



McMaster eBusiness Research Centre

**A REVIEW OF EMPIRICAL STUDIES OF PERSONAL HEALTH
RECORD SYSTEMS**

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**McMaster eBusiness Research Centre (MeRC)
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MeRC Working Paper No. 26

December 2008

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A Review of Empirical Studies of Personal Health Record Systems¹

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ABSTRACT

Electronic personal health records (PHRs) have been gathering interest as a tool for consumers/patients to access and provide input directly to their own health records, thus improving their understanding of the state of their health and helping to streamline their interactions with healthcare providers. This paper reviews the definitions and nature of PHRs and their supporting systems, as found in the current literature. A broad survey of literature covering empirical research into patient and practitioner use of experimental and early implementations of these systems, particularly implications for future system designs, is reported. Topics include: PHR architectures; PHR content; security, privacy and consent; patient information needs and expectations; system design issues; user attitudes, perceptions and experiences; and patient-practitioner messaging. Finally, reports on existing implementations are discussed, followed by a discussion of expected benefits to users and barriers to adoption of PHR systems. The general indications are that there are significant benefits of PHRs, although there are barriers to their widespread adoption due to issues of security and privacy, errors, misdiagnosis and mistreatment, and system costs. Regrettably, consumer/patient motivation for adoption of PHRs has not been considered except in the case of British parents who have been encouraged to create and maintain PHRs for their children, beginning at birth. This is in the face of the likelihood that motivation to adopt and maintain PHRs would be high for parents of children with disabilities, patients with serious chronic illnesses, and caregivers for elderly persons. These potential users would probably be early adopters, if encouraged to do so. Although these population segments do not seem to have been considered specifically yet, they deserve further study since they could provide the impetus for more widespread adoption of PHRs, with attendant benefits to the healthcare system. However, family physicians who actively use EMRs (Electronic Medical Record systems) for the clinical records of their patients tend to play an essential and central role in the implementation of PHRs, so the low rate of EMR adoption by family physicians, except in multiple partner practices, will continue to be a significant overall barrier to PHR adoption in North America for some time.

¹ This work was supported by a grant from the Natural Sciences and Engineering Council of Canada

INTRODUCTION

Computers have been in use in hospital health care in Canada for many years, beginning with administrative record keeping and clerical functions, and evolving more recently to creating and maintaining clinical patient records and other medical data. A recent survey of Canadian hospitals (Urowitz, Wiljer et al. 2008) indicated that only about half were using electronic clinical records. In most cases, hospital computerization has not led to interoperable systems, leading to situations where systems used in hospitals and areas within them are silos of information, with little interconnection or transfer of electronic information as recommended by modern business best practices. Much of this can be blamed on the lack of adoption of electronic health record and system standards. Canadian doctors, meanwhile, continue to, for the most part, to maintain paper-only clinical records in their practices, with only approximately 20 percent using some electronic medical record system (Chernos 2007); most of the computer systems in use in medical practices support only administration and billing. Recently, the generally wide availability of health-related information on the Internet has led healthcare consumers to become more active in searching online for general medical information to educate themselves on best medications, treatments, and lifestyle choices for themselves and their families (Bliemel and Hassanein 2007).

The Ontario *Ministry of Health and Long Term Care* (MOHLTC) has increased its efforts to move some forms of healthcare into the community and away from institutions—the ‘Aging at Home’ initiative, for example (MOHLTC 2007)—which would necessitate the flow of health information from healthcare institutions and practitioner offices to patients and community care providers, and in the reverse direction from patients to institutions and practitioners. This need is mirrored in the plan to have a cross-Canada exchangeable format for electronic health records by 2010 (CHI 2007) and the recent announcement of the goal for every resident of Ontario to have an electronic personal health record (PHR) by 2015 (MOHLTC 2008). The term PHR as used in this paper 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 the patient and by his/her healthcare providers.

The purpose of this report is to summarize what is known about electronic personal health records from published empirical studies, the potential for their use in improving healthcare, where the information for these records might originate, and how they might reduce healthcare costs by supporting improved patient involvement in health self management. In this paper, Section 2 presents relevant definitions, Section 3 discusses the nature of PHRs and related issues, Section 4 details a number of empirical studies of PHRs and their findings, Section 5 details some existing instances and experiences with PHRs in several countries, Section 6 describes PHR benefits while Section 7 discusses barriers to their increased use. Section 8 is a concluding discussion of the findings from the paper.

DEFINITIONS

There is no general agreement on the terminology for various types of electronic health records. For the purposes of this paper, we will adopt the following terminology:

The term Electronic Health Record, or EHR, will be used to refer to an electronic clinical record found and used in a hospital setting. This term is also used by Canada Health Infoway for its standard electronic health record implementation (CHI 2007). The nature of these records is well established historically, and they are mandated by law in Ontario. However, there are many different implementations, mostly incompatible; there are reported to be ten different systems in use in Ontario alone (MOHLTC 2005).

The term Electronic Medical Record, or EMR, will be used to refer to an electronic record of information found and used in a doctor's office or clinic. In Canada these records in electronic form are not very common, unlike other international locations; there have been few studies done to determine why the adoption rate is so low in Canada (Archer and Cocosila 2008), and what can be done to encourage their use. In some published references the terms EMR and EHR are interchanged and some papers use them both to indicate electronic doctor's office records.

The term Personal Health Record, or PHR, is considered to be a patient centred health and/or medical record in some electronic form, but there is no consensus on what information they should include. Discussions over the content have referred to the origin of the accessible information, or the system architecture. This is a continuum that ranges from tethered to standalone, with the complexity of the architecture rising from low values, representing simplicity, at the ends of this continuum to peak complexity in the middle. At one end of the continuum, a tethered PHR is connected in some way to one organization's system (typically the patient's family doctor); this implies that it can be considered some form of EHR or EMR that is accessible by the patient. At the other end, a standalone PHR is generally seen to be data stored on some portable media, possibly supported by software to view or organize the data. The intermediate approach is an integrated PHR, which gathers and presents data from multiple sources into a single view. These integrated systems are complex, but the complexity yields usability and flexibility (Tang, Ash et al. 2006); they also imply a central site that stores the accumulated data with associated access protection and presentation tools. There may be other records stored in other parts of the health care system, such as pharmacy records, clinical data, and records in the offices of alternative practitioners, for which there is no simple, common term.

Each of the PHR architectures, from standalone to tethered, has some benefits to convey to the users and promote its use, but each carries some limitations or liabilities that may discourage usage. The standalone PHR is simple and convenient, and may be portable (e.g. a 'smart' health card). However, there is little or no protection from loss, theft, or damage, as there is unlikely to be a backup (Tang, Ash et al. 2006). In tests run on devices with commercial PHR software in this category, there was either no encryption to protect the personal data, or there was poor encryption that was easily defeated, and it was based on flawed software with known weaknesses (Wright and Sittig 2007). Standalone PHRs are considered to be primarily patient driven, and as such will not generally be trusted as a method of communicating medical data between practitioners. Thus this solution will typically not include direct medical practitioner input (Tang, Ash et al. 2006). Further, unless the patient has a strong motivation to keep the information current, much valid data will not be entered, or will be out of date (Tang, Ash et al. 2006).

Tethered PHRs offer the advantage of practitioner input, but this will be limited to those associated with or practicing within the organization that hosts the PHR. Since there is a base

organization, there is likely to be a form of backup, either by reloading the personal copy of the information from the source, or through corporate backups. Unfortunately, when the patient changes affiliation from the host institution to an alternate source, the data may not be transferable due to record and/or system incompatibilities.

Integrated systems offer a blend of simple PHR and normal EMR/EHR data, providing input from multiple sources—patients and practitioners—with a secure backup of the data. These are generally implemented as portal systems with either secure Internet access (Ueckert, Goerz et al. 2003; Halamka, Mandl et al. 2008) or dedicated kiosks (Jones 2003). Additional functionalities may be offered, such as terminology translation or definitions (Lee, Delaney et al. 2007), video attachments for remote diagnosis (Oberleitner, Elison-Bowers et al. 2007), or biometric—e.g., blood pressure, or blood sugar—e.g. tracking (Berner and Moss 2005).

THE NATURE OF PHR SYSTEMS

Primary Users of PHRs

A PHR system must have many users if it is to be an effective tool for health and wellness. The primary users are the consumers or patients, healthcare providers, healthcare institutions, governments and/or payers in the system, and researchers. The primary user of a PHR is the person for which it has been created. Some groups make a distinction between a patient as a user suffering from a chronic illness or an active, acute condition, and a consumer as a user of the PHR as a health tool to monitor wellness. In some cases, such as young children, some disabled persons, or those otherwise incapacitated, it is necessary for a caregiver or other legally sanctioned person to access and update the PHR on the patient's behalf.

Healthcare providers are the primary source of medical data for a PHR. Doctors, nurses, consultants, and other medical personnel generate the medical data in the course of caring for the patient and performing their normal duties. Since much of the data may be captured in paper form, some providers have been concerned about the additional time that this additional data entry will take; actual experiences have been positive (Earnest, Ross et al. 2004) with little, if any, additional time impact.

Healthcare institutions can also provide data to a PHR (Young, Mintz et al. 2004; Cooke, Watt et al. 2006) in the course of caring for a consumer. Walk-in clinics and other non-referral based treatment centres can use a PHR to provide the necessary feedback to the regular doctor in a way that can be effectively and efficiently taken in by the practitioner and that does not rely on the patient's possibly faulty memory, or through direction to the appropriate regular doctor in a large practice. Full videos of tests such as ultrasounds or x-rays, or behavioural observations (Oberleitner, Elison-Bowers et al. 2007) can be transmitted or stored directly in the PHR and made available for the requesting practitioner. Medication renewals and alerts can provide feedback on compliance (Wang, Marken et al. 2005) when the pharmacies provide their data to the PHR. Several implementations (Ueckert, Goerz et al. 2003; Clarke and Meiris 2006) have an emergency data section that is available to emergency personnel involved in the provision of

health care, providing data such as medication sensitivities and other medical information during emergency interventions.

Governments or other payers in the system are generally concerned with PHR legal, financial, and privacy concerns. Payments within the health system have been identified as the best incentives to encourage use and deeper penetration of electronic records in the health system (Middleton, Hammond et al. 2005). Researchers need data sources that are available for use with clear ethical use guidelines, and some PHR systems have been designed (Ueckert, Goerz et al. 2003; Agrawal and Johnson 2007) or adapted (Szarvas, Farkas et al. 2007) to make anonymous data available for use by public health authorities. This clearly has an impact on public health measures and practices.

Architectures

In the context of computer systems, architecture refers to the physical components, including the network and related interconnections that make up the hardware of the system, and the logical breakdown of the components of the software that operates the system. In some cases, descriptions of the architecture of a system that controls sensitive data such as health records can be used to alleviate concerns in the public view, based on their perceptions of risks and security methods (Simons, Mandl et al. 2005). One of the key concerns is unauthorized access (Win, Susilo et al. 2006) which can be prevented by proper access authentication. Authentication is traditionally a username or ID with an associated password, but these have been superseded by other, more robust methods (Sax, Kohane et al. 2005). More secure authentication is generally based on two or more of: something the user knows, something defining where the user physically is, something relating to who the user is, or something that the user physically possesses (Sax, Kohane et al. 2005). If one focuses on the physical location as one of the parts of authentication, then that would limit the access to the patient's record to a set number of places, where trusted provider personnel are located (e.g. hospitals, clinics, or doctors' offices). In that regard, generating user access and establishing credentials from a trusted source has been proposed to be a critical issue for proper authentication. Building on the inherent trust in a doctor-patient relationship by having the physical locations of the primary points of contact in a doctor's office, clinic, or hospital provides a solution to the system trust issue (Mandl, Simons et al. 2007). Alternative access includes providing the security information necessary through the regular mail, through current validated World Wide Web techniques such as a valid security certificate from a trusted organization, or through some other trusted third party (Mandl, Simons et al. 2007).

Conventional physical hardware for a PHR system usually consists of more than one computer system working together to perform the overall system tasks for the purpose of separation of work load, separation of function, or separation of data. Multiple systems sharing a load provide enough processing capacity to respond to and service the requests for information from multiple actors within the network (Simons, Mandl et al. 2005). Separation of data prevents data from being compromised through physical theft or indirect access; this could be through separation of health data from the identifying data stored in the form of registers (Ueckert, Goerz et al. 2003), or separating encrypted data from the keys necessary to decrypt it (Mandl, Simons et al. 2007). In the separation of functions, different functional tasks are performed on separate systems, physical or logical, for the purpose of isolating replaceable or exchangeable functions; in the

Indivo system, for example, the functional breakdown is into user interface, data storage, and business logic (Mandl, Simons et al. 2007). This architecture allows the user interface to be flexible, customized, and adapted if necessary to the specific user population, and the data storage optimized for best security and privacy protection, without impact on the business logic. The business logic includes the access policies and their enforcement, based on data records that are gathered and consolidated into a coherent personal health record (Mandl, Simons et al. 2007).

When the connection between the central site and the data source or data user is considered, there can be several options and issues. In the first case, a comparison between the existing system in Australia and the proposed systems in the United States provides a description of some of the possibilities (Gunter and Terry 2005). In the Australian system there is a central system that collects health information for all patients based on information that patients and their providers have selected to be stored and available. This is referred to as a ‘push’ model, based on the concept of pushing the data from the gathering point to the central site. In the United States, the *Institute of Medicine* has been working on ensuring interoperability and comparable utility of the data generated at all points in the health care system so that they can all be gathered at central points (Gunter and Terry 2005). This is referred to as a ‘pull’ model, since the central agency requests all the data needed from the providers. Note that the pull model does not necessarily involve a central repository, since data may only be requested when needed by a requesting user/patient.

Other models have also been proposed to deal with the diverse nature of health data and distributed sources of data, including a subscription model and a patient-driven consolidation model. In the subscription model (Mandl, Simons et al. 2007), a patient establishes a PHR on the system and identifies sources of personal health data. The system administrators then define an agent to query the source periodically, looking for new data for all clients who have identified that facility as a data source. The agent will then transform the data from the original source into a form that is more appropriate for the system and store it in the database; the source of the information is also maintained so that changes in the original source may be captured. Patient-driven consolidation (Gunter and Terry 2005) is the basis of many web-based PHR systems such as *Microsoft’s HealthVault* and *Google’s Google Health*, where patients must gather their own health data and enter it into the system. In some cases there are tools to aid in the importation from well-known systems or to aid in identifying the correct or relevant information in the health file (Kim and Johnson 2004).

In order to consolidate PHR information, there must be an agreed-upon common set of terms used to define the material content of the records. There have been many standards defined in various fields in the healthcare system, including *ICD-9* to define diseases and symptoms, *RxNorm* to document doses and names of drugs used, and *CPT-4* to define medical procedures used, and an effort to define medical events in order to report adverse events or problems using the *SNOMED CT* (Standard Nomenclature of MEDicine – Clinical Terms) ontology from the U.S. *National Library of Medicine*. In other efforts, groups like *Health Level Seven* with the *HL7* message standard (Gupta, Martin et al. 2007), and the *Comité Européen de Normalisation Technical Committee 251*, and the *American Society for Testing and Materials* have been defining references to allow the interchange of health data in a meaningful way (Katehakis, Sfakianakis et al. 2001). The mechanism that has been commonly used in the actual

communication of the data is *XML*, or *Extensible Markup Language* (Katehakis, Sfakianakis et al. 2001; Liu, Wang et al. 2007); *XML* allows for the definition of classifications and sub-types that can be exchanged and how they are to be interpreted, so some of the standardization efforts have been in the definition of the associated dictionaries necessary to exchange data in the health care industry. The *Health Level Seven* group has released and had accepted as a standard *Clinical Document Architecture 2.0*, which marries the definition standards of HL7 with XML messaging definitions, in order to standardize communications within and between organizations sharing clinical data (Jagannathan 2005; HL7 2008).

PHR Contents

As important as what form a PHR takes is what information is included in it and where it comes from. At a symposium of the *American Medical Informatics Association's College of Medical Informatics* on the topic of PHRs, it was agreed that more data, from diverse sources, is better to enable proper care for the individual (Tang, Ash et al. 2006). The symposium participants identified four key sources: the patient, the practitioner(s), the institution(s), and the payer. The patient in this vision is acknowledged as having valid data to supply and the need to understand the implications of medical information in the PHR, but not necessarily the skills to do so accurately, so there is a need to provide tools to enable data entry and to translate medical language to more generally accessible terms; this translation is commonly used in the nursing profession, and it has been suggested that this profession can play a role in this regard (Lee, Delaney et al. 2007).

Another topic that was discussed at the symposium (Tang, Ash et al. 2006) documented more specific details on the suggested minimum information to be found in a PHR. From the patient, both subjective and objective information was expected. The former should include a medical history, descriptions of events, and detailed listings of symptoms. The objective measurements would include home measurements of data such as blood pressure, blood sugar levels, and weight. Additional technical capabilities are available through medical equipment at home for automated data upload and compliance validation. The practitioner would provide specific EMR data—or EHR data in the case of a practitioner primarily associated with an institution—as well as notes on visits and test results, and referral information for alternate or specialist practitioners. Institutions would be expected to include their EHR data, results of tests or other relevant data—imaging results, or video as suggested for behaviour observation (Oberleitner, Elison-Bowers et al. 2007)—notes on treatments or observations, and historical data such as prescriptions, visit dates, and future appointments (Oh, Sheble et al. 2006). Finally, the payer would update the status of the patient's account, any restrictions imposed, and requirements for ongoing care, such as required immunizations.

An alternative structure for the content is the *Minimum Data Set* (MDS); MDS is designed to provide a clear set of data, based on standard codes, to support individuals being passed from one layer of health care, such as an acute-care hospital, to another, such as home or community care (Hirdes, Fries et al. 1999). MDS is a very widely used collection of data in the geriatric setting, and is mandated by many provinces in Canada for long term care facilities and in all nursing homes in the United States. The MDS is also in use in twenty countries internationally and has been tested for validity, reliability, and consistency in capturing essential health data (Wodchis, Hirdes et al. 2003).

Security and Privacy

Security of healthcare information is considered to be a more important issue than the equivalent problem in Internet commerce, as firms involved in the latter have 'good-enough' security and offer guarantees of limited financial liability to their customers (Baker and Masys 1999), whereas the disclosure effects of sensitive health information cannot be mitigated in a similar way. In order to provide the necessary level of security, several mechanisms have been proposed. The primary issue is that any security mechanism needs to be usable, or the users will not use it (Baker and Masys 1999), either circumventing security, choosing another system to use, or not using a system at all. There is no way to ascertain where a malicious intruder may attempt to access, intercept, or physically remove data, so encryption and denying access to the data without permission needs to be active at all stages of the system (Baker and Masys 1999). However, not all encryption is good encryption (Wright and Sittig 2007) and some commercial products do not provide the protection expected by the consumer. This is not something that a user would be able to determine without technical assistance, potentially leaving data exposed to a knowledgeable data thief. Wright and Sittig (Wright and Sittig 2007) further recommend that data protection be incorporated into any future standards developed for PHRs. *Public Key Infrastructure* is both an authentication and encryption technology that could be used to satisfy both issues, but it requires significant memory and processing capacity; it has been suggested (Sax, Kohane et al. 2005) that technologic advances in portable devices such as newer cellular telephones that can run small applications could be a solution to the key retention issue. However, it is not easily scalable to large user populations, and it requires specialized equipment to interface with wireless devices. Finally, patients need to be in control of their data and the authorization of various providers to access and/or to add information (Agrawal and Johnson 2007), so that those responsible for the patient's care can perform efficiently.

Some systems that have been developed have broken data access into classes, defined roles for the users that guide the access in the system, and enabled the patients and administration to assign rules for which class of data is available for which class of user, or to specific users (Baker and Masys 1999; Agrawal and Johnson 2007). Levels of information that have been used are: non-identifying, general health, sensitive, parent-sensitive, and patient-sensitive. In this approach, the restrictions or sensitivity increase as one moves along the list. Parent-sensitive data can be discussed with patients who are not yet adults, but defined in law to be able to manage some of their own affairs; pregnancy and abortion information for teens over 16 is in this category in many jurisdictions (Baker and Masys 1999). Patient sensitive data is information that should not be available to the patient for the patient's own well-being in the view of the physician entering the data (Baker and Masys 1999).

Roles used in some systems include: researcher, patient, primary care, secondary care, emergency care, and administration. In the foregoing schemes, a researcher can access data in broad groups, but no identifying information on specific patients, and an emergency room physician can easily find the current list of medications and prior history of a patient in order to deliver the appropriate health care with reduced risks (Ueckert, Goerz et al. 2003). Further refinement would include patient-defined or administration-defined rules, so that a patient may define who may see and/or add to the record, but the administrator can prevent a patient from inadvertently creating a leak or permit reasonable operations (Mandl, Simons et al. 2007). These

rules have been implemented in the business logic level in *Indivo* (Mandl, Simons et al. 2007) or in the database access level (Agrawal and Johnson 2007). The database layer implementation has an additional feature for research: a function that removes identifying information, or generalizes specific information so that any record returned could not be distinguished from any k-1 other records, where k is a value that the institution can set based on local law or institutional ethics. This allows a researcher to have full access to the data without violating privacy restrictions, but still maintain data integrity (Agrawal and Johnson 2007).

Once the security system has been established, an audit function should be established so the user can review the list of accesses to the PHR data, and any unauthorized breach can be detected and acted upon (CHI 2007). Health care providers need to accumulate data about patients to be able to treat them effectively and be paid for their services, so there is a need for them to be able to access the data, but at the same time to guard the data against unwanted breaches; there are several pieces of legislation in Canada that govern expectations for the practitioners and provide penalties for failing to exercise care in managing the data (CHI 2007). In Canada, the federal government has enacted the *Personal Information Protection and Electronic Documents Act* (PIPEDA) to restrict use and movement of personal data without the consent of the person to which it related. Since Canadian provinces are responsible for healthcare, each province has enacted its own health information privacy acts. For example, Ontario has its *Personal Health Information Protection Act* (PHIPA) and its *Quality of Care Information Protection Act* (QCIPA). Under the provisions of PIPEDA, provincial legislation that is considered by federal authorities to be ‘substantially similar’ will supersede PIPEDA, and so PHIPA and QCIPA have been granted that recognition (MOHLTC 2004).

PHIPA is designed to allow providers to collect and use personal information in the process of providing health care to patients (MOHLTC 2004). The definition of a provider of health care—called a health information custodian in the Act—includes most of the traditional groups who provide health care, as well as the institutions that they usually work at or for. Thus doctors, nurses, dentists, hospitals, boards of health, community health workers and agencies, long-term care facilities, ambulance and emergency services, and the *Ontario Ministry of Health and Long Term Care* (MOHLTC) itself. Personal health information is defined to be identifying information relating to the provision of health care to an individual, in recorded or oral form, whether that be family health history, notes on care plans, details on organ donation, the person’s health number, or the substitute decision maker for the individual. Identifying data that would normally be stored in the same record as the health information is also protected; information not covered includes identifying information of employees of health information custodians which is related to their employment, not to the provision of health care to them as consumers. Data which had already been gathered by the custodians before the implementation date also fall under the Act, but data that is more than 120 years old, or that exists more than 50 years after the death of the individual is not covered by the Act.

Systems that are created to allow the custodians to gather, use, update, or distribute the data must also comply with the requirements of the act and to protect from unnecessary disclosure, or other misuse or unauthorized access. If a breach occurs it is demanded by the terms of the act that the individual be notified as soon as reasonable. Records need not be stored physically at the premises of the health information custodian, but can, with the individual’s consent, be stored at his/her home, or in an alternate service location; this permits the individual to hold records for

access by home-care workers, or for travelling health workers to keep records for individuals in remote regions in a local facility. The health information policies must be documented in writing by each custodian and made available to the public; if any use or disclosure occurs in a manner not contained in those practices, that fact is to be included in the health information and reported to the individuals affected as soon as is reasonable.

Consent

Consent for 'normal' use of PHRs is generally implied by the individual who provided the data in the first case, but if the data is to be disclosed to someone who is not, or does not work for, a health information custodian, consent must be explicitly given. An individual may specifically deny access or disclosure to certain health information custodians or health care providers in advance, and it is required for the custodian that is being asked for information to disclose the denial of consent to the requesting person or organization. An individual who is not capable or entitled by law to control his/her own information access may grant or have assigned a guardian to provide consent and review the data gathered. Anyone may also appoint an alternate decision maker, such as a spouse. In general, public and individual safety will override explicit denials of use or disclosure to provide health care to an individual or prevent harm coming to the individual or others through the withholding of the data; the limits on this override are limited to what is necessary to provide proper care. Similarly, in emergency cases, disclosure from one custodian to another is allowed for the purpose of providing care, without consent. Disclosure for the purposes of marketing or fundraising are generally by explicit consent, but simply names and contact information such as an address are permitted without consent for fundraising. Other organizations may have information disclosed to them, such as what is necessary for payment to be made, or must, by law, have information disclosed, such as in the case of suspected child abuse or for *Workplace Safety Insurance Board* purposes. Finally, researchers may receive data from a health information custodian for purposes defined by a plan approved by a research ethics board; the plan must explicitly list the use of the data, the method of disposal at the conclusion of the research, and the security to be used to protect the data; the plan must be carefully adhered to. Other groups may also have data disclosed to them, but only for explicitly defined purposes.

Individuals may access their own health records, except where it is professionally judged to be harmful, or if such disclosure is legally prohibited. The health information custodian must provide the data in 30 days, but may apply for a 30 day extension if it reasonably cannot comply within the original time. Individuals may request corrections to the data if they feel that it is inaccurate or incomplete and can justify the changes, but the custodian is only required to make changes to data that have been gathered by them and are not obligated to change professional opinions made in good faith. If a custodian will not change the data, they must accept a statement of disagreement from the individual and add it to the record.

Complaints about the process and resolution of disagreements arising from *PHIPA* are the responsibility of the *Ontario Information and Privacy Commissioner*; the commissioner may initiate investigations on his or her own initiative, without a specific complaint. The *Commissioner* has full access, without the need for a warrant, to data and custodian offices, but must have a warrant to enter a dwelling. Fines that are defined in the act vary depending on whether the contravention of the terms is done by an individual or an organization, and also vary by the severity of the breach. Restitution to an individual for a breach of the terms of the act is

limited to \$10,000. There are also provisions in *PHIPA* to protect individuals who disclose information in relation to a suspected breach of the terms of the act as long as the disclosure is made in good faith.

The companion act to *PHIPA* is *QCIPA* (*Quality Care of Information Protection Act*). This allows certain providers, such as hospitals, psychiatric institutions, long term care facilities, independent health facilities, labs and specimen collection sites, and the *Ontario Medical Association* to create quality of care committees, in order to review and improve the quality of care given to individuals through their organizations. The committee must be formally established and run in order to fall under the protection of the collection and use of the health data; any data may be collected regardless of consent or barriers in law, as long as it is for the purpose of reviewing quality of care. If the provision of the data by a health information custodian is made in good faith to a quality of care committee, the provider is shielded by *QCIPA* from any legal action that may arise because of the disclosure. Once collected by a quality of care committee, information can be disclosed to management or employees for quality of care purposes, or to another quality of care committee for their use in assessing quality of care; a recipient of this quality of care information may only use it for that purpose.

PHR EMPIRICAL RESEARCH RESULTS

Table 1 summarizes some of the published PHR empirical research, categorized into: 1) Patient information needs and expectations; 2) PHR system design issues; 3) User attitudes; 4) User perceptions and experiences; 5) Patient-practitioner messaging; and 6) Miscellaneous. The subsections following the table give more details of these results.

Table 1. Summary of Published Empirical PHR Research

Paper	Results
1. Patient Information Needs and Expectations	
Liaw et al 1996	Specific and directly related general information together are better for promoting personal health awareness and change
Jones et al 1999	Most patients (4 out of five) want as much information relating to their specific circumstances as possible; one in five were not satisfied with the information that they were receiving and were frequently depressed or anxious; not all information provided was consistent
Jones 2003	Information that is specific to a patient is used more and is shared with family and friends more often
Denton 2001	Patients should control their own health information, and most doctor's records on and history about a person are incomplete
Cooke et al 2006	Patients expect their personal health data to be available (some with, some without, consent) in the emergency department, and all expect

	the health information from the emergency department visit to be sent to their family doctor (some automatically, some by their request, some by the doctor's request)
2. System Design Issues	
Kim and Johnson 2002	Existing web-based PHR systems are weak in terms of patients entering their own health and medical data and doctors getting a good picture of the person's health from the medical professional summary of the contents; if the users cannot easily take advantage of a system, it will not succeed
Kim and Johnson 2004	Different medical content of a PHR that is to be patient-entered needs to take into account the users' perspectives and abilities; use of the appropriate guidance and entry format will boost usability and accuracy
Moen and Brennan 2005	Different people have different data gathering, sorting, and searching behaviours and systems need to take them into account; there is usually one person in a household who accumulates and organizes the health information for the family; language can be a barrier to usage for some
3. User Attitudes	
Hampshire et al 2004	Parents will regularly use a paper-based record of their child's health status and progress; young and first-time parents are particularly likely to use it—some need or 'investment' in the content generates interest; practitioners desire standardization for ease of entry
Moss 2005	Usage declined over time, even with reminders to bring the PCHR (Personal Child Health Record) to appointments
Wright and Reynolds 2005	Professionally designed record no better than 'grass-roots' version; parents will use a useful tool
Walton and Bedford 2007	Generally considered useful and is used—almost all parents read all sections, or all parent-focused sections; health visitors use it the most, followed by family doctors; parents whose first language is not English are more likely to write information into the PCHR in the spaces provided
Staroselsky et al 2006	Most doctor's office data is incomplete from multiple data sources not connected; there are a few patients that do not proactively participate in their own health maintenance
Willison et al 2007	Most patients are concerned about protecting their private information,

	with the concern growing over the previous five years; while almost all were concerned that opening health records to researchers would make control of the data difficult, almost as many were worried that keeping the records closed would block health research; attitudes over privacy and access to the data varied depending on who was accessing the data, favouring university researchers or doctor's office nursing staff; automatic extraction of data from electronic records was not a solution for about 5 percent, with their consent predicated on human access
Edsall and Adler 2008	Some EMR systems are not meeting doctors needs, but they are considered better than paper-based systems that they replaced; savings of time and expense were not what was understood or expected before implementation
4. User Perceptions and Experiences	
Earnest et al 2004	Most patients support patient-accessible records, but they have some concerns over privacy and security of the data, and understanding of the medical terminology; patients having access to the PHR generates more interest in their health and facilitates maintenance of their condition; practitioners were concerned over the predicted additional workload and sensitive nature of the medical notes being misinterpreted, but were generally satisfied with the actual minimal intrusion and patient understanding of the need for complete content
Lyons et al 2005	Health administrators were focused on support provided by technology and were optimistic in their views; doctors were more pessimistic and focused on the intrusion and personal encroachment; nurses and other practitioners were also pessimistic and stressed accessibility and technical design—usability—issues
5. Patient-Practitioner Messaging	
Maisie et al 2004	Web-based systems can allow patients to time-shift access to clinical personnel through data entry and messaging; providing a PHR to a new doctor in advance allows for a more focused patient-provider meeting, getting to the underlying patient health issue faster
Hassol et al 2004	Patients preferred e-mail or messaging for most simple interactions, and in-person meetings for detailed interactions; practitioners preferred telephone for simple interactions and written for more complex interactions that did not require physical presence
Adler 2006	Most patients who have access to the Internet, and some who do not, were willing to pay a small fee for one or more on-line services from

	their practitioner, with secure messaging, access to the record, and prescription refills being the most requested services
Beckjord et al 2007	Surveys of the general population found a small growth (from seven to ten percent) in patients using e-mail or on-line messaging to communicate with their doctors
Leong et al 2005	Patient satisfaction increased when e-mail access to the practitioners was provided; physician satisfaction increased regarding convenience factors; practitioner compensation for time spent was a concern
Liederman and Morefield 2003	Patients prefer messaging over telephone for non-clinical issues such as refill requests; permitting messaging does not create a large volume of messages to the doctor; doctor's productivity went up in this case; reimbursement for time spent is a concern for doctors
Kittler et al 2004	Messaging reduces the workload for doctors in standardized activities such as prescription refills and appointment scheduling; systems are expected to increase efficiency; reimbursement for doctors' time and concern over volume of messages keeping most from using a system for messaging despite already exchanging messages with select patients; doctors want to e-mail their own doctor
White et al 2004	Patients generally follow defined restrictions on messaging use, are courteous in their tone, and do not waste the provider's time with unnecessary messages; messaging allows patients to keep the doctor apprised of health issues between appointments and receive clarification without taking up clinic time
6. Miscellaneous	
Dorr et al 2007	Exchange of data between patients and practitioners using a PHR has a positive correlation with positive health outcomes in treatment of chronic health concerns
Urowitz et al 2008	Few Canadian hospitals have a mostly electronic EHR, with most reporting being between 11 and 50 percent electronic; about half felt that they were on track, and about a third felt that they were lagging in working towards the 2010 target of an interchangeable EHR within Canada; buy-in from personnel was considered to be a notable barrier, but few had actually surveyed their staff on the matter

Patient Information Needs and Expectations

The *National Health Service* (NHS) in the United Kingdom has been providing health information to consumers since the early 1990s but the form this takes has been the subject of considerable discussion between doctors and administrators (Liaw, Lawrence et al. 1996). Liaw et al compared the health behaviour and awareness of a group of patients who had not been seen recently at five general practices in Oxfordshire. The researchers sent a randomly selected sample of patients a letter inviting them to come for an office visit; the letter was accompanied by either the *Health Education Authority's* information booklet, which has basic health information and places for a patient's key data to be manually filled in from office records, a computer-generated summary of their medical records from the office, both documents, or nothing. The hypothesis was that by providing a computerized medical record to patients as opposed to the booklet, it would be seen to improve the patients' view of their personal health. Those receiving a computer summary were more likely to accept the invitation to the practice for a health check, those that received both documents were more likely to keep and use the information, but those that received the booklet were more likely to improve their awareness of their health issues. The conclusion drawn by the researchers was that neither general information, nor simply a summary of medical data, were sufficient for patients to become involved in their personal health improvement.

In a study of information needs of patients, and the possible predictors of that need (Jones, Pearson et al. 1999), researchers surveyed 525 cancer patients entering a randomized trial of computer-based information use. They asked the patients what information they'd like to have, and factored the results based on demographic information, as well as anxiety score and depression levels. Four out of five wanted as much information as they could get about their conditions, with the age of the patient and the type of newspaper read being significant predictors. One in five patients surveyed were not satisfied with the information that they received, with depression or anxiety being the key predictors of this need. The researchers also found that 15 percent of the patients reported receiving different information from different health practitioners. Later, in a related study (Jones 2003) of information accessibility, Jones found that patients preferred information clearly related to their condition, rather than simply a lot of information, and when they had that information they were more likely to share it with their family or other supporting individuals.

Another study that looked at patient attitudes and perceptions of the use of PHRs, by a doctor who offered his patients a PHR and associated software when he retired (to become medical advisor to a commercial PHR company) and followed up with them ten months later to determine their experience with the PHR (Denton 2001). The patients (about 1000) were offered the use of a PHR system and 330 accepted; this group were then mailed a survey on their experience, of which 136 responded. This was a self-selected sample, so the implication might be that they were more likely to use the PHR, having chosen to accept it. Only about half of the survey respondents had actually used it, and most of these found it easy to use and would recommend it to a friend. Those that had not used it still planned to do so; a small minority found it difficult to use, so had abandoned it. A majority of all of the respondents felt that they should have their own medical records, and that their doctors did not have their complete histories, or all of their pertinent records.

A cross-sectional telephone survey of adults who had visited emergency departments in the *Calgary Health Region* in 2002 generated 837 usable surveys (complete information) of 941 surveys completed (Cooke, Watt et al. 2006). The survey studied attitudes of patients regarding their expectations of emergency departments and waiting times. An additional topic that was surveyed was patient opinion on medical records and exchanges between the emergency department and family doctors. About two-thirds of the patients surveyed felt that their personal health record should be immediately available to the emergency doctor without their own specific consent, and all but seven of the patients felt that it should be available in the emergency department in some way. Once the visit was complete, almost three-quarters of the survey respondents said that their health results should be automatically, without any consent or direction required, available to their family doctor. The remainder wanted it available at either their or their doctor's request. There was a slight correlation of responses with the severity of the cause of the visit, with those suffering more acute problems at the emergency department expressing more desire for an automatic transfer of information.

System Design Issues

In a survey of Web sites that allow patients to create their own PHRs (Kim and Johnson 2002) the user interface was the factor that was found to be the most critical factor in the success and broad adoption of the PHR system. Kim and Johnson wanted to compare general purpose PHR systems, so they surveyed available Internet based PHRs, and found 19 sites. Four were disqualified since they were for specific conditions, two were eliminated as a result of a disease management focus, one linked to a specific hospital, and one had persistent connectivity problems during the analysis period; this left them with 11 valid systems to evaluate. All the PHR sites had sufficient security to protect user data and prevent unauthorized access to the records; several systems allowed the user to designate a doctor who could access and update the data stored there; many had a special access point to provide user defined emergency data to an emergency department medical professional. Most had sufficient data entry facilities to enter health data but there were few facilities to assist a non-medically trained user to enter important diagnostic data, treatments, or prescription information. A few of the systems used lists of medical conditions or treatments to assist users, but most used simple free text entry. Most systems allowed further entry of prescription data or other treatments, laboratory test results, and immunization details, but mostly by free text entry, with a few lists and some possible importation from other systems; some of the systems had limited features and options, to the point that some dosages could not be properly recorded. Only one system allowed a summary to be printed or called up on a browser to allow a doctor to review the complete record in sufficient detail to enable an analysis of the patient's condition and generate a diagnosis. As a result of this study, these researchers concluded that, for an online PHR system to be broadly accepted and adopted, the user interface would have to be simple in functionality for the general public to enter data, and detailed enough for a doctor to view conveniently while studying the case.

Having come to that conclusion, Kim and Johnson performed a hands-on test with patients to determine what types of user interfaces allowed patients to enter their medical data with the most accuracy (Kim and Johnson 2004). The researchers solicited patients who were receiving specific treatment for thyroid ailments to participate in tests of data entry interfaces they had created on a secure website. Participants were provided with access to the website, were given a

list of information to request from their doctor for use in the tests, and were asked to complete an authorization for the researchers to access their medical records from their doctors, for validation of the test entries. A total of 51 patients responded to their requests and registered, but only fourteen completed and returned all of the required forms, and only eleven completed the test exercises. The website was set up to test entry of information using recalled and transcribed free text, guided recalled and transcribed text, selection of information from lists, and information based on answering a set of questions with yes or no answers. Patients were asked to enter their diagnoses, goals of prescribed therapy, prescription details, and laboratory results using one or more of the given techniques. In general, when the subjects were asked to enter free text, with or without aids, misspellings and extraneous data were common flaws in the information provided. When they were asked to enter their diagnoses from memory, all entered the correct information (one misspelling and several with unnecessary phrases); when they were allowed to transcribe from their medical record, all entered correct and usable information. When they were presented with lists of possible diagnoses, all but one selected the correct item or items from the list. When entering goals of therapy in free text three of the eleven entered correct information, and five others entered related goals. When the same task was given using the set of questions the subjects had 100 percent accuracy, whereas only about half could select the information from a set of lists.

Prescription data presented problems when unaided free text entry was used; all entered the name of the drug correctly, but of a total of 12 entries, only eight had the correct strength, six had the right units, three had the right frequency, and only two had the right amounts. Their accuracy was much higher when entering free text while referring to prescription labels, and perfect from labels when picking from lists; selection of colour information for coded pills was not very successful, but this was ascribed to potential monitor and browser setting problems. Finally, free text entry from recall was far less successful than guided entry while referring to result data with little real information entered from recall (only one correct result entered) but almost all relevant data was entered under guided entry. In summary, in order to provide valid and useful data for health professionals to base patient care, a user interface must be established so that patients are guided in both selection of material upon which to base their entry, and in the content of the entries.

Research has been undertaken to determine what strategies consumers currently used to maintain their own paper-based health records (Moen and Brennan 2005), through structured interviews of representatives of 49 volunteer families in a rural area. The study discovered that there is usually one person in the household who creates and maintains the family's health records using one of four strategies: just-in-time, just-at-hand, just-in-case, and just-because. Each of these organization, collection, and storage strategies matches the individuals' perceptions of need and requirements for access to health information. The researchers felt that with the strong principles involved in each of these, PHR software created to perform the same task electronically should be informed by the research and conform to the needs for access to and the search for information. This study also discovered a language barrier within sub-groups in their study. In this case the language barrier was between the local Latino population and the medical community.

User Attitudes

The *Personal Child Health Record* (PCHR) is a paper-based record given to parents of new-born children in the United Kingdom. It contains health information and advice, as well as progress pages where parents, visiting community nurses, and physicians can make notes or record progress milestones. A survey of user attitudes used interviews of parents, health visitors, and physicians in 28 self-selected, but representative, general practices in Nottingham (Hampshire, Blair et al. 2004). Parents of children three to six months old were sent surveys, with 534 sent, and 401 returned; a physician and a health visitor from each practice were interviewed in one-on-one sessions to elicit professional viewpoints. The survey was designed to compare the usage and opinions of the PCHR between parents and clinic practitioners. 82 percent of the mothers surveyed indicated that the PCHR was good or very good, and 80 percent had used it to record information. First-time or young mothers were more likely to use it frequently, with education level, social class, and marital status having no effect on the usage levels. The mothers were more likely to take the PCHR to clinics than to an appointment to see the doctor (96 percent to 79 percent), and home health visitors were reported to be more likely to write in the PCHR than the doctors (94 percent to 75 percent). Approximately two-thirds of the mothers reported that they had read all of the information in the PCHR, and about a quarter had read about half of it. Practice members indicated that unwillingness to record sensitive information in the PCHR compromised its usefulness, and about 70 percent had problems with locating the correct area to record information in the PCHR. 93 percent of the health visitors and 75 percent of the physicians reported the PCHR to be useful or very useful, with only one health visitor and four doctors (out of 28 of each interviewed) made any negative comments on the usefulness of the PCHR.

In a follow-up to the Nottingham study, a specialist recorded the instances when parents brought the PCHR to his secondary care clinic over a four month period (Moss 2005). Reminders were sent to parents, along with the notices of appointments, to bring the PCHRs to the clinic, but only 20 percent on average actually brought their PCHRs. The older the child, the less likely the parents were to bring the document, with a maximum of 44 percent for the youngest age group. Further issues that the author reported were that the document had several variations, including different layouts, so it was difficult to find where to record information, and there was no space for recording special services, such as plastic surgery.

Parental opinions of, and ability to recall information from, PCHRs was compared between professionally designed content and layout and local Health Unit creations (Wright and Reynolds 2006). A new format was professionally designed to try to convey the current content of the PCHR in an easy to follow manner, based on input from health professionals and specialists in health promotion and marketing. Parents in the test area were recruited over fifteen months, with 2485 surveys sent out and 1369 useable responses received. Approximately 50 percent received the prototype, 20 percent completed the PCHR in the redesigned format, and the remaining 30 percent the old format. All three formats were considered good by the respondents, with the older format more likely to be taken to the doctor. There was no significant difference in the ability to recall information from either format, or in the likelihood of using the recommended alternate sources of information. The new format was less likely to be used as a source of information, despite the revamped design.

In another initiative, the NHS instituted a standardized PCHR in April 2004 and the opinions of parents were sought on the use and functionality of that document (Walton and Bedford 2007). In-person questionnaires were administered in 10 child health clinics in London and Buckinghamshire to 89 parents. The researchers reported that the great majority (98 percent) indicated that they used the PCHR, and 92 percent or more took the PCHR to appointments; the figures were lower for hospital visits (90 percent), emergency room trips (75 percent), and dental appointments (55 percent). 42 percent reported filling in the progress and health information sections in the PCHR, with the numbers higher (63 percent) in homes where English was not the first language. The main health professional using the document was the health visitor (95 percent of all contacts) followed by GPs (69 percent), and hospital staff (54 percent of paediatricians, 53 percent of nurses); doctors in the emergency departments used it least (23 percent). The PCHR was generally considered understandable. 71 percent of parents using it reported that all sections were useful, even those sections designed for health professionals. The only contentious item was a question asking for the mother's level of education—an item shown to be correlated with child health—as the practitioners were worried about the intrusion into the privacy of their patients, but 78 percent of the parents surveyed were happy to fill in the section, and 18 percent had no problem being asked, but would prefer it not be written in the PCHR; only 3 percent were unhappy about the question being asked.

The completeness of a PHR is a critical property; in a study in a general practice (Staroselsky, Volk et al. 2006), 1063 patients were recruited, with 163 returning a completed survey at the end of the study. All patients recruited were provided with a survey containing information on maintaining their health based on information recorded in their EMR at the practice—that is, prevention services, such as immunizations and disease screenings. The survey asked for updates on the content, such as having had a flu shot at another clinic, and those surveyed were tracked for six months. Data were then gathered from the EMR to determine if the contact had prompted the patients to take care of any missing tests or immunizations. A matching group of patients was not contacted and their actions served as a control. There appeared to be a large number of missing entries in the contact group's EMRs, but it turned out that a majority had been performed elsewhere; very few patients were truly overdue (between one and four participants, depending on the item) except for flu shots, where nineteen had missed the latest round. None of the truly overdue actually took action, except for two patients who got a flu shot; the control group had the same or better compliance over the six month period.

Consent to disclose information in PHRs is an issue for health researchers. A random telephone survey of 1230 adults across Canada tested: attitudes around privacy in health research, trust in those handling health data, consent attitudes regarding availability of personal data, and thoughts on automated data extraction of their data for research (Willison, Schwartz et al. 2007). About 75 percent of those surveyed were concerned about protecting their private information, and that concern had been growing over the past 5 years in general. The study found that 90 percent of those surveyed agreed that there was a cause for concern if opening records for research made control of the data difficult, but 88 percent agreed that there was a cause for concern if blocking access to the medical data hindered health research. Over two-thirds (68 percent) agreed with the statement that privacy should suffer in order to enable health research. When asked specifically about their own data, only 4 percent of those surveyed would block all access for health research, with the rest consenting: 12 percent would allow access without the need to ask permission, 23

percent with notice given to them after the fact, 23 percent would grant general access as long as they could review and possibly change later, 5 percent would give blanket permission when asked, and 32 percent would want to know and grant access on a case-by-case basis. When automatic extraction from a PHR was suggested, 27 percent were comfortable with any access, and 9 percent wanted to block all access; the researchers felt that this was because, while no person was reading through the data, the data were more likely to be used in more places with more risk of exposure or leaks. When salary or education level were also considered, the numbers granting consent declined further. When those surveyed were asked about their feelings about the person performing the data extraction, most trusted a nurse in a doctor's office, or a researcher from a university, but had concerns if the individual was a doctor's secretary or a corporate researcher. Trust in individuals extracting data was enhanced if they were trained in proper analysis technique and made aware of stiff penalties for inappropriate usage.

There are a number of commercial EMR systems available for doctor's offices. A survey of 422 self-selected family physicians reported on their satisfaction with the systems they had, on a number of function and usability dimensions (Edsall and Adler 2008). Researchers received reports on 61 systems, most with just a few users, but 13 systems together accounted for about 80 percent of the responses, with 12 or more per system; these were reviewed extensively in the study. Most systems were used in smaller practices (less than five partners) but there was a bias towards much larger practices (more than twenty partners) for some of the systems. In general the respondents were satisfied with the functionality of the systems (better than half satisfied for all but two systems), and the ease of use and flexibility (better than half satisfied for all but three systems—two with low functionality satisfaction and one other). There was lower satisfaction for support and training (five systems with less than 50 percent satisfied and overall just 60 percent satisfied) and much lower for seeing financial savings expected from the system (only six systems with over 60 percent agreeing that the system has or will save money over the first five years of use). For four systems, fewer than half of the doctors would re-select the systems and five system users (the same four and one other) felt that their systems were not worth the cost. However, when asked if they were willing to return to the paper-based system they had used before, even the lowest performing EMR system had over 55 percent preferring the computer-based system, with the majority of the doctors preferring their computer systems by more than 75 percent.

User Perceptions and Experiences

In order to gauge patient's expectations and actual experience with the use of electronic records, and gather clinic staff attitudes and experiences with generating content for electronic records, a randomized comparison of patients in a heart clinic was undertaken (Earnest, Ross et al. 2004). Recruited patients (107 individuals) were assigned to either an intervention (n=54) or control group (n=53), with the intervention group having access to an electronic PHR system that included integrated messaging with clinic staff. Seven of the eight physicians in the clinic and all four staff members participated in the evaluation. The patients and doctors were given a questionnaire, both at the beginning and at the end of the study, to assess expected benefits and risks involved. Focus groups were held for some the intervention group towards the end of the study period, and a separate one for the four clinical staff members. It was found that a majority of the patients supported accessible records, with a few concerned over the security of the data

and their privacy. The doctors were worried about the possible extra workload in providing notes that were useful for the patients, and possible intrusion through the messaging component of the system. In reality, all the clinic staff found no detectable increase in workload, with some of the doctors consciously changing their note-making style to enhance understandability for the patients. The patients had several positive reports and a few concerns that were captured in the qualitative component of the study. In general they felt that access to their records allowed them to understand their conditions better and focussed them on self-education on health care. Having access to their PHRs allowed them to coordinate their care better, such as being able to access the data from anywhere, and being able to contact the staff for updates. An example was given where a patient who had blood taken for a test and left town immediately after was able to get the results, consult with staff, and adjust her medication to deal with her condition.

Other factors in the study included patients learning more about how the doctors made decisions regarding patients' conditions, and allowing them to involve themselves in their own care as part of the team; part of this was supported by the pool of information available to reinforce their memory of the doctor's advice and allowing them to access the information on their own time, without waiting for an opportunity to connect with the staff in person. Finally, patients were put more at ease when they saw all of their results, including normal results that they previously had not been informed about. This helped to ensure the accuracy and completeness of their PHRs. A few of the patients reported difficulty in understanding the notes added by the doctors, but through education it was possible to overcome the medical jargon barrier. On the other side of the same issue, some patients worried that the doctors would not include all of the information, to either reduce patient anxiety or to avoid possible legal issues. Finally, patients were found to be worried about employers or government agencies having access to their PHRs without their consent, and the possible consequences of such access.

The U.S. *Veteran Affairs Medical Centers* (VAMC) were early adopters of electronic health information systems. In a study of 322 doctors, nurses and other supporting professionals, and administration staff at 18 VAMC sites (Lyons, Tripp-Reimer et al. 2005) opinions and concerns regarding the technology for implementing clinical practice guidelines associated with patient records within and between the three groups were collected. The participants were from widely different sites based on performance, size, and patient demographics; they were arranged into 50 focus groups broken down by profession where the facilitator started the discussion from a script and the issues were raised by participants. In total, 18 themes in four topic domains were discovered in the analysis; the main topic domains were computer tasks, workplace factors, system designs, and personal concerns. All groups had approximately equal discussion on the computer topic domain—items such as data retrieval, order entry, and decision support. Administrators spent the most time on workplace factors, such as patient records, computer literacy, and guideline implementation. Doctors' discussions focused on personal matters more than the others—items such as time, workload, and attitude. Nurses also spent much time discussing the personal matters domain, but only slightly more than the system designs theme, which contained topics such as accessibility, essential data, and charting formats. In general, administrators accentuated the positive benefits of technology, but other participants tended to look on technology factors as barriers. The doctors felt that the computer skills necessary to maintain adequate patient records were too much to ask, and the nursing staff were most concerned over their ability to keep the data up to date as a result of more limited access to

computers, when compared to other staff members. The non-administrative staff also was very concerned over the time available for tending to patients compared to the time necessary to do the required computer work.

Patient-Practitioner Messaging

In a study involving electronic messaging and PHR systems (Maisie, Lau et al. 2004), a trial system was created to allow patients to enter medical data online as part of a referral process, in advance of their appointment, rather than on a clipboard in the office and in an interview with a doctor. This allowed for a complete history to be created over a longer period of time (a few patients took several months, but most just over an hour) and that information was used to aid in scheduling patients for appointments. The study was a small one, with 61 patients using the system, and only 32 completing the survey. Most patients reported the system as easy to use, and the staff members were able to process the referrals within a day, reducing the delay in seeing patients. Most of the patients were satisfied with the process, and the specialists found that the data provided was both sufficient to correctly triage the patients, and to allow them to focus on the specifics of each patient's case—having the data in advance allowed for some study and left the appointment time for gathering more detailed data in the critical areas.

In a larger study (Hassol, Walker et al. 2004), 1421 users of a PHR system in a total user population of 4282 were surveyed, with 25 of them also interviewed in a focus group, and the ten participating providers were individually interviewed. The majority of the respondents said that the application was easy to use and that the record online was “complete, accurate, and understandable”. A few of the patients were worried about finding out bad news on the system rather than one-on-one with their doctors, or about the confidentiality of the data in general. In preferences for communication between patients and the institution, strong differences between the opinions of patients and doctors became apparent. Users preferred e-mail for many of their interactions with the providers, such as prescription renewals and general medical information, so as to avoid telephone tag, but wanted in-office communication for getting instructions of any sort; they never preferred written or telephone contact. Doctors, on the other hand, preferred telephone or written contact for routine interactions and in-person meetings to give instructions. Doctors were also concerned about the conflict between correct and complete information in notes versus the sensitivity they felt was needed when patients had access to the notes.

In a study to determine the strength of patient interest in communicating with physicians and having access to their medical records on line (Adler 2006), a doctor polled his patients over a period of a month, garnering 329 responses from 346 visits, asking for their willingness to pay for the PHR service. The instrument used was a simple checkbox survey, with questions for age-range, sex, employment status, access to the Internet, willingness to pay for some services, payment values, and most preferred service. Of those surveyed, 75 percent had Internet access. Those in younger age categories, typically either students or employed, had the highest incidence of access; 75 percent of those with Internet access were willing to pay a small fee for one or more services listed. The service selection and the preferences (patients could choose more than one) were: Secure e-mail with the doctor (67 percent), electronic refilling prescription requests (62 percent), online access to their medical records (60 percent), request appointments online (57 percent), and online billing enquiries (52 percent). The younger patients were more willing to pay, and of all patients with Internet access, 60 percent would pay \$10 or more, and 31 percent

were willing to pay more than \$50. 12 percent of those without Internet access willing to pay for services, with the overall survey preference of 47 percent willing to pay a median value of \$20 for services. The services that were deemed most important (in a question where the patients had to select just one) were e-mail (34 percent), medical record access (22 percent), and refill requests (11 percent).

In 2003 the U.S. *National Cancer Institute* launched a biennial cross-sectional survey of adults known as the *Health Information National Trends Survey* (HINTS), and a follow-up 2005 survey studied some of the changes in the intervening time (Beckjord, Finney Rutten et al. 2007). The specific topic of interest was the ability to communicate electronically with a doctor; the value had risen slightly from seven to ten percent over the two years. Those with more education, living in an urban area, having generally poorer health, or those with cancer were more likely to be in electronic contact with their doctor.

In a small study of patient and physician expectations and experiences, four physicians in a group of eight offered e-mail access to their patients and the other four provided a control that did not offer e-mail access (Leong, Gingrich et al. 2005). All participants, patients and physicians were surveyed on satisfaction, quality, convenience, and time factors. The patient satisfaction for convenience and timeliness went up for the e-mail group over the control, despite the longer response time for e-mail messages than for telephone messages; the lack of telephone tag and set hours was believed to be the compensating factor. The physicians in the e-mail group had higher satisfaction results for convenience, amount of time spent, and volume of messages. Most patients and six of the eight physicians indicated that patients and physicians should be able to use messaging to communicate; the two dissenting physicians were in the control group.

In a similar study (Liederman and Morefield 2003) another eight providers, their staff, and their patients were surveyed on the use of an e-mail messaging system. 238 of the 645 registered users responded to the survey, with messaging preferred over the telephone by both patients and providers for lower priority contacts, such as appointment scheduling and prescription refill requests. Over 85 percent of the patients found e-mail easy to use and they were satisfied with the system; their satisfaction was strongly linked to the timeliness of the providers. The providers, too, were generally satisfied with the system and found it easy to use; they had been concerned that there would be a high volume of messages coming in but the levels experienced were reasonable in their view. The providers believed that the system improved communication with patients, and they valued the insurance reimbursement function that was implemented in the system. In evaluating the visits per day and the *Relative Value Units* (a standardized measure of doctor productivity) per day and comparing the study period with a similar period the preceding year it was found that the physicians using the system had improved their productivity by almost 15 percent.

In yet another survey (Kittler, Carlson et al. 2004) of a messaging and online records access system, just the physicians using it were surveyed on their opinions of the system and its value; the survey was run six months after the system was installed, and 24 of 43 of the clinic doctors using it responded. The opinions were generally positive, particularly in the cases of prescription refill requests (88 percent), referral requests (84 percent), and appointment scheduling (71 percent). In the survey, 71 percent felt that the system would improve efficiency and 62 percent reported that they would recommend the system to colleagues; ten percent felt that it was too

early for them to decide whether or not to recommend the system. None of the doctors opted to use the secure messaging system, despite many (58 percent) of them already exchanging e-mails with a small number of patients using generally insecure standard e-mail software. Most of the e-mails were reported to be clinical questions and some refill and referral requests. The study authors were interested in the reported findings that 38 percent of the doctors in the surveyed group already e-mailed their own doctor, and a further 19 percent would like to. The main barrier cited by the physicians in the study was that e-mail messaging was not currently part of their reimbursement schedule.

As in previous research, the doctors involved were initially concerned that they would be inundated by messages if the patients were allowed to communicate with them by electronic messaging. To test that patients really did understand the rules imposed by a doctor's office, a study was undertaken (White, Moyer et al. 2004) in two primary care clinics involving 98 (out of 103 on staff) physicians and their patients. Patients were actively encouraged to use the system and given the expectations and restrictions on types of communication, and warnings about content discouraged for reasons of privacy and sensitivity; these expectations were repeated on an automatic message sent acknowledging receipt of all messages from patients. Patients were asked if the identifiers could be removed from their messages and the messages stored in a database for the study; over 95 percent agreed. Over 3000 messages between physicians and patients were collected over eleven months and the identifying information was removed by one of the researchers. 326 messages were selected at random and messages that were not relevant—blank bodies, automatic vacation replies, study questions, foreign language, or not physician-patient messages—were removed, leaving 273 messages to analyze. Three of the researchers independently coded the messages and discrepancies were resolved by consensus. There were nine categories of message. The most common, accounting for almost 90 percent of the messages, were updates provided to the physician, prescription refill requests, health questions, and messages relating to medical tests taken or planned. Messages were also coded for the number of requests per message, sensitive content, the need for a doctor's response, and the tone of the message. The majority of the messages (83 percent) had a single issue, and were usually to the point, formal in tone, and relevant to the patient's file and treatment; very few had sensitive content and none were urgent—urgent issues were to be handled by telephone as per the guidelines given to the patients. Only about half required a response from the physician and less than one percent of the messages were deemed to be non-courteous. The expected work overload from messages did not materialize.

Miscellaneous

In a broad literature review (Dorr, Bonner et al. 2007) of 109 articles covering 112 PHR system descriptions (with 31 appearing in more than one report) it was determined that the majority of the articles reported positive results in improving the level of care; about two-thirds of the peer-reviewed articles reported positive findings, as did 94 percent of the uncontrolled experiments. The articles covered primarily chronic illnesses, such as diabetes, heart diseases, mental health issues, and multiple disease cases. In the instances where there was a randomized controlled trial, there was overall a positive correlation between exchanging data using a PHR and positive health outcomes ($r=0.28$, $p=0.05$).

Canada Health Infoway has committed to having exchangeable EHRs by 2010, so general and acute care hospital administrations were surveyed to determine where they felt they were on the path to the goal (Urowitz, Wiljer et al. 2008). An e-mail survey request was sent to 213 identified CEOs of general and acute care hospitals in *Scott's Canadian Medical Directory* with the request to either respond directly, or to pass the survey to a senior manager to complete; there were 83 responses, a 39 percent response rate. Unfortunately, a small group of responses were similar enough to be either from one hospital with multiple respondents, or a group of very similar institutions. There were also a few responses that appeared to be from a grouping of related hospitals that should have ideally responded individually. When those surveyed were asked about their hospital's EHR system, about half had one, and less than three percent had completely electronic systems. The largest grouping of hospitals (almost forty percent) was in the eleven-to-fifty percent EHR category. About half felt that they were on track in the conversion to an exchangeable EHR, but about a third believed that they were lagging behind the planned upgrade. When questioned on the barriers to making data available to patients, the administrators felt that financial issues were the biggest impediments; lack of personnel buy-in was also cited by a significant group, although few hospitals had surveyed their staff, and none had asked for patient opinions. The respondents felt that staff would be willing to give patients access to test results and diagnoses but no more; they also believed that the patients would want access to the full record.

EXISTING INSTANCES AND EXPERIENCES

National Health Service (U.K.)

The National Health Service (NHS) in the United Kingdom has been providing patients with computer-based health information through kiosks since 1989 (Jones 2003) and paper health records for infants since 1990 (Walton and Bedford 2007). In 1991 the U.K. passed the *Access to Health Records Act*, which allowed patients to have access to their health records (Liaw, Lawrence et al. 1996). The *Euro-Canada Health Consumer Index* reports that over 80 percent of practicing GPs in the U.K. use an electronic patient record (Walberg, Björnberg et al. 2008). Studies have focussed on the patient experience with personal health records, primarily in paper based formats (Liaw, Lawrence et al. 1996; Walton and Bedford 2007), and additional studies of access methods for computerized PHRs (Jones 2003). These studies found that patients will use the data, but not simply by itself; they need explanatory information, either in the form of a supplement, linked pages online, or text and illustrations mixed in with the medical data.

Germany

In Germany, the *University Hospital Muenster* has launched an online PHR at akteonline.de (Ueckert, Goerz et al. 2003) as a special project, and included obstetrics, gynaecological oncology, and paediatrics online. They reported a demonstration version of the site in English in their report, but it has been replaced by a German only version; in a translated view, it appears to be for patients in "special projects". Germany is not reported in the European health survey as having national programs for EHRs, although patients are listed as having personal access to their own records under certain circumstances (Walberg, Björnberg et al. 2008) so this is more of a local effort. With information for patients in the programs supported online, this could be shared easily with other health care providers, thus gaining some benefits outside the hospital

environment. The authors (Ueckert, Goerz et al. 2003) report on efforts to provide reasonable access in the form of: health care providers having to log in with their own identifier; the ability of a patient to designate a provider who is allowed update access to some parts of the record; the ability of the patient to designate a “deputy” to manage aspects of the record for the patient without giving away their password; the ability to allow access to the data on a “one time” basis to some other person at the patient’s discretion; and the ability for the patient to provide an emergency subset, accessible through information on a wallet-card. Finally, the project has emphasized security, reflected in the architecture of data storage and access methods. There is no report on patient opinions contained in the article, but the authors’ view is that it leads to the “empowerment of patients” (Ueckert, Goerz et al. 2003).

Australia

Australian researchers have reported on some installations of personal health record systems, but the main focus is on security and risks in PHRs. Croll and Croll (Croll and Croll 2007) report on risk exposures and methods of designing and validating quality in software systems used to support PHR systems. They reported that the risk of data being incorrectly linked is very high, allowing disclosure of incorrect information; it had already happened. Australian use of PHRs shows a concern over incorrect data leading to incorrect treatment (Win, Susilo et al. 2006). The systems in use do not appear to allow patients to modify their own data; they must instead send a request or a comment to a practitioner to change the data (Win, Susilo et al. 2006).

United States

There have been a number of reports on U.S. experience with PHR systems, but many are trial systems created to demonstrate a concept or prove a link between constructs which, while important, do not allow a full evaluation by users or practitioners. One comprehensive report discusses three systems (*MyChart*, *PatientSite*, and *Indivo*) which are hosted, developed, or supported by large institutions (*Palo Alto Medical Foundation*; *Beth Israel Deaconess Medical Center*; and *Children’s Hospital Boston* and *MIT*, respectively) (Halamka, Mandl et al. 2008). All resulted in positive responses from the patients and practitioners involved. There are many issues and challenges, such as what should be (medically, ethically) and can be (legally, morally) reported to the patient, how should users be authenticated, support for legal minors, and messaging. The research also considers how the systems need to evolve in the future, particularly expansion beyond current institutional confines into more of a health portal system with messaging between patients and practitioners or other patients, and integrated databases of information sources. *Microsoft* and *Google* both have pilot projects running involving storage of personal health data online (*Microsoft HealthVault* and *Google Health*), but security and privacy consultants are recommending against using them due to expected privacy exposure risks (Johnston 2008).

BENEFITS OF PHRs

Communication

Several studies of PHRs have pointed to communication as being a very important factor in PHR use; they were primarily referring to communication from a patient to a practitioner (Hassol,

Walker et al. 2004), but communication also covers communication from one practitioner to another in team practice (Young, Mintz et al. 2004; Walton and Bedford 2007), or for referrals to specialists (Maisie, Lau et al. 2004). Benefits assigned to communication include accuracy of information; when passing data in electronic form, there was less chance of error in interpretation or intent (Maisie, Lau et al. 2004; Ash and Bates 2005). Providing an asynchronous method of communication between a patient and a healthcare practitioner allows busy practitioners to manage their time without ignoring the personal communication aspects of the process (Hassol, Walker et al. 2004).

Coordination

Closely associated with communication is coordination; providing an efficient, accurate, and effective communication tool allows for coordination of services for a patient or group of patients by a team of healthcare practitioners (Young, Mintz et al. 2004) and collaboration between practitioner and patient in maintaining and improving health outcomes, particularly through improved self-management (Earnest, Ross et al. 2004). An added benefit from the coordination aspect is ensuring care for at-risk patients—such as those with one of many mental health issues—in cases where they need treatment but are overlooked in a busy practice; where each practitioner is unsure of which patients the others have seen, these patients can be monitored and alerts generated if they have not presented themselves to the practice or clinic in the assigned time (Young, Mintz et al. 2004). With reasonable enhancements as needed, PHRs can also provide coordination between geographically distant team members (Oberleitner, Elison-Bowers et al. 2007).

Efficiency

Efficiency is of general benefit when healthcare resources are stretched as is the case in many areas of the Canadian healthcare system. In a primary care clinic, patients can see the next available practitioner who is able to quickly review the data and be up to date on the patient without a lengthy history gathering session or questionnaire. By having standardized data and a programmatic system through which to view it, a practitioner can quickly review data and trends in measures of patient historical data, such as blood-sugar levels, or blood pressure readings with alerts triggered depending on thresholds determined by the needs of the patient (Berner and Moss 2005). Improved efficiency can reduce costs and improve care in a rostered situation, or allow for more patients in a fee-for-service model.

Within a centralized PHR system, data can be made available as it is entered (Berner and Moss 2005), and its access can be at the convenience of the user (Hassol, Walker et al. 2004). The timeliness of the data can include the time of entry so that correct sequencing of data or lab results can be ensured, improving accuracy and reducing errors. Anytime and anywhere accessibility helps practitioners to manage their schedules without sacrificing the time spent with patients, and allows patients to ask questions when they come to mind, not just when a practitioner is available. Finally, systems that allow self-scheduling and reminders of appointments reduce the chance that follow-ups will be missed or overlooked (Oh, Sheble et al. 2006).

Accuracy and Authority

Accuracy and authority are both supported by well designed PHR systems. By limiting choices in classes of data entry, inappropriate entries can be avoided and errors reduced (Ash and Bates 2005). With proper audit trails, the changes made can be traced back to the person responsible and the validity of the update can be weighed in light of the source (Agrawal and Johnson 2007). In the same way, providing an information source within the PHR system allows the patient to receive correct and up-to-date information, tailored to their circumstance (Jones 2003; Halamka, Mandl et al. 2008) with the source authority certified.

BARRIERS TO INCREASED PHR USE

Security and Privacy

In an age of identity theft and data snooping, one of the most common concerns raised over online PHRs is security and privacy (Clarke and Meiris 2006; Croll and Croll 2007). Systems can be encrypted and password protected, but that is not necessarily sufficient in the case of bad systems, or poorly chosen passwords (Wright and Sittig 2007). Also, in providing security this way, those who may need to manage several PHRs for dependants may have problems with managing several passwords, either choosing easy to remember, and thus obvious ones, or by setting all of them to be the same. If security and access methods are too strict or cumbersome, many of the benefits of accessibility and timeliness are eroded. In addition, there are many laws involving security of data and the liabilities of the organizations providing the service can be severe if security is breached (Agrawal and Johnson 2007; MOHLTC 2004).

Access to the data in a patient's PHR can be an issue as a result of the equipment requirements. Not all patients would have access to a relatively secure Internet access point. Some provision could be made, as in the U.K. (Jones 2003), for special kiosks or computers for patient use in offices and clinics, but time of availability can be an issue. Use of a public Internet access point, such as a library or café carries privacy and disclosure risks. Finally, if the user interface is not user-friendly, or cannot capture the data that the patient wishes to enter, it is not worth accessing (Kim and Johnson 2002; Sittig 2002).

Improper disclosure of information is a problem for a patient, depending on to whom the disclosure is made. There are concerns about what insurance companies may do if certain information is improperly disclosed to them (Croll and Croll 2007) and the potential embarrassment or risk when others find out that a patient is being treated for certain problems (France 1996) can be significant. When Canadians were surveyed about their attitudes about who should be able to access their records for research purposes, their trust in correct practices and proper use of the data depended on who was accessing the data and for what purpose (Willison, Schwartz et al. 2007).

With professional medical practitioner support being critical to the success of PHRs, the concept of invasion of privilege is one not to be dismissed (France 1996; Tang, Ash et al. 2006). Doctors have long had sole responsibility for managing their records, and may not be trusting of the data provided by others through a PHR.

Errors, Misdiagnosis and Mistreatment

Errors in data are a problem in many areas, and when the data is personal data relating to a patient's health, there is cause for concern. Some patients are worried that, if their data is not correct, misdiagnosis or mistreatment may result (Croll and Croll 2007); further, based on experiences with early systems, it is often the data storage and access systems that create the errors, based on incorrect access or data linkage, and that is not visible to either the patient or practitioner (Croll and Croll 2007). There are no standards currently set for PHR systems, resulting in the barrier to entry for commercial systems being relatively low, so continued presence in the market and support for installed systems may be a concern (Middleton, Hammond et al. 2005). Some studies have found that records are incomplete (Staroselsky, Volk et al. 2006) but the benefit of PHR systems is that patients themselves can aid in their completion and repair.

System Costs

Finally, for a system that may be built for a reasonable population of patients, its costs, complexities, and requirements are significant (Middleton, Hammond et al. 2005; Clarke and Meiris 2006; Tang, Ash et al. 2006). In a government supported healthcare system, such as the Canadian model, the taxpayers are the ultimate payers for the system. In an insurance supported system, such as the U.S. model, the purchasers of insurance, or the direct payers with no insurance, are the same: the patients themselves. There have been few if any studies on the Return on Investment of such a system and even so, the values are hard to quantify (Ash and Bates 2005).

DISCUSSION

In general, patients want to be able to access and control their own health records through online access (Denton 2001; Adler 2006). There are several reasons why patient access can be important. In the first case, records may be missing or incomplete as a result of a patient having being seen by several doctors at varied locations that are not part of the same larger support system, so having patient accessibility can be employed positively to validate, verify, and fill in the records for the primary care team (Denton 2001; Staroselsky, Volk et al. 2006). For chronically ill patients, many studies have shown that the PHR is a contributing factor in positive outcomes, with a notable correlation between active PHR use and health outcomes (Dorr, Bonner et al. 2007). Reasons given for this effect are varied, but the use of the PHR by the care team as a communication and activity tracking method (Young, Mintz et al. 2004), and active participation in self management of patient health care in order to achieve and maintain good health (Earnest, Ross et al. 2004) have been often cited. Unfortunately, though, not all patients take their health seriously enough to take the steps suggested when presented with a PHR showing negative results (Staroselsky, Volk et al. 2006). Further, while parents generally participate in providing a healthy start for their children, their interest in continuing the support of a PHR for their children does decline over time (Hampshire, Blair et al. 2004; Moss 2005). It seems that only when there is a direct and identifiable risk to health do patients take the maintenance and use of a PHR seriously, such as the parents of disabled children, people with chronic illnesses, or when patients are in emergency department settings (Cooke, Watt et al. 2006).

The content of a PHR can be important to maintaining a patient's health, and it can also be useful to the provider. The professionalism of the content's presentation is not as important as content that provides value to the patient (Wright and Reynolds 2006), particularly if it can be customized to the patient's specific case through analysis of the content and presentation of or links to helpful and supporting information (Liaw, Lawrence et al. 1996). However, when patients are anxious, depressed, or facing difficult health decisions, they may want more information than other users, and generally, the more they get the more they want (Jones, Pearson et al. 1999). But, having this content available to patients online opens the opportunity for inappropriate access or accidental exposure. Many patients are very concerned over privacy and security issues surrounding PHR data (Earnest, Ross et al. 2004; Willison, Schwartz et al. 2007) but they are generally supportive of medical research needs in allowing access to their data for legitimate research (Willison, Schwartz et al. 2007). Also of concern to patients is that, given access to medical notes in the PHR, they will have to become more conversant with medical terminology and related details in order to understand and take corrective action to maintain or improve their health (Earnest, Ross et al. 2004).

Healthcare practitioners have their own set of concerns and attitudes to PHRs specifically and to the advance of technology in healthcare in general. Doctors who must fill in information in health records are concerned over consistency of presentation, so they do not have to search for the correct place for their entries (Hampshire, Blair et al. 2004; Moss 2005); Doctors, though, prefer a computer-based system over paper-based systems, no matter how weak, inefficient, and hard to use they are (Edsall and Adler 2008). In the introductory phase of eHealth initiatives, practitioners are often concerned that their workload will increase, but that increase has never materialized in reported cases (Earnest, Ross et al. 2004; Kittler, Carlson et al. 2004; White, Moyer et al. 2004). What has been an issue that has not yet been resolved is practitioner concerns over compensation for time and effort in using eHealth initiatives for patient support (Liederman and Morefield 2003; Kittler, Carlson et al. 2004; Leong, Gingrich et al. 2005). The administrators of organizations are mostly optimistic on the expected results from technological initiatives and see them as supportive changes for the organization and its staff. Doctors, nurses, and other health professionals are, on the other hand, pessimistic when it comes to the expected results; doctors are concerned over the possible encroachment on their authority and patient-time, and nurses are primarily concerned over access to the system in their working environment. Hospital administrators in Canada feel that they are lagging the introduction of fully electronic medical records, and some of their hesitation is based on opinions that their staff and the public are not ready for them yet, even in the absence of opinion surveys of these communities (Urowitz, Wiljer et al. 2008).

For a PHR to be used and useful, it has to be easy to use for both patients and practitioners. The user interface is the critical component of the system (Kim and Johnson 2002), and should guide the patient in entering any data that practitioners will need for diagnosis and treatment planning (Kim and Johnson 2004). In addition, the interface should present a complete and understandable summary of the data to practitioners so that they can provide the correct health care (Kim and Johnson 2002). In addition to the user interface, organization and presentation of data should be able to match user data gathering and organization strategies so that they will feel comfortable with the process (Moen and Brennan 2005).

Closely associated with PHR systems currently in use are practitioner-patient messaging systems; these allow the patient to provide feedback to the practitioner on the content of the PHR and developments in the patient's health between appointments. Some progress is being made in implementing these systems and getting them accepted by practitioners (Beckjord, Finney Rutten et al. 2007), while patients are willing to pay for the opportunity of communicating with practitioners online (Adler 2006). When patients are questioned over preferred communication media, they prefer messaging for simple, non-critical interactions; practitioners prefer telephone or letters for these exchanges (Liederman and Morefield 2003; Hassol, Walker et al. 2004). Both groups preferred face-to-face meetings for more important or sensitive messages. In general, both parties found the convenience afforded through 'time-shifting' of messages in an asynchronous exchange of messages with an on-line messaging tool to be worth the additional effort it took (Maisie, Lau et al. 2004; Leong, Gingrich et al. 2005). The satisfaction of patients in their consumption of healthcare resources rose when they were able to communicate electronically with healthcare providers, and the providers were satisfied with the convenience of using a messaging system for the routine and mundane requests (Leong, Gingrich et al. 2005); in addition, practitioners' overall productivity improved while their workload decreased (Liederman and Morefield 2003). With a PHR system, kept up-to-date by either direct patient input or messaging from the patient over time, practitioners can make the time spent in the appointment more productive by being able to focus on that which must be done face-to-face (Maisie, Lau et al. 2004). Most messages exchanged between clinics and patients do not require a practitioner's response, and tend to be either basic requests or updates and feedback on changes (Maisie, Lau et al. 2004); these messages are almost invariably polite and courteous, and follow whatever rules on content that have been established by the clinic (White, Moyer et al. 2004).

In conclusion, the general indications are that there are significant benefits of PHRs, although there are barriers to their widespread adoption due to issues of security and privacy, errors, misdiagnosis and mistreatment, and system costs. Regrettably, consumer/patient motivation for adoption of PHRs has not been considered except in the case of British parents who have been encouraged to create and maintain PHRs for their children, beginning at birth. This is in the face of the likelihood that motivation to adopt and maintain PHRs would be high for parents of children with disabilities, patients with serious chronic illnesses, and caregivers for elderly persons who are living at home. These potential users would probably be early adopters, if encouraged to do so. Although these population segments do not seem to have been considered specifically yet, they deserve further study since they could provide the impetus for more widespread adoption of PHRs, with attendant benefits to the healthcare system. However, family physicians who actively use EMRs (Electronic Medical Record systems) for the clinical records of their patients tend to play an essential and central role in the implementation of PHRs, so the low rate of EMR adoption by family physicians, except in multiple partner practices, will continue to be a significant overall barrier to PHR adoption in North America for some time.

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