

Personal health records: a scoping review

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ABSTRACT

Electronic personal health record systems (PHRs) support patient centered healthcare by making medical records and other relevant information accessible to patients, thus assisting patients in health self-management. We reviewed the literature on PHRs including design, functionality, implementation, applications, outcomes, and benefits. We found that, because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record adoption. Many PHR systems are physician-oriented, and do not include patient-oriented functionalities. These must be provided to support self-management and disease prevention if improvements in health outcomes are to be expected. Differences in patient motivation to use PHRs exist, but an overall low adoption rate is to be expected, except for the disabled, chronically ill, or caregivers for the elderly. Finally, trials of PHR effectiveness and sustainability for patient self-management are needed.

INTRODUCTION

Widespread internet use and the availability of medical information on the web have made patients much more aware of symptoms, diagnostic tests, diseases, and treatment options. Much of the North American population relies on information from the internet for healthcare education and to make and reinforce decisions about medications, treatments, and lifestyle choices for themselves and others.^{1,2} Forty-two percent of the US population keeps health records for themselves and their families, with 87% of these in paper format.³ Many trials of electronic personal health record systems (PHRs) have shown that they supplement and improve patient and family access to knowledge for self-management of health and wellness issues. Although one study found 91 different PHR commercial products in use by firms, institutions, or governments,⁴ only 7% of American adults use PHRs. Growth in PHR use parallels the adoption of electronic medical record systems (EMRs) by primary care physicians (PCPs). This growth is because the EMRs are often used as a source of data for PHRs, and PCPs play a predominant role in advising and supporting patients in education and health self-management.⁵ PHRs have the potential to change and possibly to improve patient-provider relationships, enhance patient-physician shared decision making, and enable the healthcare system to evolve toward a more personalized medical model.⁶

There are a number of different fundamental designs for PHRs. We use the term PHR to refer to

the records themselves and to the information systems used to support them. Electronic versions can include internet-based portals or computer-based applications. PHRs can be 'tethered', where subsets of information are provided by organizations that maintain patient data electronically, such as physician EMRs, health plan providers, hospitals, or employers.⁷ Untethered PHRs can be installed on isolated personal computers or internet-based portal services where only the user enters and maintains personal health data. Paper-based PHRs may also be used by patients to monitor their illnesses, and these can be carried physically by patients to doctor appointments, for example. Note that 'patient' is used interchangeably with 'consumer' in this paper, because all patients are consumers, and consumers almost always become patients.

The objective of this paper is to review the literature on PHRs and to describe the design, functionality, implementations, applications, outcomes, and perceived and real benefits of PHRs, with an emphasis on experience in the USA and Canada.

METHODS

Medline, Embase, CINAHL, Business Source Complete, IEEE and ACM Digital were searched from 1985 to March 2010. Included articles focused on studies assessing PHRs. For the purpose of this study, PHRs were defined as electronic or paper-based collections of health or wellness data arising from multiple sources about an individual's health, that are managed, controlled, or shared by that individual or designate.

Search terms relating to PHRs included phr, ephr, patient internet portal, patient portal, patient-shared/held/carried record, patient accessible records, personal medical record. Two reviewers independently screened titles and abstracts to determine inclusion status. A second screen of article full-text, again by two independent reviewers, ensured that the studies described PHRs (see figure 1). Qualitative and quantitative articles of any study type were included.

Screening identified 2836 papers, of which 130 met the criteria. Article data were extracted manually into a database. Meta-analysis of the findings was not attempted because most of the papers lacked a common set of attributes that could be combined.

RESULTS

Ninety-two of the included studies reported research or evaluation data or referenced relevant descriptive supporting papers, and are categorized (based partially on Tang *et al*⁸) in table 1 as reporting on:

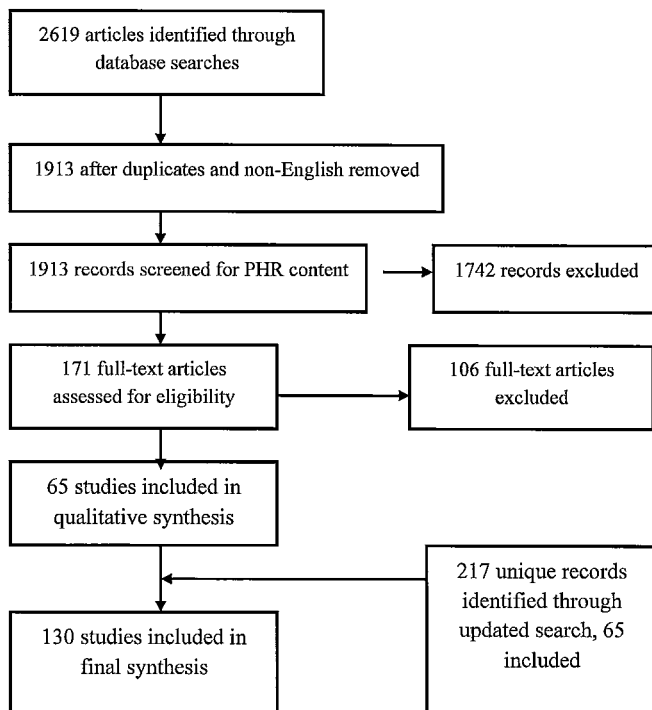


Figure 1 Flow diagram for paper selection process.

- ▶ System attributes (record content, architecture, privacy and security, functionality, cost and financing)
- ▶ Purpose (patient–provider communications, education and lifestyle changes, health self-management)
- ▶ Adoption and acceptance (adoption and use, acceptance and satisfaction, usability)
- ▶ Barriers to PHR adoption and use
- ▶ Clinical outcomes and process changes.

In table 1, the total number of papers exceeds 92, because some contributed in more than one category. Functionality, patient–provider communication, and adoption and use were the categories most frequently addressed. Generally, most studies were oriented toward the care provider point of view, and only a few focused on self-management of chronic conditions. Some findings from the papers are discussed in more detail below.

System attributes

System attributes relate to the characteristics of PHR systems.

Content

Little consensus exists on what information to include in PHRs. Information from practitioner sources should use easy-to-understand language for laypersons.¹¹ Information entered by patients may not be as complete, accurate, and organized as data exchanged between healthcare providers.¹⁷ Suggestions for data to be included in PHRs appear in table 2, based primarily on recommendations of the American Medical Informatics Association's College of Medical Informatics,⁸ with additions from other researchers.^{9 10 20} Certain chronic illnesses may require additional information.

Content must be important, understandable, and credible to patients and their caregivers, and appropriate for web access by patient-authorized individuals.¹⁸ Physician experience has shown that patient problem lists, clinical notes, medication and allergy data, and laboratory and diagnostic test results can be shared with patients.¹⁹ An attempt should be made (particularly

Table 1 Categorization of PHR papers and study type

Categories	No.	References
System attributes		
Record content	13	Cohort studies ^{9 10} Qualitative ^{8 11–13} Observational ¹⁴ Survey ^{15–17} Descriptive ^{18–20}
Architecture	14	Cohort studies ¹⁰ Qualitative ⁸ Survey ^{21 22} Descriptive ^{18 23–31}
Privacy, security	14	Cohort ^{32–34} Survey ^{15 21 25 35–37} Descriptive ^{30 38–41}
Functionality	27	RCTs ^{42–44} Cohort ^{9 23 34 45 46} Qualitative ^{12 47} Survey ^{15 16 48–50} Descriptive ^{18 19 24 29 51–56}
Cost, financing	6	Systematic review ^{6 57} Cohort ⁵⁸ Survey ^{15 59 60} Descriptive ⁶¹ Systematic review ⁶²
Purposes of PHRs		
Patient–provider communication	22	RCTs ^{43 63–66} Cohort ^{10 46 67 68} Qualitative ^{8 12 47 69} Observational ¹⁴ Survey ^{36 37 48 70} Descriptive ^{29 55 71} Systematic review ⁵⁷
Education, lifestyle changes	10	RCTs ^{65 72} Cohort ^{23 73} Qualitative ^{8 12 74 75} Descriptive ^{76 77}
Health self-management	6	Qualitative ¹² Descriptive ^{5 78–80} Systematic review ⁶
Adoption, acceptance, and usability		
Adoption and use	39	RCTs ^{42 43 65 81–83} Cohort ^{9 23 32 45 46 67 68 84} Qualitative ^{11–13 47 85–87} Observational ¹⁴ Survey ^{11 15 16 22 59 70 88 89} Descriptive ^{19 24 25 52 54 55 90–92}
Acceptance and satisfaction	6	Survey ^{36 48 70} Descriptive ⁹³ Systematic review ^{57 94}
Usability	9	Qualitative ^{11 12} Observational ^{95 96} Survey ^{11 36} Descriptive ^{52 53 90}
Barriers to adoption and use	6	Survey ^{15 21} Descriptive ^{8 61 91} Systematic review ⁹⁷
Clinical outcomes and process changes	10	RCTs ^{10 42 43 63–65 72 73 82 83}

PHR, personal health record system; RCT, randomized controlled trial.

in the case of bad news) to adjust office workflows so physicians can discuss results with patients before they appear in online records.

Table 2 Data recommended for inclusion in PHRs

Data	Data sources					
	Patient	Caregiver	PCP	Other physicians	EMR	Insurance claims
Personal information	X	X				
Problem lists	X	X			X	
Procedures, hospitalizations	X			X	X	X
Major illnesses	X	X	X	X	X	X
Provider list	X		X	X	X	
Allergies	X				X	
Home monitor data	X	X				
Family history	X				X	
Social history, lifestyle	X				X	
Preventive health recommendations			X	X		
Immunizations	X				X	
Examinations, diagnoses			X	X	X	
Medications	X				X	X
Laboratory tests, appointments	X				X	X
Notes	X	X	X	X	X	

EMR, electronic medical record system; PCP, primary care physician; PHR, personal health record system.

Architecture

Allowing patients to enter or view their own health data in their healthcare provider's EMR can convey much more to the patient than stand-alone PHRs,⁸ enabling patients to gather their entire fragmented medical history in one place. Information that patients may keep for their personal use may also be valued by healthcare providers. Shared medical records are almost universally endorsed across ethnic and socio-economic groups.²² Linkages between PHRs and PCP EMRs thus appear to be critical to the successful use of PHRs.

A personally controlled PHR, integrated with a primary care EMR, can manage communications for prescriptions and appointments at reasonable cost.²⁸ System interoperability is critical to giving consumers access to health records in hospital, physician, and laboratory systems, but this relies on the adoption of interoperability standards such as HL7 that support record sharing between systems.²⁷ Other related approaches involve centralization of all patient records at regional level, with access through online portals.³¹ Portability may also be important to consumers,¹⁰ although Lafky and Horan²⁵ found that the top preference of patients was to have information shared only within their circle of care.

Privacy and security

Two-thirds of adult consumers are concerned about the privacy and security of their health information, but most of those using PHRs are not worried about privacy implications.³⁵ Those who are concerned about privacy may change their attitudes with appropriate framing of arguments favoring record use.³² The chronically and acutely ill and those who frequently use healthcare services tend to be less concerned about privacy than are health professionals.³⁶ Current security protection mechanisms need to be enhanced for record protection,⁴⁰ but to maintain privacy, security levels must not become so tight that health records are unusable.^{30, 33} Work is underway (eg, Weider and Chan³⁹) to address security issues regarding wireless transmission of patient medical data, including the privacy, integrity, and confidentiality of the data, and the authentication and authorization of users.

Functionality

PHR functionalities can be classified as⁶: (1) information collection, (2) information sharing and exchange, and (3) information

self-management. Retrospective analyses of PHR implementations can provide data on functionalities.⁵⁷ Functionalities include sending and receiving electronic messages to and from doctors' offices; completing prescription renewal forms, appointments, and referral authorizations; viewing lists of current medications and allergies; and accessing health and practice information.³⁴ Decision support can also assist patients in managing chronic illnesses, based on monitoring data.^{19, 29} The nature of the patient's illness affects preference for functionalities. For example, a ranked priority list of patients with diabetes⁵⁰ included (priority percentages): a personal log to record and compare blood glucose levels (86%); a daily blood glucose log calculator to estimate diabetes control for the past 3 months (86%); links to educational websites (71%); an electronic newsletter for answers to questions, diabetes-friendly recipes, and information on community events (67%); online scheduling for routine appointments (67%); and e-reminders for appointments (67%).

Cost and financing

Public agencies are unlikely to fund PHRs unless they will reduce healthcare costs or substantially improve efficiency. Evaluating PHRs to determine if they improve health and reduce costs⁶¹ can be expensive. A systematic review of electronic health records in hospital settings⁶² showed evidence for cost reduction but little improvement in treatment quality. Similar studies are needed for PHRs. Consumers with serious chronic diseases, disabilities, or multiple health problems may experience direct and immediate benefits from PHRs, motivating continued use. Some data¹⁵ indicate that consumers might be willing to pay US\$1.80 to US\$4.50 per month for PHR support. Consumers with serious chronic illnesses may be willing to pay more.

Purpose of PHRs

Patient—provider communication

The benefits and satisfaction with PHRs have included easy access to test results and better communication with healthcare practitioners.^{8, 29} A paper-based PHR was used successfully by patients to keep up-to-date records for encounters with different healthcare providers, reducing the need for inter-provider communications to access updated medical information.¹⁰ Patients prefer email communication for some interactions (eg,

requesting prescription renewals, obtaining general information, and in-person communication for others (eg, treatment instructions).⁵⁶ Physicians generally prefer telephone or face-to-face communication. One EMR web portal designed to assist the self-management of ambulatory patients with diabetes included secure e-communication with the physician's office, preventive healthcare reminders, and disease-specific tools and information.¹² Over 2.5 years patient emails increased steadily. Participants reported that the system enhanced communication with the office, and that the reminder system was helpful.

Education and lifestyle changes

In addition to personal data and data from the provider EMR and monitoring devices (eg, weight, blood glucose), a PHR could store other data on, for instance, social status, family history, or living and work environment.⁸ It could also include information on healthy lifestyles (diet, exercise, smoking, weight loss, and working habits). In one study patients could access education and automated advice programs and add their own information to hospital systems.²³ In this case, patients primarily reviewed laboratory results; patients and physicians reported enhanced communications and patient understanding. Jerden and Weinehall⁷⁶ reported lifestyle changes associated with a paper PHR. After 6 months, 25% of patients reported changes in their health situation (exercise, diet, and habits related to stress). Patients may also benefit from sharing information on their conditions with others having similar problems⁷⁴ using online patient communities, e-forums, private messaging, and comments. An example of such an online resource for cancer patients is the Caring Voices site at the Princess Margaret Hospital in Toronto, Canada.⁷⁷

Health self-management

Patient health self-management can be supported by PHRs that allow patients to record, edit, and retrieve their healthcare data, including blood glucose and blood pressure measurements, weight and activity logs, and stress scales.^{6, 12} Frequent monitoring can lead to early detection of critical situations and timely intervention.⁵ Self-care monitoring tools are becoming more mobile and reliable, particularly in 'smart home' applications.⁷⁸ Encouraging innovations are appearing in mobile monitoring and decision support tools for active individuals.^{79, 80}

Adoption, acceptance, and usability

In the well-known Delone and McLean model of information systems success,⁹⁸ there are several inter-related measures of success, including system quality, use, user satisfaction, individual impacts, and organizational impacts. In this section we review findings on related PHR characteristics, such as adoption, use, acceptance, satisfaction, and usability. A sustainable PHR implementation depends on positive results from all these characteristics as well as favorable individual and organizational impacts. While it is not the purpose of this study to review the Delone and McLean model of success in the PHR context, it is highly relevant in this environment.

Adoption and use

People with disabilities and chronic conditions, frequent users of healthcare services, and people caring for elderly parents tend to have the most interest in PHRs.^{25, 89} Whether they actually adopt and use them is another matter. Simply providing online access to medical records is not useful unless the technology is integrated into the patient's existing health and psychosocial support infrastructure.⁴⁷ Participants tend to want unfettered

access to health records and expect to use technologies to communicate with clinicians.¹³ Consumers tend to keep at least some paper records on test results and medications. Patients with chronic disease are more likely to keep summaries of their health histories, medications, and physician names. Others keep diaries, appointment notes, and questions for subsequent visits.¹³

Low provider awareness and preparedness, and high patient expectations for personally controlled PHRs can reduce their chances of successful adoption and subsequent use. Other factors influencing adoption and use include educational and technical support for users and providers to handle access issues, especially among older consumers. Adoption issues among healthcare providers include new workflow demands and resistance to change, inadequate technology literacy, responsibility for ensuring the accuracy and integrity of health information across multiple interconnected data systems, and confidentiality and privacy risks.¹⁴ Ralston *et al*⁵⁵ found monthly user rates per 1000 enrollees in an online health maintenance organization (HMO) system were: medical test results reviews (46), medication refills (37), patient-provider clinical messaging (27), after-visit summary review (27), medical condition review (20), appointment requests (10), immunization review (10), and allergy review (6). The adoption and use of PHRs reflect intense interest in patient health self-management, because PHRs can empower patients. In a study of 210 individuals, Lafky and Horan²⁵ found that one of the most important motivations for PHR users with disabilities is being able to use the system for support in emergencies, but this usually requires portable solutions such as paper records or smart cards. Users of PHRs tethered to healthcare providers have indicated a high value for PHRs in emergencies.⁴⁷

Physicians are less likely than patients to anticipate benefits,¹⁵ and more likely to anticipate problems from patient PHR use.²² They also have concerns about physician use of patient-entered information⁸⁶ and whether PHR adoption will create unreimbursed work.^{15, 88} Physicians are generally receptive to patient access to most laboratory and other EMR information, but with restricted access to physician notes.¹⁵ In some cases⁸⁶ providers seemed to view PHRs as a source of medical information when the patient's record is unavailable. Education of physicians thus appears to be needed on how PHRs can also support patient empowerment, disease prevention and control, and health self-management.

Acceptance and satisfaction

Denton⁷⁰ found three compelling reasons motivating patients to maintain PHRs: serious chronic illnesses, unexpected health events, and the availability of inexpensive and secure computers. In a study of healthy, chronically ill, mentally ill, and pregnant patients, Fisher *et al*⁴⁸ found that patient access to online medical records fitted three classifications: participation in care, quality of care, and self-care strategies. Patients felt that access helped reinforce trust and confidence in doctors and made them feel more like partners in healthcare. A measure of adoption success is sustainability—"the degree to which an innovation continues to be used after initial efforts to secure adoption are completed."⁹³ Sustainability was rarely if ever mentioned in any of the papers reviewed, although satisfaction, a related term, was often reported. For example, a survey of 4200 patients with access to certain healthcare provider EMR information³⁶ reported that they found the system easy to use and their medical record information was complete, accurate, and understandable. Patient attitudes to the system were mostly positive,

but some patients were mildly concerned about confidentiality and privacy, and of learning about abnormal test results electronically. Clinicians were less positive and preferred telephone rather than email for routine interactions. Most studies suggest at least modest benefits ranging from enhanced doctor–patient communication to patient access to medical records.⁹⁴ A systematic review⁵⁷ assessed the effectiveness of paper PHRs for cancer patients and found that most patients welcomed them.

Usability

Usability (user interface and support) is key to the adoption and use of PHRs. Kim *et al*⁹⁰ developed a web-based patient-centered PHR in a housing authority for low-income families, the elderly, and the disabled. Patients were assisted weekly by graduate nursing assistants. Patient use of the system was low, but users were satisfied with the system in general, paid more attention to their health conditions and care, and shared records with primary care providers, specialists, and nurse practitioners. They agreed that the system had improved their overall healthcare quality. This suggests that usability contributes through both the interface and user support for the elderly, for people who are uncomfortable with technology, and for the disabled who have technology difficulties.

Atreja *et al*⁹⁵ found that the perceptions of multiple sclerosis patients were similar to those of non-disabled patients (need for better health information, belief in the trustworthiness of online health content, excessive reliance on search engine results for health information). Use barriers were similar to those faced by the elderly (low contrast, inappropriate font size, poor navigational design, etc), while additional barriers were more specific to the disease (problems with flashing or moving objects, crowded or cluttered screens, and difficulty seeing red). These findings may be generalizable to the design of self-support systems for patients with specific diseases.

Usability also relates to non-user interface issues, such as communications management, where prompt response in high

priority situations is important. This may involve re-engineering office workflows to increase patient satisfaction.¹² Negative experiences may result from misunderstanding medical terms in doctors' notes or laboratory tests. Solutions could include aids to assess the significance of laboratory and other diagnostic tests, hyperlinks that define technical terms, annotation of records that patients find in error,¹¹ and electronic notifications when new or changed information appears. Hassol *et al*³⁶ found that electronic messaging assists patients communicating with providers about routine details (eg, renewing prescriptions), but is less appropriate for discussing complex and sensitive issues such as informing a patient about a new chronic condition or about disease management.

Barriers to PHR adoption and use

PHR adoption has many perceived and real barriers. As with any new technology, failure can often be linked to little consumer involvement during planning, design, and implementation.⁹⁷ Lack of trust in the provider is another barrier,²¹ as are poor computer and internet skills, fear of technology, inadequate access, low health literacy, and limited physical and cognitive abilities.⁹¹

The ideal PHR appears to be one that provides access to all or most of the patient's clinical information.^{8 61} This requires information from the consumer to be integrated through interoperable networks that gather information from facilities that have treated the patient, possibly assembled in the patient's primary care provider's EMR. Such PHRs are 'integrated' with the healthcare system. There are a number of technical and non-technical barriers to successfully implementing such ideal PHRs^{8 15 61 97} (summarized in table 3).

Clinical outcomes and process changes

Ten outcome evaluation studies were found involving randomized controlled trials (RCTs) of PHRs. Although statistical results and their significance were reported in each study, there

Table 3 Barriers to PHR implementation

Barrier	Related issues
Healthcare system and incentives	<ul style="list-style-type: none"> ▶ Balancing between physician and patient autonomy ▶ Lack of technology training, interest, or ability of physicians ▶ Resistance to change ▶ Scope of work and responsibilities of healthcare providers ▶ Physician compensation and incentives ▶ Provider concerns about liability risks
Consumer confidence and trust	<ul style="list-style-type: none"> ▶ Safeguarding the privacy of consumer medical information
Technical standards for system interoperability	<ul style="list-style-type: none"> ▶ Data interchange standards ▶ Minimum data set standards in specific provider specializations ▶ Security and privacy standards ▶ Certification of health information technology products
Lack of EMR adoption by practitioners, institutions	<ul style="list-style-type: none"> ▶ A major problem in the USA and Canada
Lack of health information technology infrastructure	<ul style="list-style-type: none"> ▶ Lack of resources supporting system integration ▶ Range of existing non-compatible systems ▶ Need for mediating networks, organizational structures to support integration ▶ Limited online services at healthcare providers and institutions
Digital divide	<ul style="list-style-type: none"> ▶ Considerations of racial, education, and socio-economic status ▶ Health literacy ▶ Special needs: visual, cognitive, or physical limitations ▶ Financial resources
Empirical justification	<ul style="list-style-type: none"> ▶ Improved cost efficiency ▶ Healthcare effectiveness
Uncertainty in market demand	<ul style="list-style-type: none"> ▶ Lack of success by many small vendors ▶ Increased certainty needed to drive investment in development of higher quality PHRs

EMR, electronic medical record system; PHR, personal health record system.

was little similarity among the conditions measured and meta-analysis was therefore not feasible. Of the 10 RCTs found, only three involved electronic PHRs. Two of these three^{65–72} focused on whether health promotion or coaching interventions changed prevention, detection, or management. Only Bourgeois *et al*⁷² found improved recognition of signs of myocardial infarction or stroke. In a similar study involving paper records,⁸³ knowledge, attitudes, and behavior concerning health promotion improved if patients were given computer-generated summaries and booklets. The third electronic PHR study¹⁰ found significant effects of patient access to vital health information on provider–patient communication through documentation of immunizations, allergies, medications, and surgical interventions.

In the six other PHR (paper-based) studies, one⁷³ found no behavior change from preventive measures associated with written educational materials. In three of these studies,^{43 63 82} communications between providers and patients were examined; no improvements were reported in patient satisfaction with communications or with information provided to patients. One study of the effectiveness of a patient-held paper record for schizophrenic patients⁶⁴ found no effect on satisfaction or the use of secondary care services. Finally, one study evaluated a comprehensive strategy of regular examinations and documentation to help improve diabetes care for participants.⁴² They found small improvements in HbA1c and diastolic blood pressure levels, but could not ascertain if this was due to effects of keeping medical records or to more regular examinations of the participants.

In general, the results of the few reported PHR RCTs are disappointing in that few significant effects were seen in the clinical endpoints. Although most users reported value in having access to more information, little if any improvement in actual health outcomes was reported.

DISCUSSION

Our scoping review has found that a significant amount of research is being done on PHR adoption, use, and satisfaction for various groups of users, with the main focus on providers. There is some evidence for the inclusion of certain functionalities in PHR systems, especially from the patient perspective, as gleaned from the utilities they use most. However, the clinical effectiveness and cost effectiveness of PHR interventions has not been adequately confirmed. From the limited and heterogeneous literature that was synthesized, the following themes emerged:

1. Primary care physicians play a key role in the management of their patients' health. Based on our review, we believe that sharing some proportion of their EMR records with patient PHRs can provide patients with useful information that allows them to be positively engaged in health self-management. A key to PHR adoption in North America is therefore rapid and continuing growth in physician adoption of EMRs from its current relatively low rate. In 2008, EMR adoption by primary care physicians was in the range of 24–28% in the USA, and 20–23% in Canada.⁹⁹ Primary care EMR adoption is likely to have grown considerably since then in both countries, due to provincial subsidies for EMR adoption in Canada, and the implementation of meaningful use requirements and significant allocations to healthcare information technology in the American Recovery and Reinvestment Act of 2009 in the USA.
2. Although a number of good quality studies of PHRs have produced interesting results, many of these studies have been physician-oriented. Patients in the studies had access to their information through their doctors' or hospital EMRs

(tethered PHRs). EMRs are designed to provide doctors with the functionality and information they need, and their use for patients does not necessarily meet patient needs. Some studies^{9 12 29 47 74 76 100} included certain considerations of patient-oriented support such as the ability to join communities of interest, general information from high quality internet sites, information from healthcare professionals and internet sites on treatment programs for lifestyle, weight management, support for self-monitoring programs for chronic conditions, etc. But many did not. Until such integrated support is made available to patients, PHRs are not likely to demonstrate their full potential for supporting tangible or intangible improvements in patient health outcomes.

3. People with serious chronic conditions, individuals with disabilities, parents with small children, people with a strong interest in maintaining healthy lifestyles, and the elderly or their caregivers are more likely to adopt PHRs. Therefore, although a low overall PHR sustainable adoption rate can be expected, steps need to be taken by developers to improve the performance of PHRs and their long-term benefits for the people most likely to use them. This includes involving potential user groups with specific health self-management needs directly in requirement specification, design, and testing, to ensure that the PHRs match the cognitive abilities of their intended users and thereby support health self-management and disease prevention.
4. In a recent review of consumer health informatics, Gibbons *et al*¹⁰¹ report that applications that provided individual tailoring, personalization, and behavioral feedback had the most significant impact on patient health outcomes. However, research is needed to develop a more detailed understanding of what motivates people to not only adopt but to continue using PHRs. Long-term sustainability of PHR use by patients was an issue that was not mentioned in any of the literature we examined. Sustainability involves not just positive results from factors such as adoption, use, acceptance, satisfaction, and usability, but favorable individual and organizational impacts. This is extremely important if healthcare systems are to avoid the specter of financing apparently successful PHR innovations that are abandoned or under-utilized by patients after an initial flurry of use.
5. RCTs are needed to test assumptions about the comparative effectiveness of PHRs on outcomes for various patient populations, using systems designed specifically for patient health self-management and disease prevention.

Limitations

One of the limitations to this study is that new papers are being published quite regularly on PHRs, and some may have been missed in this study. Second, although we have tried to discuss some of the most important findings in the literature, it is impossible in a limited space to detail all the aspects we found that affect PHR attributes, purposes, benefits, usage, user satisfaction, and barriers to adoption and use.

CONCLUSIONS

The objective of this study was to describe existing electronic and paper-based PHR research and to determine whether PHRs can provide benefits to consumers/patients. We found many relevant papers, indicating a generally growing interest in PHR use, but there is much more to be done in tailoring PHRs for patient health self-management and sustainability. Although there is a large amount of survey, observational, cohort/panel,

and anecdotal evidence of PHR benefits and satisfaction for patients, more research is needed that gathers evidence to evaluate the results of PHR implementations in the context of works such as the Delone and McLean model of information systems success.⁹⁸ At this point there is little solid evidence from RCTs or other studies of proven effectiveness in improved patient health outcomes through the use of PHRs. More research is also needed that addresses the current lack of understanding of optimal functionality and usability of these systems, and how they can play a beneficial role in supporting self-managed healthcare.

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