

Personal Health Records for Patients with Chronic Disease

A Major Opportunity

S. Wells^{1,2}; R. Rozenblum²; A. Park²; M. Dunn³; D.W. Bates^{2,3}

¹Section of Epidemiology and Biostatistics, School of Population Health, University of Auckland, Auckland, New Zealand;

²Department of General Internal Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts;

³Department of Health Care Policy and Management, Harvard School of Public Health, Boston, Massachusetts

Keywords

Personal health records, electronic health records, chronic disease, adoption

Summary

Background: Personal health records (PHRs) connected to a physician's electronic health record system hold substantial promise for supporting and engaging patients with chronic disease.

Objectives: To explore how U.S. health care organizations are currently utilizing PHRs for chronic disease populations.

Methods: A mixed methods study including semi-structured interviews and a questionnaire was conducted. A purposive sample was developed of health care organizations which were recognized as exemplars for PHRs and were high performers in national patient satisfaction surveys (H-CAHPS or CAHPS). Within each organization, participants were health IT leaders or those managing high-risk or chronic disease populations.

Results: Interviews were conducted with 30 informants and completed questionnaires were received from 16 organizations (84% response rate). Most PHRs allowed patients to access health records and educational material, message their provider, renew prescriptions and request appointments. Patient generated data was increasingly being sought and combined with messaging, resulted in greater understanding of patient health and functioning outside of the clinic visit. However for chronic disease populations, there was little targeted involvement in PHR design and few tools to help interpret and manage their conditions beyond those offered for all. The PHR was largely uncoupled from high risk population management interventions and no clear framework for future PHR development emerged.

Conclusion: This technology is currently underutilized and represents a major opportunity given the potential benefits of patient engagement and shared decision making. A coherent patient-centric PHR design and evaluation strategy is required to realize its potential and maximize this natural hub for multidisciplinary care co-ordination.

Correspondence to:

Sue Wells
Section of Epidemiology and Biostatistics
School of Population Health
University of Auckland
Private Bag 92019 Auckland Mail Centre
Auckland
Email: s.wells@auckland.ac.nz

Appl Clin Inform 2014; 5: 416–429

DOI: 10.4338/ACI-2014-01-RA-0002

received: January 3, 2014

accepted: March 5, 2014

published: April 23, 2014

Citation: Wells S, Rozenblum R, Park A, Dunn M, Bates DW. Personal health records for patients with chronic disease: A major opportunity. *Appl Clin Inf* 2014; 5: 416–429 <http://dx.doi.org/10.4338/ACI-2014-01-RA-0002>

1. Background

Chronic diseases such as diabetes and chronic respiratory disease affect quality of life, limit daily activities and cause long-term disability. Nearly half of all American adults suffer from a chronic condition, with one in four having multiple comorbidities [1]. Asked why he robbed banks, Willie Sutton reportedly said “because that’s where the money is.” The same could be said for chronic disease. Patients with multiple comorbidities account for around two-thirds of the annual U.S. spending on health [1] and could gain substantially from targeted care to improve health outcomes.

To address the escalating burden of chronic disease, the agenda has focused on the importance of the patient-clinician interaction, shared decision making and patient engagement in the care process [2-4]. These approaches have been associated with improvements in clinical outcomes, health service efficiency and positive business metrics [3, 5].

One strategy to promote patient engagement, patient-clinician communication and continuity of care is the use of personal health records (PHRs) connected to a health provider’s electronic health record (EHR). Also known as a patient portal, this type of PHR provides an internet entry point to a patient’s own health data. Paired with functionality like secure messaging, the PHR increases the range of interactions a patient can have with their care team.

The federal government incentive program for ‘meaningful use’ of EHRs [6] includes objectives focusing on timely patient access to their health information. While it is likely that many more physicians will soon implement PHRs in response to the program, will this pay dividends for those patients with chronic disease? Compared to the ‘healthy’, these patients have greater information needs, greater complexity of care and require sustained co-ordination, typically across multiple providers. While they are less likely than healthy adults (62% vs. 81%) to have internet access [7], circumstances are changing with the rapid rise in adoption of smart phone technology [8]. Indeed, once chronic disease patients have internet access, they are more likely to seek health information online [7] and also to adopt PHRs than those without chronic disease [9, 10].

2. Objectives

The aim of this study was to investigate how leading U.S. health care organizations are currently utilizing PHRs for chronic disease populations.

3. Methods

3.1 Sampling frame

The authors asked members of the Office of the National Coordinator for Health Information Technology (ONC), health information technology (HIT) experts, and patient-centered care experts to identify health care organizations that they recognized as PHR leaders. The recommended sites were then screened to ensure they met two criteria:-1) they had a PHR in place for at least 12 months and 2) scored in the top 75th percentile for two overall patient rating questions (*‘global rating of care’* and *‘willingness to recommend’*) within the Hospital or Clinician Group Consumer Assessment of Healthcare Providers and Systems (HCAHPS or CAHPS) surveys [11].

3.2 Study instruments

A mixed methods study was conducted that included semi-structured interviews and a web-based survey (supplementary files ► Appendix 1 and ► Appendix 2). This approach was chosen as qualitative methods can provide “rich descriptions of complex phenomena” [12] typical of healthcare organization and IT implementation. Based on our (RR, DWB) prior research [13], literature review and expert opinion, interview questions were constructed to explore PHR uptake and use of by patients with chronic disease. Questions covered registration, content, monitoring, perceived value

and future design. The survey provided complementary data including organizational demographics, PHR functionalities and registration statistics.

3.3 Study participants

Within each eligible organization, HIT leaders and clinical directors who were managing 'high-risk' or chronic disease populations were invited to participate. After receiving consent, a time for a telephone interview was scheduled and participants were sent a web-link to the survey. The study instruments were piloted with one site to ensure clarity and minor changes were made based on the feedback. One author (SW) conducted the interviews early-mid 2013 which were digitally recorded and a transcribing service provided verbatim manuscripts. Interviewee consent was given verbally and each was informed about the confidentiality of their responses.

3.4 Analysis

Researchers imported transcribed interviews into AtlasTi (ATLAS.ti GmbH, Berlin, Germany) and entered data from the surveys into Excel (Microsoft Windows 7). Using a grounded theory inductive approach as described by Straus and Corbin [14], three authors (SW, AP, RR) systematically coded the transcripts to identify, categorize and sort key concepts. Codes were then grouped into emergent themes and relationships after iterative reading and discussion with the two other authors (MD, DWB). Potentially identifying information was masked to protect the participants.

4. Results

Nineteen health care organizations met our sampling criteria. Of these, 16 (84%) agreed to participate, two declined and one did not respond to our invitation. We conducted 30 interviews (mean 50 minutes) with informants from sites located in all major U.S. regions. The informants held roles of Chief Information Officer (6), Directors of e-Health Services (11), other titles such as VP Information Technology, Management Analyst, Medical Informaticist, or Biomedical Informatics specialists (5) and Medical Directors or internists with specialist interests in Chronic Disease Management, Quality, Primary Care, or Population Health (8). The majority (80%) were physicians.

The survey was completed by all participating organizations. Thirteen of the 16 (81%) reported that they were integrated delivery systems (► Table 1). Three quarters of the institutions had hosted a PHR for six years or more. Overall, 9 million people had PHR user accounts, with seven organizations having over 300,000 people registered.

PHR functionality

► Table 1, ► Table 2 and ► Table 3 describe the PHR functionalities available or planned in the near future at participating organizations. All patients could access their problem list, medications, allergies, time/date of visits, laboratory results, message their care team and request appointments or prescription refills. All but one institution also included the immunization history. The majority of organizations offered (or planned to implement soon) test results for pathology and radiology and patient reminders such as for appointments or preventive care. The clinical summary, part of Meaningful Use Stage 2 criteria, was being planned or already offered by 15/16 of the sites. Over two-thirds (11/16) had or were planning to provide access to visit notes made at the time of a patient's appointment. During the course of the interview other features were often mentioned (but not systematically elicited). Organizations (7/16) had also given patients the ability to self-schedule their appointments online.

All interviewees agreed that the most popular PHR features were the ability to view laboratory results, send and receive messages and request an appointment or prescription refill. Educational material was universally available, usually tailored to a patient's problem list and linked to an external supplier such as the National Library of Medicine or 'vetted' companies specializing in patient edu-

educational resources. The reading level of material was set between grades 5–8 and commonly available in Spanish and English.

Strategic positioning

The PHR was in general viewed as a service provided to all rather than a mechanism with specific value for chronic disease patients. We found a disconnect between use of the PHR and programs for high-needs patients or other high-risk population strategies such as those aimed at improving care co-ordination and reducing readmissions. These groups were often managed separately by case managers from registries.

Patient involvement

Patients were involved with decisions about the PHR through high level committees such as multi-disciplinary portal oversight committees or patient and family councils. Most sites had conducted evaluations of their PHR via focus groups (8/16), PHR usability testing with direct observation (5/16) and patient surveys (8/16). Individual patients could also provide input through the PHR helpline and website customer feedback buttons. However, while patients with chronic disease were often serendipitously involved, no interviewee reported targeted inclusion or evaluation of these patients at any level of these assessments - from committee membership to usability testing. Two organizations were in the process of replacing their internally developed “home-grown” portals for commercially developed PHRs. The onus was therefore shifting to vendors to ensure usability and to embed patients within the design process.

Condition-specific pages

Condition-specific pages, used in five organizations, were the only core functionality targeted for patients with chronic diseases beyond those offered for all. These were derived by filtering the data in the EHR so that only information relevant to a condition such as heart failure (e.g. test results, medications, reminders and linked educational material) appeared on a webpage. None of the interviewees reported tailoring educational material to a patient’s combined risk profile or providing any online functionality to help patients manage and interpret the overlap between conditions (e.g. hypertension, diabetes and kidney disease).

Physician Annotation

While provided as a standard feature, three interviewees discussed the value of annotation as a unique ‘coaching’ moment for patients with chronic disease. This functionality gave physicians the ability to personalize advice on patient-facing records. Examples were annotating patient instructions or agreed goals to the clinical summary report or adding a personalized comment to laboratory results prior to release.

Home monitoring data

Home-monitoring through which patient data could be added to the EHR after clinician approval was available in 8/16 institutions. Examples included blood pressure, glucose, peak flow, weight, pedometer steps and seizure frequency. Data were usually entered as free text in a message to the doctor’s clinic, or entered via a disease-specific template. However, patients had few, if any, tools available to enable them to manipulate or visualize the data. While there were instances of pilots using wireless devices to automatically upload data to the patient’s EHR, these were not generally in routine use. Impediments included technical difficulties and lack of integration between the telemedicine program and PHR. For example, one interviewee said that telemonitoring was the domain of a care co-ordinator for intensive case management who was not necessarily connected (electronically or literally) to other members of the care team.

Other patient-generated data

Data that could only be generated by the patient was highly valued as it allowed both the patient and care team to prepare in advance for the visit, provide more complete and accurate data, and focus discussions on care planning and treatment options. Many organizations (10/16) were experimenting with pre-visit structured questionnaires and templates that could be filled in online by the patient. Various types of data were gathered from these forms. For some organizations, the motivation was to streamline office visits by pre-empting data that would normally be collected during an appointment, such as family and social history, asthma or other condition-specific status. One organization had trialled sending medication reconciliation questionnaires to the patient through the PHR and found patients could ably identify discrepancies. Other organizations used electronic forms to gather a broader picture of the patient's health status by sending more complex questionnaires related to quality of life or a comprehensive health profile (e.g. Medicare Total Health Assessment).

A minority of organizations (4/16) were experimenting with methods to capture patient data as a means to deliver patient-focused decision support. One example was eliciting pain scores from patients via the PHR and given the score, the patient would receive immediate advice based on an automated algorithm.

Interviewees reported that the more organizations opened up the electronic record to receive patient-generated data, the richer the patient-provider experience. Combined with secure messaging, the inclusion of patient-reported data resulted in a far greater understanding of patient health and functioning outside of the clinic visit. (► Box 1. Quotes A, B).

Patients with multiple comorbidities

Most (24/30) interviewees thought that the PHR could be improved to better handle multiple comorbidities from a patient's perspective, but few had suggestions for change. However, two rejected the notion that PHRs should be expected to handle multiple comorbidities any better than they currently do, largely because of the complexity inherent in doing this electronically. Many (15/30) thought that the strongest value of the portal for these patients was the two-way conversations between office visits and access to their health information in a single location, although they acknowledged that the sheer volume of data might be overwhelming. In terms of human resource to support patients navigate their health data, all PHRs had provisions for proxy access by an authorized family member or home care-giver. However, proxy access was often limited to 'within organization only' – thus often preventing this support.

Future PHR design and functionality

Most participants envisioned the future PHR as a platform where the patient could become an active and informed participant in their care. There seemed to be a large range of enhancement activities occurring, but no overarching framework or direction for future design to improve PHRs for those with chronic disease. Accessibility was a common theme with many organizations planning mobile applications (and even voice navigation) to reduce barriers to portal adoption.

Enhancing educational resources was a common goal. For example, three organizations were looking at the possibility of actively "pushing" relevant educational information out to patients. This might include information on a new patient support group operating in the neighborhood, or for a given diabetes profile to pro-actively transmit small articles that might be useful. The benefit of using the PHR in this regard was the ability to automate delivery of pre-loaded educational material tailored to a patient's clinical profile.

There were some instances of using the PHR as a means to streamline and co-ordinate the patient's care experiences. For example, for one delivery system, instead of a patient receiving separate messages from multiple providers, this would be centrally bundled as a single communication that also facilitated scheduling with these diverse providers. Another viewed the platform as a critical tool for dynamic shared goal setting and care planning. As most health care happens outside of the clinic visit, the PHR allowed patients to provide important interim data for such conversations. (► Box 1. Quotes B, C)

Further out on the horizon was an interest in creating a sense of the patient journey over time. For example, several highlighted the potential for visualization, decision aids or other decision support tools that could help patients better understand their data and disease control. One participant talked about the possibility of incorporating decision analytic trees that would allow the patient to see the impact of behavior change, such as weight loss and medication adherence, on his or her condition. Finally, interviewees also discussed harnessing the power of social networks within the context of the PHR to promote and even “game-ify” behavior modification. This might include online communities for particular conditions or clinician-moderated support groups.

5. Discussion

This study identified what leading U.S. health care organizations routinely offered patients through their PHRs with a particular focus on chronic disease populations. The portal was in general viewed as a service provided to all without a mechanism to ensure patients with one or more chronic disease were specifically involved in design and development- -a critical gap given the need to engage this population more deeply in their care. Most organizations included a number of standard features in their PHRs, such as convenient communication with the care team, increased provider interaction (e.g. annotation of laboratory results) and access to health records and high quality educational material. All the organizations have also embraced patient-generated data becoming part of the medical record. While these are positive steps forward for patients, there was remarkably little targeted support for patients with chronic diseases. As well as bolstering multi-condition functionalities, this could be a key step toward the PHR becoming a tool that enables patients to be more active partners in their care.

The PHRs of today are systems in their early development, perhaps akin to a Model T Ford of what could eventually evolve [15]. Future plans are numerous but seem to be haphazard. Strategic design, building on an explicit theory of change or sound theoretical or evaluation frameworks [16-18], is critical if organizations hope to leverage the PHR as a tool for shared decision making and care planning. Future strategies that foster greater patient activation by allowing them to better understand their conditions and support self-management are particularly promising [19]. The use of decision aids is being promoted widely [4] and the PHR has a role here for tailored dissemination to patients. In addition, PHRs need to be well aligned with existing strategies for care co-ordination and other organizational programs for those at highest risk.

The unique needs of people with chronic conditions are currently underexplored by organizations deploying PHRs. Qualitative studies focusing on vulnerable populations such as those with chronic disease to inform PHR design and development have been conducted [16, 20-23]. Content, look-and-feel, site performance, functionality and navigation all impact on usability and patient activation [21, 23]. Patients with congestive heart failure found access to their records helped them learn about their condition, improved their ability to co-ordinate care, served as a memory aid and increased their participation [20]. Patients with chronic inflammatory bowel diseases (IBD) believed that a patient diary within the PHR was key to illness ownership and empowerment since the patient determined content, recorded facts of their illness experience and that the diary contributed to the medical records [16]. Patients with IBD also thought that for a PHR to be truly ‘useful’ it would need to be personalized to the specific needs of the patient and that informational requirements would vary with the natural history of the disease [16].

Studies of US PHRs have largely been descriptive, investigating PHR adoption and use [10, 24-28], policies and governance [29, 30], and as a means for improving patient centeredness [31]. Our findings indicate a wider availability of data, particularly clinical notes (e.g. clinical summary, visit notes), pathology and radiology reports, than previously reported [29, 31]. This may be a reflection of Meaningful Use policy [6] as well as the reassurance gained from the Open Notes project [32]. After releasing visit notes, providers did not experience bombardment from confused patients. Rather, patients who read at least one visit note reported increased medication adherence and felt more in control [32].

The limited number of specific PHR functionalities for chronic disease may due to a number of factors. Recent HIT policy has been extremely influential in driving EHR uptake and will encourage

PHR implementation as well [33]. However, while providing guidance on the clinical building blocks for health IT data, standards and knowledge transfer, the EHR incentive program has no specific prescription for those with chronic disease [33]. In addition there is a relative sparseness of evidence. A recent systematic review [34] investigated the clinical impact of secure messaging and patient access to their own medical record. They identified generally positive results, especially for the use of secure messaging to improve glucose outcomes for patients with diabetes and increased patient satisfaction [34]. We agree with experts who have called for a PHR research agenda to guide implementation of PHRs and components of PHRs that are most likely to be effective and useful for patients [35, 36]. Specifically there is a need to focus on developing a patient-centric PHR that reflects a patient's preferred form of accessing and using their data.

The strengths of the study include a high response rate from the identified institutions. The interviewees represented both clinical and IT perspectives and most of them had been at their institution for some time. The analyses were conducted by a team with mixed disciplinary backgrounds (clinical, sociological and management) and perspectives. The weaknesses were that these institutions represent mainly integrated delivery systems and demonstrate what well-funded, well-organized systems have achieved. As such they are not a representative sample of all health organizations with PHRs nor reflect the experience of smaller providers. Using our sampling strategy it is also likely that some innovative institutions were not identified and it is possible that our number and choice of informant roles was too small to provide adequate representation of the issue. However, the use of PHRs is not widespread and therefore they do represent much of the current offerings and experience in this area of PHRs for chronic disease patients. Further interviews with institutions that aren't considered PHR exemplars would also be useful, although it is likely that they would show even less development than we identified. An additional weakness was that reported functionalities were not validated other than by aggregating and cross-referencing all data from each institution. Moreover, in this study we did not include patients and as such, their views on this topic. Nevertheless, our conclusions are likely to capture the dominant provider opinions.

6. Conclusions

PHRs represent a vehicle for patient engagement and activation and a tool for self-management support. However, even in the best healthcare systems in the U.S they are underused. The potential leverage of PHRs (on health outcomes and costs of care) within the HIT infrastructure of real working institutions is, at present, just potential and will deserve rigorous evaluation as it develops. PHRs with greater focus and interoperability between clinical teams, patients and their home care-givers must be given a priority for research and development. In light of changing payment schemes that hope to incent value instead of volume, the moment is ripe to investigate PHRs as a tool to help achieve such aims. There is an urgent need to invest in high quality PHR research for patients with chronic diseases, and government agencies such as ONC and CMS should monitor this research to determine if a more proactive stance is needed to encourage the development of sufficient patient-centered functionality and maximize this natural hub for multidisciplinary care co-ordination.

Clinical Relevance

Personal health records (PHRs) connected to a health provider's electronic health record (EHR) are a powerful vehicle to support patient-clinician interaction, patient information needs, and engagement in the care process. We investigated how these tools were currently being targeted to high costs, high needs patients with chronic disease. We found that leading US healthcare organizations offer PHRs as a service for 'all', but currently missing opportunities to maximize the content for patients with chronic disease and utilize this technology for care co-ordination and population management.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects, and was reviewed and approved by thePartners Institutional Review Board (2010-P-000179/20).

Acknowledgements

The authors thank the many people who agreed to be interviewed for this project and those who helped facilitate the interviews.

Authorship

All listed authors have made substantial contributions to: (1) conception and design, acquisition of data and/or analysis/interpretation of data and (2) drafting and/or critical revision of the article for important intellectual content.

Funding sources

During the conduct of this study, Susan Wells was funded by The Commonwealth Fund as a 2012/13 Harkness Fellowship in Health Policy and Practice

Conflicts of Interest

In her current role, Susan Wells is partly funded by the Stevenson Foundation and has received research grants from the Health Research Council of New Zealand, Roche Diagnostics Ltd, and from National Heart Foundation of New Zealand outside the submitted work.

David W Bates reports personal fees from SEA Medical, personal fees from Zynx, grants and personal fees from EarlySense. In addition, he has a patent on decision support software licensed to Medicalis with royalties.

Marie Dunn completed a 2013 summer internship at InterSystems Corporation.

Box 1 Quotes from interviewees regarding organizational experience with PHRs

- A. *"I...had a patient who had a movement disorder.....his leg would start shaking at odd times but it would never happen when he was in the office. But he took a video of it with his iPhone when he was in bed one night. And then.....uploaded it to YouTube and sent me the link so I could view it."*
- B. *"We also instituted a new feature last year that allows a patient to upload photos....such as... "Here's my suture site, is this infected?" ...But because we also allowed patients to upload PDF files, we started seeing diabetes logs coming in that way. We started seeing food diaries coming into our weight management program. We started seeing headache logs coming in for a neurology group."*
- C. *"...when you see somebody in the context of an office visit, we're really just getting a snapshot. We don't get the full-length feature film of what goes on in their everyday lives andwe really don't know for sure how wildly their blood sugars are spiking or how labile their blood pressure may be...And that may affect our... advice for lifestyle changes and those sort of things."*

Table 1 Characteristics of Organizations, PHR, patient registrations and PHR Communication Functions

Organization	Type ¹	PHR Type ²	Years Implemented	Patient Registrations (Active accounts) ³	PHR Communication Functions			
					2-Way Messaging	Request Prescription Refill	Request Appointment	Patient Reminders
1	IDS	Home grown switching to vendor soon	10	312,000	Y	Y	Y	F
2	AMC	Home grown	13	60,000	Y	Y	Y	Y
3	IDS	Home grown	9	>500,000 (>500,000)	Y	Y	Y	Y
4	IDS	Vendor previously home-grown	8	259,000 (230,000)	Y	Y	Y	Y
5	IDS	Vendor previously home grown	10	>500,000 (>500,000)	Y	Y	Y	Y
6	IDS	Vendor	12	200,000	Y	Y	Y	Y
7	IDS	Vendor	11	200,000	Y	Y	Y	Y
8	IDS	Vendor	1	55,000	Y	Y	Y	F
9	ACN	Vendor	12	(400,000)	Y	Y	Y	Y
10	IDS	Home grown	7	337,000	Y	Y	Y	Y
11	IDS	Home grown switching to vendor soon	5	375,000 (208,000)	Y	Y	Y	F
12	IDS	Hybrid model	5	220,000	Y	Y	Y	Y
13	IDS	Hybrid model	8	397,000	Y	Y	Y	Y
14	IDS	Home grown	8	129,800	Y	Y	Y	Y
15	ACN	Vendor	4	<50,000	Y	Y	Y	F
16	IDS	Vendor	8	122,000 (93,000)	Y	Y	Y	F

Y= yes, currently available, F = Future plans to implement,

1. IDS Integrated Delivery System; AMC Academic Medical Center; ACN Ambulatory Care Network

2. Hybrid model- PHR is part home grown and part vendor supplied

3. missing data (registrations or active accounts defined as unique patients logging in the past year) as per survey responses, where the estimate is >500,000, the actual numbers not shown to protect institutional identity

Table 2 PHR Clinical Functions currently offered by organization

Organization	PHR Clinical Functions											Clinical Summary
	Problem List	Medication List	Allergies	Record of Visits	Immunizations	Laboratory Results	Pathology Results	Radiology Results				
1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	F
2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	F
3	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Y	Y	Y	Y	Y	Y	Y	Y	F	F	F	Y
5	Y	Y	Y	Y	Y	Y	Y	Y	F	F	F	Y
6	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	F	F
7	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	F	Y
8	Y	Y	Y	Y	Y	Y	Y	Y	Y	F	F	Y
9	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10	Y	Y	Y	Y	F	Y	Y	Y	Y	Y	Y	Y
11	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
12	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
13	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
14	F	Y	Y	Y	Y	Y	Y	NR	NR	Y	Y	NR
15	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	F	Y
16	Y	Y	Y	Y	Y	Y	Y	F	F	Y	F	Y

Y = Yes, currently available, F = Future plans to implement,

Table 3 PHR Clinical Functions currently offered by organization and additional PHR features reported during interviews

Organization	PHR Clinical Functions					Additional PHR Features Reported During Interviews ¹					
	Family History	Social History and Lifestyle	Visit Notes	Operation Notes	Home Monitoring	Chronic Condition-Specific Pages	Pre-Visit Templates or Questionnaire	Capture Patient Data to Deliver Decision Support	Self-Schedule Appointment		
1	F	F	No	No	Y	Y	Y				
2	F	Y	Y	F	No	Y	Y	Y	Y		
3	No	No	Y	Y	Y	Y					
4	F	No	No	No	Y				Y		
5	Y	F	No	No	Y				Y		
6	Y	F	Y	F	No		Y	Y			
7	Y	No	Y	Y	Y	Y	Y				
8	F	F	F	Y	No				F		
9	No	No	Y	No	Y	F	Y	Y			
10	Y	Y	F	Y	F		Y				
11	Y	Y	Y	No	F		Y		Y		
12	Y	No	Y	F	F		Y				
13	No	No	F	No	No		Y		Y		
14	F	F	No	No	Y	Y		Y			
15	Y	Y	F	F	F				Y		
16	Y	Y	No	No	Yes	F					

Y = Yes, currently available, No = No, not offered, F= Future plans to implement, NR = No Response on survey and Not Reported in interviews
 1. Additional PHR Features were reported during the interviews rather than systematically captured via the survey and therefore may be an incomplete view of actual current status.

References

1. US Department of Human and Health Services. HHS Initiative on Multiple Chronic Conditions. Secondary HHS Initiative on Multiple Chronic Conditions 2012. <http://www.hhs.gov/ash/initiatives/mcc/>.
2. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T. *Through the Patient's Eyes: Understanding and Promoting Patient-centered Care*. San Francisco: Jossey-Bass, 1993.
3. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs* 2013; 32(2): 207–214.
4. Legare F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Affairs* 2013; 32(2): 276–284.
5. Charmel P, Frampton S. Building the business case for patient centered care. *Healthcare Financial Management* 2008; 62: 80–85.
6. Centers for Medicare and Medicaid Services. Stage 1 vs Stage 2 comparison table for eligible professionals. Secondary Stage 1 vs Stage 2 comparison table for eligible professionals 2012. <https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stage1vsStage2CompTables-forEP.pdf>.
7. Fox S, Purcell K. Chronic disease and the Internet. <http://www.pewinternet.org/Reports/2010/Chronic-Disease.aspx>: Pew Internet and American Life Project, 2010.
8. Zickhur K, Smith A. Digital differences. <http://pewinternet.org/Reports/2012/Digital-differences.aspx>: Pew Internet and American Life Project, 2012.
9. Hsu J, Huang J, Kinsman J, Fireman B, Miller R, Selby J, Ortiz E. Use of e-Health services between 1999 and 2002: a growing digital divide. *Journal of the American Medical Informatics Association* 2005; 12(2): 164–171.
10. Yamin CK, Emani S, Williams DH, Lipsitz SR, Karson AS, Wald JS, Bates DW. The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine* 2011; 171(6): 568–574.
11. Centers for Medicare and Medicaid Services. HCAHPS: Patients' Perspectives of Care Survey. Secondary HCAHPS: Patients' Perspectives of Care Survey 2012. <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS.html>.
12. Sofaer S. Qualitative methods: what are they and why use them? *Health Services Research* 1999; 34(5 Pt 2): 1101–1118.
13. Rozenblum R, Jang Y, Zimlichman E, Salzberg C, Tamblyn M, Buckeridge D, Forster A, Bates DW, Tamblyn R. A qualitative study of Canada's experience with the implementation of electronic health information technology. *CMAJ Canadian Medical Association Journal* 2011; 183(5): E281–288.
14. Strauss A, Corbin J. *Basics of qualitative research: grounded theory procedures and techniques*. California: Sage Publications, 1990.
15. Bates DW, Wells S. Personal health records and health care utilization. *JAMA* 2012;308(19):2034–6
16. Winkelman WJ, Leonard KJ, Rossos PG. Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *Journal of the American Medical Informatics Association* 2005; 12(3): 306–314.
17. Venkatesh V, Morris M, Davis G, Davis F. User acceptance of information technology: toward a unified view. *MIS Quarterly* 2003; 27(3): 425–478.
18. Winkelman WJ, Leonard KJ. Overcoming structural constraints to patient utilization of electronic medical records: a critical review and proposal for an evaluation framework. *Journal of the American Medical Informatics Association* 2004; 11(2): 151–161.
19. Bernabeo E, Holmboe ES. Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs* 2013; 32(2): 250–258.
20. Earnest MA, Ross SE, Wittevrongel L, Moore LA, Lin C-T. Use of a patient-accessible electronic medical record in a practice for congestive heart failure: patient and physician experiences. *Journal of the American Medical Informatics Association* 2004; 11(5): 410–417.
21. 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. *Journal of the American Medical Informatics Association* 2010; 17(2): 203–211.
22. Ralston JD, Revere D, Robins LS, Goldberg HI. Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. *BMJ* 2004; 328(7449): 1159.
23. Siek KA, Khan DU, Ross SE, Haverhals LM, Meyers J, Cali SR. Designing a personal health application for older adults to manage medications: a comprehensive case study. *Journal of Medical Systems* 2011; 35(5): 1099–1121.

24. Ancker JS, Barron Y, Rockoff ML, Hauser D, Pichardo M, Szerencsy A, Calman N. Use of an electronic patient portal among disadvantaged populations. *Journal of General Internal Medicine* 2011; 26(10): 1117–1123.
25. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in enrollment and use of an electronic patient portal. *Journal of General Internal Medicine* 2011; 26(10): 1112–1116.
26. Lyles CR, Harris LT, Jordan L, Grothaus L, Wehnes L, Reid RJ, Ralston JD. Patient race/ethnicity and shared medical record use among diabetes patients. *Medical Care* 2012; 50(5): 434–440.
27. Roblin DW, Houston TK, 2nd, Allison JJ, Joski PJ, Becker ER. Disparities in use of a personal health record in a managed care organization. *Journal of the American Medical Informatics Association* 2009; 16(5): 683–689.
28. Sarkar U, Karter AJ, Liu JY, Adler NE, Nguyen R, Lopez A, Schillinger D. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association* 2011; 18(3): 318–321.
29. Collins SA, Vawdrey DK, Kukafka R, Kuperman GJ. Policies for patient access to clinical data via PHRs: current state and recommendations. *Journal of the American Medical Informatics Association* 2011; 18 (Suppl 1): i2–i7.
30. Reti SR, Feldman HJ, Safran C. Governance for personal health records. *Journal of the American Medical Informatics Association* 2009; 16(1): 14–17.
31. Reti SR, Feldman HJ, Ross SE, Safran C. Improving personal health records for patient-centered care. *Journal of the American Medical Informatics Association* 2010; 17(2): 192–195.
32. Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, Feldman HJ, Mejilla R, Ngo L, Ralston JD, Ross SE, Trivedi N, Vodicka E, Leveille SG. Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. *Annals of Internal Medicine* 2012; 157(7): 461–470 doi: 10.7326/0003-4819-157-7-201210020-00002.
33. Blumenthal D, Tavenner M. The „meaningful use“ regulation for electronic health records. *New England Journal of Medicine* 2010; 363(6): 501–504.
34. Goldzweig C, Towfigh A, Paige N, Orshansky G, Haggstrom D, Beroes J, Mlake-Lye I, Shekelle P. Systematic Review: Secure Messaging Between Providers and Patients, and Patients' Access to Their Own Medical Record: Evidence on Health Outcomes, Satisfaction, Efficiency and Attitudes VA-ESP Project #05–226. Washington: Department of Veterans Affairs, 2012.
35. Ahern DK, Woods SS, Lightowler MC, Finley SW, Houston TK. Promise of and potential for patient-facing technologies to enable meaningful use. *American Journal of Preventive Medicine* 2011; 40(5 (Suppl. 2)): S162–S172.
36. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association* 2008; 15(6): 729–736.