003. www.providersedge.com/.../The_Personal_Health_Working_Group_Final_Report.pdf.
2. Undem T. Consumers and Health Information Technology: A National Survey. April 2010. <http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey>.
3. Ostbye T, Yarnall KS, Krause KM, Pollak KI, Gradison M, Michener JL. Is there time for management of patients with chronic diseases in primary care? *Ann Fam Med* 2005;3(3):209-14.
4. Grant RW, Wald JS, Schnipper JL, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. *Arch Intern Med* 2008;168(16):1776-82.
5. Ralston JD, Hirsch IB, Hoath J, Mullen M, Cheadle A, Goldberg HI. Web-based collaborative care for type 2 diabetes: a pilot randomized trial. *Diabetes Care* 2009;32(2):234-9.
6. Holbrook A, Thabane L, Keshavjee K, et al. Individualized electronic decision support and reminders to improve diabetes care in the community: COMPETE II randomized trial. *CMAJ* 2009;181(1-2):37-44.
7. Shcherbatykh I, Holbrook A, Thabane L, Dolovich L, COMPETE III investigators. Methodologic issues in health informatics trials: the complexities of complex interventions. *J Am Med Inform Assoc* 2008;15(5):575-80.
8. Nazi KM. Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users' characteristics, needs, and preferences. *J Am Med Inform Assoc* 2010;17(2):203-11.
9. Kahn JS, Hilton JF, Van Nunnery T, et al. Personal health records in a public hospital: experience at the HIV/AIDS clinic at San Francisco General Hospital. *J Am Med Inform Assoc* 2010;17(2):224-8.
10. Brennan PF. Project HealthDesign: rethinking the power and potential of personal health records. June 17, 2009. <http://www.projecthealth-design.org/>.
11. Grant RW, Middleton B. Improving primary care for patients with complex chronic diseases: can health information technology play a role? *CMAJ* 2009;181(1-2):17-8.