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

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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, 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. As detailed in Table 1, the interventions resulted in some but variable improvements in diabetes-related process and outcome measures. 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. 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.
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. The development of

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<th>Authors</th>
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<td>Grant et al</td>
<td>Arch Intern Med (2008)</td>
<td>244</td>
<td>Access to DM-specific PHR + patient submission of electronic “Diabetes Care Plan”</td>
<td>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</td>
<td>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&lt;.001)</td>
<td>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</td>
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<td>Ralston et al</td>
<td>Diabetes Care (2009)</td>
<td>83</td>
<td>Access to PHR + Web-based care management (including frequent contact and tailored advice from a care manager)</td>
<td>Change in HbA1c, total cholesterol, systolic and diastolic blood pressure at 12 months</td>
<td>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</td>
<td>HbA1c improvements likely due to care manager, not access to PHR; resources required for care manager intervention likely not available for many practices</td>
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<td>Holbrook et al</td>
<td>CMAJ (2009)</td>
<td>511</td>
<td>Access to DM-specific PHR + telephone reminder system, mailing of diabetes care tracker, instruction to schedule additional visit with family physician</td>
<td>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</td>
<td>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 ))</td>
<td>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} )</td>
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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. The development of
next-generation PHR tools, funded by the Robert Wood Johnson Foundation 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.

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