



McMaster eBusiness Research Centre

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Scan**

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**WORKING PAPER No. 34  
September 2010**



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# **ELECTRONIC PERSONAL HEALTH RECORDS: AN ENVIRONMENTAL SCAN**

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## ABSTRACT

Electronic Personal Health Record systems (ePHRs) are systems that support patient centred health and/or medical records in electronic form and that are accessible to patients themselves. These can help patients and their families to access informed knowledge that can assist in self management of conditions and diseases. The objective of this study is to review the literature on ePHRs and to describe the design, functionality, implementations, applications, outcomes, and the perceived and real benefits of ePHRs. The major conclusions from the study are: 1) Since primary care physicians play a key role in their patients' health, and since patient ePHRs will likely be linked in some way to their physicians' Electronic Medical Record systems (EMRs), the key to ePHR adoption in North America is the rapid and continuing growth in physician adoption of EMRs; 2) Many ePHR systems that have been studied are physician-oriented. Thus, many have not included additional patient-oriented functionalities that are needed for maximum effectiveness. Until such ePHR systems are provided for patients, it is unlikely that tangible and/or intangible improvements in health outcomes will be demonstrated; 3) Not every consumer or patient is motivated to use an ePHR, so a low overall adoption rate is to be expected. However, ePHRs should be well designed and implemented with the involvement of the major stakeholders (consumers and their families, physicians, healthcare agencies and funding agencies), to provide a range of functionalities that will support health self management and disease prevention for patients who are motivated to use them; 4) Randomized controlled trials are needed to test assumptions about the effectiveness of ePHRs designed specifically for patient health self management in a variety of patient populations; 5) The diffusion of ePHR use to those who are genuinely motivated to adopt this type of support will be at a significant cost if it is to be done effectively. Until solid information can be collected and the future of such systems is decided, support for ePHRs will be a major public policy issue for healthcare systems administrators and funding agencies.

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**Keywords:** Electronic personal health records (ePHRs), literature review, adoption, functionalities, evaluation, patient-physician communication, security and privacy, usability, content, architecture.

## INTRODUCTION

Widespread Internet use and the availability of medical and healthcare information on the web have made patients much more aware of diseases, symptoms, analyses, and treatments. A large percentage of the North American population relies on information from the Internet to educate themselves and to make and reinforce decisions about medications, treatments, and lifestyle choices for themselves and others<sup>1,2</sup>. One survey<sup>3</sup> showed that online consumers are much more likely to tap the Internet to search for general or specific health-related information than they are to communicate with health professionals or use a health plan, hospital, or provider web site. A major concern is that Internet sites can provide outdated or inaccurate information and are not always supported by certified medical experts or institutions. Disturbing evidence comes from Wainstein et al.<sup>4</sup> who found that approximately one person in five will change a physician-directed decision based on Internet information.

In addition to seeking health information, a Harris Interactive Poll in 2004 showed that about half the US population keeps health records for themselves and their families (42%), almost all in paper format (87%)<sup>5</sup>. To supplement and improve the likelihood that patients and their families have access to knowledge that can assist self management and support patient centred health, there have been many trials of electronic personal health record systems (ePHRs). Some ePHRs are available commercially, either to individual consumers or indirectly through their healthcare providers or insurance agencies. A recent US survey indicated that Americans pay more attention and become more engaged in their health and medical care when they have easy access to their health information online<sup>6</sup>. Another study found 91 different ePHR products either in use by firms, institutions, or governments and/or available commercially<sup>7</sup>. However, use of ePHRs has been limited, with only 7% of American adults reporting use of ePHRs. This number increases to 14% for those people who actively keep health records in some form. In the United Kingdom the *National Health Service's* electronic *Healthspace* consumer access portal shows even lower levels of use<sup>8</sup>. Higher-income individuals are the most likely to have used an ePHR, but lower-income adults, those with chronic conditions, and those without a college degree are more likely to experience positive effects from having their information accessible online.

Personal health records systems started as paper based systems, many of which involved record keeping for women during pregnancy or records of immunizations of children. Paper-based personal health record systems will be referred to in this study as PHRs. ePHRs are in electronic format. The files can be stand alone, residing on a personal computer or memory stick, or online. Notable online commercial versions are Microsoft's *HealthVault* and *Google Health*. Patient portals that allow patient access to institutional health records also have expanded to include ePHR capabilities. ePHRs can be separate entities or tied into an electronic medical record (EMR) system. One example of an ePHR incorporated into an existing EMR (Electronic Medical Record system) is the *Indivo* system at *Children's Hospital* in Boston, MA.

The adoption and use of ePHRs parallels the adoption of EMRs by primary care physicians since these can be a valuable source of downloadable information to patient ePHRs. Primary care physicians and other healthcare professionals play a predominant role in guiding patients with advice and support through education and self management of their conditions. This contributes

to current healthcare system trends towards increasingly patient centred and managed approaches that may reduce costs and improve outcomes<sup>9</sup>.

Certain professional medical associations are also promoting ePHRs. For example, in an official policy statement, the American Academy of Pediatrics (AAP)<sup>10</sup> supports the development of educational programs for families and clinicians on effective and efficient use of ePHRs; incentives to facilitate ePHR use and maintenance; and child- and adolescent-friendly standards for ePHR content, portability, security, and privacy. Furthermore the AAP indicates that properly designed ePHR systems for pediatric care can empower patients and can improve access to health information, improve coordination of preventive health and health maintenance activities, and support emergency and disaster management activities for all children, including those with special healthcare needs and those in foster care.

From the consumer's point of view, ePHRs have the potential to dramatically change (and possibly improve) patient-provider relationships, enhance patient and shared decision making, and enable the healthcare system to evolve towards a more personalized medical model through the integration of more individualized healthcare information in patient care<sup>11</sup>. While seeking help to manage their health, patients with access to an ePHR portal<sup>12</sup> may still continue to search the Internet to find information beyond what the portal provides.

Key issues important to the use of ePHRs<sup>13</sup> include: 1) security standards to ensure privacy and integrity of personal health information, 2) control over who should have access to personal health information, 3) standards or functional specifications for the features of an ePHR, 4) standards or functional specifications for populating ePHRs, 5) provision for incentives to encourage the adoption of ePHRs, and 6) public education campaigns to increase consumer awareness of the benefits and values of ePHRs.

The objective of this paper is to review the literature on ePHRs and to describe the design, functionality, implementations, applications, outcomes, and the perceived and real benefits of ePHRs that have been used thus far, with a particular emphasis on North America. We also sought to determine whether ePHRs have been shown to provide tangible and intangible benefits to consumers.

In this paper, ePHRs will refer both to the records themselves and to the information systems used to support them so they can be created, updated, corrected, and accessed by patients and consumers and by their healthcare providers. We will also use 'patient' interchangeably with 'consumer'. As consumers of healthcare resources, individuals make decisions to manage their own health with the support of others (general practitioners, specialists, nurses, family, etc.) in their circle of care.

## **ARTICLE REVIEW PROCESS**

This study began with an online search of databases likely to include articles on ePHRs and (paper-based) PHRs. Medline, Embase, CINAHL, Business Source Complete (BSC), IEEE and ACM Digital were searched for terms relating to personal health records, including "phr", "ephr", "patient Internet portal", "patient portal", "patient-shared/held/carried record", "patient

accessible records”, “personal medical record”, and “personal health record”, as well as similar terms formatted slightly differently. Searches sought material from 1985 to March 2010. Studies were excluded if they were not in English, or if they were letters, editorials news items, program announcements or opinion pieces. Quantitative or qualitative studies were included. Two people independently reviewed titles and abstracts to determine if they met inclusion criteria. Full-text of articles was screened by two reviewers independently to ensure that the study described ePHRs and PHRs; review articles were included. Articles were determined to be studies of ePHRs/PHRs if they met the following definitions:

- The ePHR/PHR was defined as “electronic or paper based collections of health or wellness data arising from multiple sources about one person’s health.”
- The data were managed, controlled, and shared by that individual and/or designate(s) (e.g., family members or other informal caregivers).

Article information was reviewed and extracted manually into a database. Data elements included general study characteristics (e.g. population, setting, design), items related to the ePHR/PHR system (type, functions and components), and outcome measures and results. Queries were run to summarize the data quantitatively. A qualitative descriptive approach was used to summarize how ePHRs/PHRs were being used and studied. Papers that reported primary research data were reviewed in detail. Based on our findings we focussed on scoping review methods and did not attempt a meta-analysis of our findings since most of the papers lacked a common set of statistical attributes that would be useful to such an analysis.

More than 2600 papers were screened (see Figure 1). Of these, 130 met the criteria for this review.

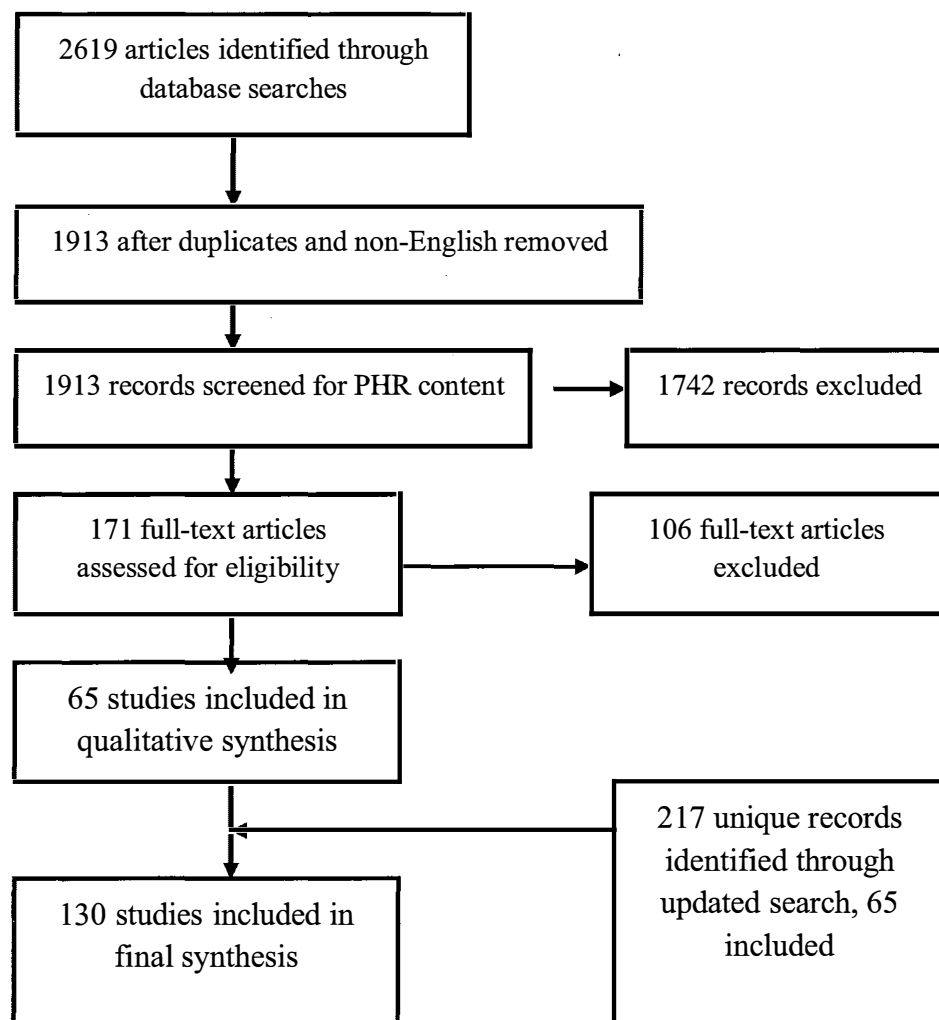
## RESULTS

72 of the studies that were selected included quantitative primary research data. These studies were grouped for detailed review into the categories associated with the structure, use, and outcomes related to PHRs and ePHRs. These categories relate to:

- System attributes
  - Content (9 studies<sup>14-22</sup>)
  - Architecture (6 studies<sup>16,23-27</sup>)
  - Privacy and security (11 studies<sup>14,23,27-35</sup>)
  - Functionality (22 studies<sup>14-18,20,24,36-50</sup>)
  - Cost and financing (4 studies<sup>14,51-53</sup>)
- Purpose
  - Patient-provider communication (17 studies<sup>21,30,40,46,49,50,54-64</sup>)
  - Education and life style change (8 studies<sup>17,36,62,65-69</sup>)
- ePHR Use
  - Adoption, attitude, and satisfaction (37 studies<sup>14-15,17,20-21,24,28-29,36,38-41,44,46,49-50,52,55,57,59,62,64,70-83</sup>)
  - Usability (8 studies<sup>17,29,38,42,70,72,84-85</sup>)
  - Barriers to ePHR adoption and use (4 studies<sup>14,86-88</sup>)

- Clinical and process outcomes (includes only the ten randomized controlled trials found in the study<sup>18,39-40,56,61-62,65,68,76-77</sup>)

Functionality, patient-physician communication, and adoption and use were the most common aspects of PHRs and ePHRs discussed in the papers selected. Many of the studies contributed in more than one category. In general, most tended to be oriented towards the care provider point of view, with a few related specifically to self management of chronic conditions. The above categories are discussed in the following sections, with details given about ePHR experience to date that are based on the most relevant, illustrative, and high quality papers listed above, along with supporting information from other studies where appropriate.



**Figure 1. ePHR/PHR Article Search Process**

## **STATUS AND NATURE OF ePHRS**

### **System Attributes**

#### ***Content***

The content of an ePHR is important for all potential users (patients, informal caregivers, and clinicians) but, like all technology, ePHRs will only be used if the effort to keep the resource up to date is less than the perceived benefit. With the continuing growth of interoperable eHealth systems, much more data are becoming available that can be integrated into an ePHR. In addition to content, data format and presentation is also important. Language used to describe patient conditions must be readily understood by all users. Data in PHRs and ePHRs can come from healthcare providers and their EMRs (primary care, specialists and hospitals) and from patients. One study suggested that information entered by patients is important but not likely to be as complete and accurate as data exchange between healthcare providers<sup>22</sup>. Currently, there is very little consensus on standards for what information ePHRs should include.

Raisinghani and Young<sup>13</sup> list ePHR data types and sources that could provide useful data

- problem lists from the patient, caregiver, or the EMR
- procedures and hospitalizations from the patient, EMR, or insurance claims
- major illnesses, current and past from the patient, EMR, and insurance claims
- provider list associated with patient problems including primary care clinicians, specialists, allied health care providers from the patient and various EMRs
- allergies from the patient and EMRs
- home-monitored data from the patient and automated equipment interfaces, e.g., exercise, blood glucose levels, spirometry data
- family history, potentially across generations from the patient and EMRs
- social history and lifestyle preferences from the patient and EMRs
- immunizations and other preventive care interventions from the patient, EMRs, and registries
- medications, current and past including prescription data from the patient, EMRs, and insurance databases
- laboratory tests including results and appointments from the patient, EMRs, and insurance databases

Bridgford and Davis<sup>15</sup> provided similar content in a comprehensive patient-held (paper-based) diabetes record or “databank”, used by 115 patients in a multi-ethnic sample. This included data on appointments, home blood glucose monitoring, hypoglycemic events, other significant health events (e.g., hospitalizations), medical history, results from consultations, laboratory results, diet, lifestyle, and monitoring (e.g., retinopathy)<sup>18</sup>.

Halamka et al<sup>41</sup> describe experiences over a period of seven years with three independent ePHR systems, where patients were given access to practitioner EMR records and provided with communications access to their primary care clinics. Patients could amend their own records online, and provide information on their self-managed care experiences. With these systems, experience showed that patient problem lists, clinical notes, medication and allergy data, and laboratory and diagnostic test results can be shared with patients. However, an attempt should be made (particularly in the case of bad news) to adjust office workflows so the physician discusses



the results with the patient before they appear in the online record. Adjustments were made to ensure acceptability of data to be shared, that security was in place, and that patients were screened for their ability to use and understand the data. Patients wanted a single ePHR that could access records from all their sites of care, integration with Internet knowledge resources, access to communities of other patients with similar diseases, and potential to participate in clinical trials, post-market pharmaceutical vigilance, or public health surveillance via ePHRs.

Walton and Bedford<sup>20</sup> found that parents valued a paper PHR that included their child's developmental data and almost always brought it with them to appointments. DeLenardo<sup>16</sup> describes the challenges in building a patient portal with breast cancer content. They found that, to be acceptable, content must be important to patients, understandable, credible to both patients and their caregivers, and appropriate for web publication. They used a team consisting of an oncologist, a pharmacist, a dietitian, a systemic therapy nurse, an in-patient nurse, a supportive care coordinator, and a community representative to build the web content.

### *Architecture*

ePHRs can be isolated computer systems or web based systems. They can be tethered to a healthcare provider, health insurance company or other payer, employer, or related entity<sup>89</sup>. A major symposium on ePHRs<sup>87</sup> concluded that allowing patients to enter their own health data and/or view their own health information stored in their healthcare provider's EMR can convey much more relevant data to the patient than stand-alone ePHRs. With ePHRs, patients may be able to accomplish what the healthcare system has not been able to do thus far - to gather their entire fragmented medical history into one place. To be efficient, primary care organizations should facilitate this collection of data from themselves and other healthcare resources to feed both their own records and ePHRs. Other information that patients may want to enter for their own personal use, such as tracking medical conditions or lifestyle documentation may also be of value to healthcare professionals. Shared medical records are almost universally endorsed across ethnic and socioeconomic groups<sup>80</sup>. Linkages between ePHRs and primary care physician EMRs thus appear to be critical to the successful use of ePHRs. Denton<sup>57</sup> completed a study that investigated the proportion of patients who used ePHRs linked to their physicians' EMRs. He found three compelling reasons motivating patients to maintain their own ePHR records: serious chronic illnesses, unexpected health events, and the availability of inexpensive yet secure computers and systems that can support ePHRs.

A personally controlled ePHR that is integrated with a primary care EMR can efficiently manage communications for prescriptions and appointments at reasonable cost<sup>90</sup>. Most patients are also interested in Internet-accessible records. The primary determinants of support of Internet-accessible records are previous experience with the Internet and patient expectations of the benefits and drawbacks of reading their own medical records<sup>80</sup>.

System interoperability is very important to the goal of giving consumers access to their own health records, aggregated and managed in a suitable way so that they may view them and contribute their own data as they see fit. Consumers may then be given access to some or all clinical records of their data or provided with downloads of the information. Other related approaches involve centralization of all patient records at regional levels so physicians, patients,

and others with appropriate permissions may access and/or update the records through online portals<sup>91</sup>. Although this centralization of records may be cost effective, it is more difficult to customize to meet individual user needs and may attract database attacks.

Successful interoperability between a patient-centered health record application and enterprise level clinical systems relies on the adoption of appropriate standards<sup>92</sup>. Portability is also important to consumers interested in ePHRs. Lafky and Horan<sup>75</sup> asked participants to rate the level of interoperability they would prefer in their PHRs. The top preference was to have information shared only within one's own circle of care, i.e. the most restrictive model. At the same time, participants rated interoperability and portability factors as least important of the operational features of ePHRs. Others argue that ePHR interoperability with other systems that can provide clinical patient information in a standardized form is an important functionality<sup>87</sup>, even though it is not always feasible.

### ***Privacy and Security***

Consumer privacy issues may slow the diffusion of ePHRs to the consumer community. Privacy concern in the consumer population is also an elusive and moving target, making it difficult to establish lasting policies on privacy safeguards. Privacy beliefs can be used to classify consumers into Privacy Fundamentalists (reject consumer benefit and seek legal regulatory privacy measures), Privacy Pragmatists (evaluate risks and decide whether to trust organizations or seek legal oversight), and Privacy Unconcerned (ignore concerns about privacy). A 1995 Harris Interactive/Westin survey classified US consumers as 25%, 55% and 20% in each of these categories respectively. A similar survey by Harris Interactive/Westin in 2001 found that the percentages had shifted to 34%, 58% and 8% respectively (all data referenced from <sup>28</sup>). In another more recent but related survey, 91% of the participants were very concerned about keeping their health information secure and private. However, fewer (approximately 25%) said they would avoid using an ePHR because of privacy issues<sup>93</sup>. Lafky and Horan<sup>75</sup> found that almost 60% of consumers favoured the statement "The privacy of my medical information is very important and I want it protected at all times" while approximately a third chose "I want to balance the privacy of personal medical information with my health needs." Few (10.5%) agreed with the statement "The privacy of my personal medical information is of no great importance."

A recent US survey<sup>6</sup> found that about two-thirds of adult consumers remain concerned about the privacy and security of their health information, but the majority of those using an ePHR were not very worried about the privacy of information contained within the ePHR. Some studies<sup>19,29</sup> have found that the chronically and acutely ill and those who frequently use healthcare tend to be less concerned about privacy than do health professionals. Angst and Agarwal<sup>28</sup> found that issue involvement and argument framing may help to influence attitude change towards privacy concerns with ePHRs. Wang et al<sup>33</sup> described a secure web-based portal that provided patient access to EMR records within a major healthcare system. More than 125,000 patients logged in, and over 37,000 messages were sent by patients to their physicians, with no major security concerns.

Mobile support for consumers interacting with ePHRs, such as real time gathering of their health measures (blood pressure, heart rate, respiration rate, etc.) will become more widely used as

technology advances. Although wireless systems have a reputation for being less secure, much work is being done<sup>94</sup> to address security issues regarding the wireless transmission of patient medical record data, including privacy, integrity, and confidentiality of the data, along with the authentication and authorization of users.

### ***Functionality***

To provide high quality ePHR support for prospective users, it is essential to understand what functionalities would be desirable for entering, manipulating, sharing, and displaying information. As with any innovation, it is difficult for potential users to envision an ePHR and how it would be used before actually attempting to use one. Thus some of the most useful results on needed functionalities have come from retrospective analyses of ePHR implementations. As it turns out, there is not necessarily agreement among or between physicians and consumers on what functionalities are needed<sup>60</sup>, since needs may range all the way from public health surveillance to self-help tools for patients<sup>24</sup>.

In a study that included groups of healthy, chronically ill, mentally ill, and pregnant patients, Fisher et al<sup>59</sup> found that patient access to online medical records fitted three classifications: participation in care, quality of care, and self-care strategies. In this case, record access was used to prepare patients for consultations, compensate for poor or complex communication during consultations, and reduce the fragmentation of care, but this had little impact on health behaviour intentions. Patients felt that record access helped to reinforce trust and confidence in doctors and made them feel more like partners in healthcare. Winkelman et al<sup>50</sup> proposed four themes of patient-perceived information and communication technology usefulness: promotion of a sense of illness ownership, of patient-driven communication, of personalized support, and of mutual trust. These four themes can serve as focal points for the evaluation of information technology designed for patient use. Technically, ePHR functions drive data, infrastructure, and interoperability requirements, as well as adoption. Primary functions fall into categories, based on the patient's use of information<sup>11</sup>: 1) Information Collection - helps patients to enter their own health information and to retrieve their information from external sources; 2) Information Sharing and Exchange - allows patients to share their health information with others; and 3) Information Self-Management -allows patients to better manage their own health/healthcare (e.g. functions that allow patients to record, track, and edit information about their health/healthcare, as well as obtain relevant patient oriented disease information and decision support).

The nature of the patient's illness will have a significant bearing on the functionalities that the patient prefers. For example, an ePHR for patients undergoing a course of assisted reproduction<sup>49</sup> included 15 major functions that classified into personal information, general information and communication functions. The couples in this study rated most functions as useful but preferred personalized to general functions. They used the Internet-accessible ePHR frequently and extensively, suggesting that functions offered were very useful in this environment. Note that patients in this classification have quite different needs from patients with chronic illnesses, since the former are involved in relatively short term use, whereas chronically ill patients adopting ePHRs are likely to be lifetime users.

A broad classification of potential functionalities might include sending and receiving electronic messages to/from doctors' offices; completing request forms for prescriptions, appointments, and referral authorizations; viewing a list of current medications and allergies; and accessing health library and practice information<sup>33</sup>. A functionality priority list developed in consultation with diabetic patients<sup>95</sup> included (priority percentage in brackets): Personal log to record and compare blood glucose levels (86%); Daily blood glucose log calculator to estimate diabetes control for past 3 months (86%); Links to educational diabetes websites (71%); Electronic newsletter for FAQs, diabetes-friendly recipes, community events of interest (67%); Online scheduling system for routine appointments (67%); Electronic reminder system for provider appointments (67%); E-mail system for non-emergency questions directly to providers, with responses in one business day (62%); Links to community resources for physical activity and meal-planning information (62%); Opportunities to form interest groups (62%); Access to online personal trainer for tips on daily activities or exercise programs (57%); Access to individual nutrition and meal planners (57%); and Opportunities to talk with other patients with similar concerns or interests (57%).

A medications module in an ePHR can help to improve the accuracy of physician EMR medication lists, reduce errors and adverse drug events, and improve patient-provider communication regarding medications and allergies. The module would be most usable if it allowed patients to view and modify their own list of medications and allergies or similar lists downloaded from the EMR, and to report non-adherence, side effects and other medication-related problems to providers. In turn, providers could verify the information and update the EMR as needed<sup>96</sup>. Ralston et al<sup>46</sup> measured patient and provider access to a web portal that provided shared medical record access in a US health maintenance organization (HMO) over a three year period. Functionalities supported were integrated with clinical care. Monthly user rates per 1,000 enrollees 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). 94 % of enrollees were satisfied or very satisfied with the system overall. Highest satisfaction (satisfied or very satisfied) was with medication refills (96%), patient provider messaging (93%), and medical test results (86%). Patient use and satisfaction with the portal and shared record were greatest for those services that were most actively part of clinical care and patient-provider communication. Findings supported a view that tight integration of portal services with clinical care and the physicians' EMR are important in meeting patient needs.

### ***Cost and Financing***

Most researchers agree that ePHRs would help to focus and support patients on the self management of their health, but there is the question of who will pay the costs of this service. With the rising societal impact of healthcare costs, it is unlikely that public agencies will want to support the funding of ePHRs anytime soon. This may change if and when a body of evidence develops that ePHRs result in a major benefit to society, by reducing overall costs of healthcare. It will require a significant investment from public and/or private sources to gain the experience with ePHRs that is needed to determine their effectiveness in improving health<sup>86</sup>. Meanwhile, consumers, employers, or service providers may have to pay the costs of such systems, so

willingness to pay becomes a major issue. Do consumers want and need services offered by such systems and, if so, how much would they be willing to pay?

Healthcare providers are necessarily concerned that ePHR systems will not provide sufficient return on investment (ROI). Studies of related systems are rare, but Simon and Simon<sup>51</sup> studied the selection, implementation and ROI of an EMR in one medium-sized physician practice. They found that an EMR can provide both tangible (monetary) and intangible (clinical/quality of care) returns for the healthcare provider, but little is said about benefits to patients. In a systematic review of the benefits and costs of eHRs on whether and to what extent they are worthwhile in hospital settings, Uslu and Stausberg<sup>97</sup> found considerable evidence for a reduction of costs, but little sign of improvement in treatment quality. Similar studies could be used to determine the benefits of ePHRs. For example, an approach to improve willingness to pay is to use emphasis frames (individual-focused, collective-focused, and joint)<sup>53</sup>. Early adopters are more susceptible to individual-focused frames that make causal attributions at the individual level, whereas later adopters are significantly influenced by collective-focused frames that made causal attributions at the societal level. The framing effect significantly influences both early and later adopter willingness to pay.

Estimating the intangible return on investment from ePHRs in improved quality of health is a long term issue depending on behaviour changes that may result from ready access to information by consumers and improved communications with healthcare providers. This intangible long term return is a key to consumer adoption. Many consumers might be willing to pay a small monthly fee to support their ePHRs, but they must have the motivation to do so. This would not likely be the case for healthy consumers who may see no reason (in the short term) why they should maintain and consult their health records regularly, since this may have little noticeable impact on healthcare quality. However, consumers with serious chronic ailments or physical disabilities, or seniors with multiple health problems, may see a direct and immediate benefit from ePHRs. Preliminary data gathered from a general sample of Canadian consumers<sup>14</sup> indicates that consumers in general would be willing to pay in the range of \$1.80 to \$4.50 (US) per month for ePHR system support. Consumers more highly motivated to maintain and use such records might be willing to pay more. Short term ePHR usage for special purposes might also encourage higher consumer rates of pay. For example, a patient-accessible medical record designed specifically for patients undergoing a course of assisted reproduction<sup>49</sup> resulted in positive responses on its usefulness, with few concerns about privacy, and 76% of users expressed a willingness to pay for such a service in the future.

## **PURPOSE**

### **Patient-Provider Communication**

So far there has been limited statistical evidence supporting the overall benefits that have been suggested from ePHR use (see the Outcome Evaluation section below). However, perceived benefits have been noted from consumers who have indicated satisfaction with early and relatively primitive versions of ePHRs, with particular value from easy access to test results and better communication with healthcare practitioners<sup>87</sup>. Fisher et al<sup>59</sup> explored how patients use access to full medical records, its impact and the benefits and drawbacks of using it. Three themes emerged from their study. Patients use record access for participation in care, quality of

care, and self-care strategies. Record access was used to help prepare patients for consultations, compensate for poor or complex communication during consultations, and to reduce the fragmentation of care. Their system had a small impact on health behaviour intentions. However, patients felt that record access reinforced trust and confidence in doctors and helped them feel like partners in healthcare. In another study of a patient web portal that allowed patient access to physician EMRs, patients could view and respond to health reminders, critique electronic chart information maintained by their doctor's office, enter additional clinical information, and prepare information summaries before an office visit<sup>26</sup>. This approach required the development of a collaborative care model, including an analysis of the business, architectural, and workflow requirements of the portal and the physicians' EMR, and aligning two systems that served 90 physicians and 8700 patients. The physicians were in ten primary care practices, and acceptance by physicians varied widely. In some clinics, e-mail was preferred for communications, with volume kept under control by administrative staff.

Gysels et al<sup>60</sup> assessed the effectiveness of paper-based PHRs in supporting continuity and cancer patient involvement in care. Seven randomized controlled trials (RCTs) and six non-experimental studies were identified, but evaluations were not conclusive, as in our own analysis of RCTs (see below). In fact, although randomized trials found no effect, non-experimental evaluations shed light on the conditions for successful use. In one reported implementation where patients could access physician clinical notes and test results<sup>70</sup>, patients indicated that medical jargon was a minor obstacle. Some physicians in this study felt that the system might increase workloads and distort clinical interactions, but no such adverse consequences were reported after the trial. All ultimately supported giving patients online access to clinical notes and test results.

In a study of an ePHR that allowed patients online access to selected portions of their providers' EMRs<sup>29</sup>, most users felt that the system was easy to use and that their medical record information was complete, accurate, and understandable. Patients preferred e-mail communication for some interactions (e.g., requesting prescription renewals, obtaining general medical information), whereas they preferred in-person communication for others (e.g., getting treatment instructions). Patients did not prefer telephone or written communication, but physicians were likely to prefer telephone communication.

Cimino et al<sup>36</sup> studied patient access to hospital clinical data, allowing patients to add to and review their medical data. Educational resources and automated advice programs were included. Patients varied in their use of the system, from once a month or less to one or more times per day. All patients primarily used the system to review laboratory results, which is not surprising since this was a hospital system. Patients and physicians felt that the system enhanced patient understanding of conditions and improved communications.

Another web portal designed to assist ambulatory patients with diabetes self-management was based in the physician's office EMR<sup>17</sup>. Its functionalities included secure, electronic communication with the physician's office, preventive healthcare reminders, and disease-specific tools and information. The primary focus was on assessing patient-practice communication. During the 2.5 year period of the trial, patient e-mail messages increased steadily from none at the beginning to over 300 per month at the end of the trial, but there was no change in the

number of patient encounters or telephone calls (about 13,000 per month). Participants felt that the system enhanced communication with the office, and that the reminder system was helpful. They liked having access to lab tests remotely, but were frustrated when tests were not released and messages not answered. Patients did not change communication patterns quickly as a result of the system.

## **Education and Life Style Change**

End users of ePHRs include consumers and their caregivers and family members, so information made available from practitioner sources should not be in a lingo that is difficult for laypersons to understand. In addition to personal data, downloaded data from the patient's physician EMR, and data from monitoring devices (e.g. weight, blood sugar, etc.) an ePHR could store other data relevant to the health of an individual such as social status, family history, or living and work environment. It could also include externally provided educational information on maintaining a healthy lifestyle such as advice on diet, exercise, smoking cessation, weight loss, and working habits. Jerden and Weinehall<sup>67</sup> examined the extent of patients reporting lifestyle changes as a result of using a patient-held (paper) health record. A booklet regarding their health was distributed to all participants. The booklet was designed so patients could keep records about life style changes. After a period of six months, 25% of patients reported having made changes in their health situation. Exercise, diet and habits related to stress were the most common habits that were addressed by the patients. Age, educational level, health status and smoking habits did not influence the proportion of patients reporting lifestyle changes. Another study<sup>66</sup> investigated how patients might benefit from sharing information on their own conditions with others having the same problems. This was done through an online patient community for amyotrophic lateral sclerosis (ALS) that supported the interchange of information between patients. Available tools included a forum, private messaging, and comments on each other's profiles. An analysis of the message exchanges indicated that patients benefited from dialogues that helped to inform disease self-management.

A number of institutions have implemented online sites that provide education and community support networks for people with diseases and other conditions. A good example of such a site is maintained by the *Princess Margaret Hospital* in Toronto, Canada<sup>98</sup>. Their *Caring Voices* site and community network provides online support for individuals who may be suffering from any of a variety of cancers.

## **ePHR USE**

### **Adoption, Attitude, and Satisfaction**

It is difficult to define ePHR adoption success, since it is not clear that even a majority of all consumers would want to consider the use of an ePHR for health self management. The chronically ill, people with disabilities, frequent users of healthcare, and people caring for elderly parents seem to have the most urgent interest in ePHRs<sup>75,93</sup>. One measure of success would be a significant improvement in health outcomes (discussed in a following section). A second would be the satisfaction of users actually adopting and continuing to use an ePHR over a lengthy time period (e.g. two years). Such a measure was not available for individual users in any of the studies. Most satisfaction measures were reported in more general terms, as demonstrated in a

survey of over 4200 patients with access to selected portions of healthcare provider EMRs<sup>29</sup>. In this study, users indicated that the system was easy to use and that their medical record information was complete, accurate, and understandable. Patient attitudes about the use of web messaging and online access to their EHR were mostly positive, and they were satisfied that their medical information was complete and accurate. Although a minority of patients was mildly concerned about confidentiality and privacy of their information and about learning of abnormal test results electronically, patient attitudes about access to EMR information was mostly positive. Clinicians were less positive about electronic communications, and differed from patients regarding preferred means of communication for different types of interactions.

Ross and Lin<sup>99</sup> reviewed published papers on the potential benefits and drawbacks of facilitating patient access to their medical records, including the analysis of clinical notes, surveys of patients and practitioners, and studies of patient-accessible medical records. Most studies suggested that there are at least modest benefits from doing so, such as enhancing doctor-patient communication, which is of minimal risk to patients. Another systematic review<sup>60</sup>, that assessed the effectiveness of paper-based PHRs in supporting continuity and cancer patient involvement in care, found that most patients welcomed the introduction of PHRs.

A study of Internet access to patient records by patients with inflammatory bowel disease<sup>50</sup> suggested a framework of patient-perceived information and communication technology usefulness: promotion of a sense of illness ownership, of patient-driven communication, of personalized support, and of mutual trust. The main conclusion was that simply providing online access to medical records is not useful unless the technology is integrated into the patient's already existing health and psychosocial support infrastructure. In a study of how consumers and health professionals envision ePHRs enhancing their future care, Walker et al<sup>19</sup> found that participants want unfettered access to their health records, and they expect to use home monitors and other technologies that support communications with clinicians. Although health professionals agreed somewhat, there was some reluctance about patients viewing the doctor's visit notes, based on patient lack of comprehension, possible litigation, and resulting demands on provider time. Most of the consumer participants indicated they kept records, usually on paper, including copies of test results and medication information. Patients with chronic disease were likely to keep summaries of their health histories, medications, and physician names. Others kept diaries, appointment notes, and lists of questions for subsequent visits.

Although most patients are willing to use ePHRs, at least for certain functions such as viewing test results and tracking medications, less information is available about provider attitudes toward ePHRs. In a study of a university operated managed care organization, Weitzman et al<sup>21</sup> found that low levels of awareness/preparedness paired with high expectations for personally controlled PHRs were problematic. Educational and technical support for both users and providers are necessary to handle the issues that they meet, including: access, especially among older consumers; workflow demands and resistance to change among providers; inadequate health and technology literacy; responsibility for ensuring accuracy and integrity of health information across multiple interconnected data systems; and understanding confidentiality and privacy risks.



ePHRs have become of intense interest as healthcare is becoming more of a self management issue, since maintaining one's own ePHR can assist in empowerment. In a study of 210 individuals, Lafky and Horan<sup>75</sup> found that users with disabilities differ from others in their ePHR preferences; one of the most important motivations for such users is the way in which an ePHR will provide support when emergency services are required. This indicates a preference for smart card solutions for the disabled since these are portable. Users of ePHRs tethered to a healthcare provider have also indicated a high value for ePHRs in emergency situations<sup>50</sup>.

Some research suggests that, although physicians are generally in favour of ePHRs<sup>14</sup>, they are less likely than patients to anticipate benefits, and more likely to anticipate problems from their use by patients<sup>80</sup>. They also tend to have concerns about the use of patient-entered ePHR information by physicians<sup>82</sup> or whether ePHR adoption will create additional work that is not reimbursed<sup>14,74</sup>. From interviews and online questionnaires with more than 30 primary care physicians, Archer and Fevrier-Thomas<sup>14</sup> found that physicians were generally receptive to the use of ePHRs by their patients, including access to most laboratory and other information contained in their EMRs, but with some restrictions on access to physician notes. On the other hand, Witry et al<sup>82</sup> found that providers seemed to view ePHRs as a source of medical information when the patient's record is not available, and were unaware of patient-centered features in ePHRs and how such features might affect patients and their medical practice. Physicians perceived several unique barriers, including the potential of ePHRs to facilitate narcotic abuse, low levels of patient computer and health literacy, low levels of patient motivation, and difficulties with ePHR and electronic medical record interoperability. This study should not be seen as a general indication of physician attitudes towards ePHRs, since many physicians have successfully supported patient ePHR use. It is more of an indication of a need for increased awareness among physicians of how ePHRs can support patient empowerment, disease prevention and control, and health self management that would benefit both patients and physicians.

## **Usability**

ePHR usability (implying considerations of the user interface and user support), is clearly a major key to the adoption and use of ePHRs. Kim et al<sup>72</sup> developed a web-based patient-centered ePHR that fitted into a community-based resource sharing and support model/strategy in a housing authority for low-income families and the elderly or disabled. Patients were assisted as needed by graduate nursing assistants once a week. A survey found that 92% of the actual users were satisfied with the system in general; 80% said that they now paid more attention to their health conditions and care; 82% shared their records with either primary care providers, specialists, or nurse practitioners; 82% felt that they were now able to provide more accurate health information to their healthcare providers; 93% said that their healthcare provider found their records useful; 93% indicated that face-to-face meeting time with healthcare providers was now used more efficiently; and 86% agreed that the system had improved the quality of the overall healthcare they received. This suggests that usability applies not just to the interface but to user support for the elderly, technophobes, and the disabled with technology difficulties.

Atreja et al<sup>84</sup> demonstrated the importance of user interface design in their study of the physical and cognitive problems that limit the ability of multiple sclerosis (MS) patients to access online

disease management support sites. They used focus groups to gather MS patient perceptions, and considered MS visual and fatigue impairments as well as cognitive and memory problems in interface and portal redesign to overcome barriers to portal use. They found that some web-related perceptions of MS patients are similar to non-disabled patients (need for better health information, belief in trustworthiness of online health content, excessive reliance on search engine results for health information). Other barriers to use are similar to those faced by the elderly (low contrast, inappropriate font size, poor navigational design, etc.), while additional barriers are more specific to the disease (problems with flashing or moving objects, crowded or cluttered screens, and difficulty seeing the color red). Such an approach can be generalized to strategies for the design of web sites that support patients with specific diseases, but it may be necessary in addition to provide flexibility in tailoring web sites to individual needs. Kim et al<sup>72</sup> found that free text fields are very useful for saving patient-entered information that does not fit readily elsewhere, in an ePHR designed for elderly and disabled patients.

Usability also relates to non-user interface issues, such as the management of electronic communications from patient to office, where prompt response is important to patients, especially in high priority situations. This may involve reengineering office workflows to offload communications to office staff who can handle them with little difficulty, thus increasing patient satisfaction with the system<sup>17</sup>. Negative experiences from interacting with ePHRs may result from difficulties in understanding medical terms that appear in doctors' notes or laboratory tests. Solutions could include aids that help assess the significance of lab and other diagnostic tests, hyperlinks that define technical terms, and a means to annotate records that patients find in error<sup>70</sup>. Other suggestions include electronic notifications when new or changed information appears in a record. On the topic of communications, an electronic messaging interface tends to be one dimensional as compared to face to face discussion between patient and physician. Hassol et al<sup>29</sup> point out that electronic messaging may be well suited for patients communicating with providers about routine details such as renewing prescriptions, but it is less appropriate for discussing complex and sensitive issues such as informing a patient about a new chronic condition or discussing complicated medical management issues. It may also threaten patient confidentiality, decrease office visits and revenue, or marginalize the art of medicine.

### **Barriers to ePHR Adoption and Use**

There are a variety of perceived or real barriers to ePHR adoption, and some implementations have failed because they disregard the very real impact of consumer involvement during the planning, design, and implementation process on successful adoption. Lack of trust in the provider is one barrier. For example, one major study<sup>23</sup> examined the implementation of an ePHR system provided at no cost to employees of a large US firm. Employees were not consulted in advance of the implementation. The system allowed employees to enter their own data for themselves and their family members. In turn it provided online reports, updates, searches, and reminders requested by employees. However, only 20% of the employees used the system monthly or more often. Of these, only 37% were satisfied. Findings indicated that employees had a lack of trust in the employer and other employees who might access their data, lack of confidence that the ePHR could provide desired information during a healthcare visit or emergency, and insufficient communication from the employer concerning information sharing. A study of the use and utility of a free web-based ePHR in a low-income elderly population<sup>73</sup>

found that only 13% of eligible residents used it, and use was correlated with the availability of in-person assistance. Here, the barriers included poor computer and Internet skills and/or technophobia, inadequate access, low health literacy, and limited physical and cognitive abilities. In this case, people who could benefit most from the ePHR system were least able to use it.

It is generally recognized that the ePHR architecture with the most promise is one that supports access to all or most of the sources of clinical information that pertain to the particular consumer<sup>86-87</sup>. This allows information from the consumer to be integrated through interoperable network systems with information from other sources such as primary care physicians, specialists, test laboratories, hospitals, etc. Such ePHRs can be said to be “integrated” with the healthcare system. Although integrated ePHRs may be the best solution, there are barriers to their implementation<sup>14,86-88</sup>. These include:

- The healthcare system culture and incentives where concerns include:
  - a balancing act between physician and patient autonomy,
  - a lack of training, interest, or ability of physicians with technology,
  - user resistance to change,
  - the scope of work and responsibilities of healthcare providers,
  - physician compensation and incentives, and
  - provider concerns about liability risks;
- Consumer confidence and trust, and safeguarding the privacy of consumer medical information
- Lack of technical standards for the system interoperability that is essential to making integrated ePHRs a reality, including:
  - data interchange standards,
  - minimum data set standards in specific provider specializations,
  - security and privacy standards,
  - certification of health information technology products
- The lack of ubiquitous adoption of electronic health record systems by healthcare institutions and practitioners. In fact, the US and Canada lag the rest of the developed world in practitioner and institutional adoption of electronic medical record system adoption<sup>100</sup>.
- Lack of health information technology infrastructure including:
  - lack of resources to support system integration given the variety of existing systems,
  - need for mediating networks, organizational structures to support integration,
  - the limitation of online services offered by healthcare providers and institutions
- The Digital Divide:
  - considerations of racial, education, and socio-economic status,
  - health illiteracy,
  - special needs for individuals with visual, cognitive, or physical limitations,
  - lack of financial resources;
- The general lack of empirical justification based on both improved cost efficiency or healthcare effectiveness;
- Uncertainty in market demand due to the lack of success by many small vendors. More certainty would drive investment in the development of higher quality ePHR systems.

## CLINICAL AND PROCESS OUTCOMES (RANDOMIZED CONTROLLED TRIALS)

Ten outcome evaluation studies were found that involved randomized controlled trials (RCTs) of ePHRs/PHRs, with the results summarized in Table 1. Although statistical results and their significance are reported in each study, there is little similarity among the conditions measured so a meta-analysis is not feasible. Of the ten randomized controlled trials of personal health record systems that were found, only three involved ePHRs. Two<sup>62,65</sup> were focused on whether health promotion or coaching interventions were successful in changing prevention, detection or management of screened conditions. In both cases there was no significant effect except<sup>65</sup> that an improved recognition of signs of heart attack or stroke was noted. However, in a similar study involving paper health records<sup>77</sup>, knowledge, attitudes, and behavior concerning health promotion were found to improve if both a computer-generated summary and a booklet were provided to patients. The third ePHR study<sup>18</sup> found a significant impact 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, one<sup>68</sup> found that the impact of written educational materials on behavior change for preventive measures in the general population was not significant. In three separate paper based PHR studies<sup>40,56,76</sup>, communications between providers and patients were examined, and no improvements were reported in patient satisfaction with communications or with information provided to patients. In one study of the effectiveness of a patient-held paper record for schizophrenic patients<sup>61</sup>, there was no effect on satisfaction or the use of secondary care services. Finally, one study reported on a comprehensive strategy of regular examinations and documentation provided to help improve diabetes care for participants<sup>39</sup>. The results were small improvements in HbA1c and diastolic blood pressure levels, but it is not clear whether this was due to additional documentation or to more regular examinations of the participants.

**Table 1. Randomized Controlled Trials of ePHRs/PHRs**

<b>Paper</b>	<b>Objective</b>	<b>Measures/ Total Sample Size (TSS)*</b>	<b>Outcomes</b>
[65]	Employee health promotion with ePHRs	Flu illness & prevention; Cardio health & sun protection / TSS 99 (company employees)	Beliefs in vaccination changed; vaccination rates did not change; improved recognition of signs of heart attack & stroke
[56]	Patient-held record (paper) for patients with advanced cancer, palliative care needs	Patient satisfaction with communication with institutional and home healthcare professionals /TSS 231 (Advanced cancer outpatients or home hospice patients)	No improvement in provision of information to patients, or in patient satisfaction with information provided by healthcare professionals.
[39]	Comprehensive strategy involving both patients and professionals, including paper PHRs, to improve diabetes care.	Yearly examination of HbA1c, creatinine, total cholesterol or total cholesterol/HDL ratio, microalbuminuria, weight, BMI and blood pressure, advice on smoking and physical exercise, eye and foot exams / TSS 1350 (diabetic outpatients)	Small improvements in HbA1c and diastolic blood pressure levels
[40]	Use of supplementary patient-held (paper) record in cancer care.	Global health status, emotional functioning, cognitive functioning measured with standard instruments/ TSS 650 (radiotherapy patients with cancer)	Both groups had a high level of satisfaction with communication and participation in their care (ns. diff. between control, intervention groups).
[76]	Use of a paper patient-held record (PHR) for patients with cancer, in several environments	Patient satisfaction with information and communication, patient and healthcare professional views of PHR/ TSS 188 (patients newly diagnosed with lung or colorectal cancer (hospital), and patients with cancer at any stage (community)).	PHR did not improve patient satisfaction with information or communication.
[61]	Effectiveness of a patient-held (paper) record for patients with schizophrenia receiving shared care	Verona Service Satisfaction Scale-54 and Krawiecka and Goldberg (K & G) rating scale of psychopathology at 12-month follow-up. Other outcomes were use of secondary care services/ TSS 201 (schizophrenic patients)	No effect on either primary or secondary outcomes
[62]	Effectiveness of Internet portal-based coaching intervention to promote patient-PCP discussion about chronic conditions.	1-week, 3-month patient surveys assessed visit experiences, target conditions, and quality of life; chart abstractions assessed diagnosis and management during PCP visit/ TSS 241 (chronic patients)	No differences in detection or management of screened conditions, symptom ratings, and quality of life between groups.
[77]	Effect of computer-generated PHR summary and/or written health record on patient attitudes, knowledge, behavior re health promotion.	Attitudes to patient-held records, and pre- and post-intervention knowledge and behaviour concerning health promotion, were assessed using questionnaires/TSS 364 (General Practice patients)	Effectiveness of a computer-generated patient-held health summary and an explanatory booklet together is greater than either separately in changing patient knowledge, attitudes, and behaviour concerning health promotion.
[68]	Use of written health education materials change healthcare behaviors in the general population.	Personal Health Record Booklets (PHRBs) with evidence-based recommendations for reducing risk of cancer and cardiovascular disease distributed to intervention sample / TSS 25,000 (General Pop'n)	No increases in rates of Pap tests, mammograms, and skin operations were detected in either short (3 months) or long-term (1 year) follow-ups.
[18]	Impact of ePHRs on patient access to vital health info. and assess effect on provider-patient communication	Questions about personal possession of documentation of vital health information /TSS 150 (US VHA Veterans)	Initially, most subjects had poor documentation of health info. At follow-up, sig. diff's. occurred between cohort with ePHRs and cohort without re documentation of immunizations, allergies, medications, operations.

\*Total Sample Size (TSS) is the total of both control and intervention groups.

In general, the results from the RCTs are disappointing. Although most ePHR/PHR users felt that there was value in having access to more information, little if any improvement in health outcomes was reported in most cases.

## CONCLUSIONS

Table 2 provides a brief summary of some of the main findings of the study, although it is impossible to provide a comprehensive summary in such a small space. One of the objectives of this study was to determine whether the literature has shown that ePHRs can provide tangible and intangible benefits to consumers. The following list of the overall conclusions addresses this objective.

1. Primary Care Physicians (PCPs) play a key role in the management of their patients' health. Sharing some proportion of their EMR records with patient ePHRs can provide a major part of ePHR information, so a key to ePHR adoption in North America is the rapid and continuing growth in physician adoption of EMRs.
2. Although there have been many good studies of ePHRs that have brought forward some interesting results, many of these studies have been physician-oriented. That is, patients have been given access to their doctors' or hospital EMRs, which are designed to provide doctors with the functionality and information they need. Hence, many have not included patient-oriented support such as the ability to join communities of interest, general information from high quality Internet sites on the latest in specific diseases and their treatments, information from healthcare professionals and Internet sites on treatment programs for lifestyle, weight management, and support for self-monitoring programs for heart disease, diabetes, etc. Until such ePHR support is available, it is unlikely that a randomized controlled trial will be able to show significant progress in tangible and/or intangible improvement in health outcomes by the use of ePHRs.
3. Not everyone is or will be motivated to want or to use an ePHR to help manage and support his or her healthcare, so a low overall adoption rate is to be expected. However, when ePHRs are implemented, they should involve motivate users directly in their design, and provide a range of functionalities to support health self management and disease prevention. This includes people with serious chronic ailments, disabled individuals, parents with small children, people with a strong interest in maintaining a healthy life style, and the elderly and/or their caregivers. Not all will want to adopt ePHRs, but careful attention to their needs will improve the likelihood that they will adopt and continue to use ePHRs in managing their health.
4. Randomized controlled trials are needed to test assumptions about the effectiveness of ePHRs for various patient populations. These should test systems designed for patient health self management and disease prevention, and not systems originally designed for physicians.
5. The diffusion of ePHR use to those motivated to adopt this type of support can be costly if it is to be done effectively. How this is to be supported until solid information can be collected and the future of such systems is decided is a major public policy issue for administrators and funding agencies, for healthcare systems that are already struggling to support existing services.

**Table 2. Summary of Findings from ePHR Environmental Scan**

<b>Category</b>	<b>Findings</b>
Content	Little consensus on what ePHRs should include. Suggestions include problem lists, procedures, major illnesses, provider lists, allergies, home-monitored data, family histories, social history and life styles, immunizations, medications, lab test results. However, patient needs are condition and illness dependent. Ability to enter and modify one's one data is important, and links to relevant Internet data and support from allied health professionals can be useful.
Architecture	ePHRs tethered to or integrated with the doctor's EMR are preferred choice in North America. Thus, widespread EMR adoption by doctors must precede successful diffusion of ePHRs. Other solutions involve regionally centralized systems that integrate all patient records at one site, and accessed via online portals. Flexibility and the ability to accommodate a range of user needs is needed or acceptance will be low. All solutions involve system interoperability issues that are slowly being resolved through the adoption of content and communication standards.
Privacy and Security	Consumer privacy concerns may impede the widespread use of ePHRs. 2/3 of adult consumers are concerned about privacy and security of health information, but most ePHR users don't worry about information held in ePHRs. Record access can improve patient trust in doctors and treatment regimes. Record access must be securely managed by appropriate policies and procedures to maintain user confidence.
Functionality	A wide range of functionalities is possible, depending upon patient needs, and these in turn depend upon the nature and the term of the patient's illness or condition. Generally, needs can be classified into: participation in care, quality of care, and self-care strategies.
Cost, Financing	Unless ePHR systems can be integrated with existing EMR systems with little obvious cost increases, health authorities and insurance companies will be unwilling to pay for their development and use until they are shown to be cost-effective. Patients highly motivated to adopt ePHRs may be willing to pay a small monthly fee with a maximum of about \$5 US.
Patient-Physician Communication	Most studies suggest modest benefits from improved doctor-patient communications due to ePHRs. E-mail communications almost uniformly implemented. Doctors less positive than patients about e-mail use, but triaging by office staff can re-direct non-critical messages. There is potential for better disease prevention through reminders and online information. Medical jargon in online records can be an obstacle to good communication.
Education, Life Style Change	Educational support relevant to the patient's disease or condition should be available, as well as information and support from allied health professionals on diet, weight loss, smoking cessation, work habits, etc. Communities of interest can provide helpful interactions and discussion of experiences with others suffering from the same conditions.
Adoption, Attitudes, Satisfaction	Most patients welcome the use of ePHRs, and want unfettered access to their medical records. Patients with chronic disease, disabilities, caregivers for elderly, tend to be more motivated towards ePHRs. Relatively healthy patients will likely not be interested in adoption. Patients with ePHR access have had the highest satisfaction with medication refills, provider messaging, and medical test results. To maximize adoption, all stakeholders (particularly doctors and patients) must be involved in the design and acceptance of any proposed system.
Usability	Human computer interactions must be considered in ePHR system design, but additional human support is also needed for people with poor computer skills, low health literacy, and limited physical/cognitive abilities.
Barriers to Use	ePHR implementations fail when barriers to their use are not addressed. Barriers include: existing healthcare system culture and incentives that are affected and may need to change, consumer confidence and trust, lack of technical standards for system interoperability, lack of ubiquitous availability of electronic systems that provide needed data, lack of health information technology infrastructure, digital divide considerations among consumers, lack of empirical justification to implement, less quality system development due to market uncertainty.
Clinical, Process Outcomes (RCTs)	Only three ePHR RCTs were found. Little conclusive evidence on impact of ePHRs on health outcomes. However, ePHRs are typically perceived and accepted by users as being useful in health self management, including support for medical monitoring devices. Providers typically become more enthusiastic about ePHR use after they have experience with them. An RCT trial may need to take more than a year for significant changes in health outcomes to be observed.

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