A Community View:
How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings
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INTRODUCTION

This series of essays on personal health records is the result of collaboration between two Illinois organizations: Northern Illinois Physicians for Connectivity and the Chicago Patient Safety Forum. Together, the two organizations brought together healthcare providers, healthcare administrators, insurers, and technology visionaries in the Chicago Metropolitan area through a series of educational and planning meetings in 2007 and 2008 to discuss ways to improve patient safety in Illinois through the use of healthcare information technology. Over time, one issue that emerged as a top priority from a community perspective was a consumer-centered approach to healthcare based on the use of personal health records. The essays in this monograph arose from those discussions. They aim to raise awareness and lower uncertainty about the benefits of personal health records (PHRs) among all stakeholders in Illinois, including consumers of healthcare, healthcare providers, purchasers of healthcare, and policy makers. By increasing general knowledge about their incredible potential to improve the quality and safety of healthcare, we hope to accelerate the adoption of personal health records. Usability is another important factor in increasing technology adoption. Throughout these essays, we have included specific examples of uses of PHRs.

There are eleven perspectives covered by this document:

- Private Practice Providers
- Academic Providers
- Private Hospitals
- Integrated Delivery System Providers
- Federally Qualified Health Clinic
- Long-Term Care Facilities
- Pharmacists
- Nurses
- Consumers
- Rural Healthcare Providers
- Employee Benefits

There are three technical essays:

- Privacy and security of PHRs
- Technical aspects of linking PHRs electronically to EHRs
- Technical challenges unique to persons with disabilities

The author of each chapter was given permission to voice his or her own opinion and viewpoint. It is not the intention of the Chicago Patient Safety Forum and Northern Illinois Physicians for Connectivity to suggest that there is a consensus about personal health records among the various stakeholders represented in this compendium. Rather, this document presents a range of opinions which are sometimes contradictory.
Each essay focuses on issues of high priority to its author. The writing styles vary considerably, as do the opinions they express.

What follows is a brief preview of the content and main messages of each chapter.

The first chapter provides an overview of personal health record technology, summarizing a classification scheme and potential benefits of PHRs. The literature surrounding health information technology is riddled with acronyms and unfamiliar terminology. For this reason, Appendix 1 lists acronyms, and Appendix 2 lists terminology definitions. We encourage the reader to peruse these appendices while reading the first chapter. A complete listing of PHRs on the market (as of December 2008) is included in Appendix 3.

The second chapter examines the value of, issues attendant with, and alternative strategies to the adoption and use of PHRs by private practices; the provider segment whose participation is arguably the most crucial and the most problematic to achieving our goal.

The third chapter is written by an academic healthcare provider and will define and explicate the present state of affairs of personal health records:
- early attempts to use personal health records
- barriers to easily accessible medical information
- potential of accurate individual patient medical information to empower the patient and inform his or her medical decisions

The fourth chapter addresses the ability of hospitals and their physicians to interact effectively with a Personal Health Record. It also highlights the framework and system requirements necessary for a PHR to be effective in this setting.

Electronic Health Records, by design, are structured to consolidate a patient’s medical information into one record, thus allowing seamless availability and exchange of clinical data among healthcare providers. In the fifth chapter, the authors have taken their experience with the implementation of electronic medical records across the continuum of care (hospitals, physician groups, health plans, etc.) and attempted to list the roadblocks, success factors, and strategic considerations involved in creating a fully integrated healthcare environment. The chapter also describes the evolution of the PHR within this same integrated health system. The authors assert that a PHR should have secure integration with an Electronic Medical Record, 24/7 accessibility, clinical information that is updated real time, and functionality, which allows a patient access to his or her healthcare providers via the Internet.

The sixth chapter will look at the barriers to using PHRs in the federally funded healthcare environment and review current strategies to make comprehensive, culturally effective, lifelong PHRs available for those citizens who have limited access to both technology and healthcare as a result of economic disparities. The chapter will also discuss the role of American health agencies in developing an improved healthcare system that will eliminate health disparities and improve health outcomes across all socioeconomic groups.

The seventh chapter, from the perspective of long-term care facilities, gives an overview of PHR technology that now exists. The chapter offers recommendations on how to expand the systems
to full PHRs as well as a summary of the obstacles to and benefits of accomplishing this objective by 2014.

The eighth chapter gives the retail pharmacy perspective on PHR technology and discusses the role of pharmacies in this emerging technology.

The ninth chapter discusses how nurses can leverage PHRs to improve the health and health behaviors of their patients. With the advent of consumer technologies, new and exciting roles for nursing have emerged, such as the ‘nurse coach’. This chapter will present examples of new PHRs, how they are being used by nurses, and how they facilitate the trans-disciplinary approach to improving patient care.

The tenth chapter provides a hypothetical scenario of a consumer using a PHR. It is written from a consumer viewpoint and discusses both the potential promises and problems of PHR use.

The eleventh chapter addresses the challenges of the cost/benefit ratio related to PHR/EHR and the competition for capital within rural healthcare organizations. Further challenges include the lack of necessary bandwidth to fully maximize the benefits of PHR/EHR, as well as low interest in expansion of connectivity by providers of this service due to low population volumes.

Healthcare payors are struggling with unsustainable cost inflation. While Medicare and Medicaid face enormous, unfunded entitlements and possible default, many employers find themselves struggling to maintain health benefits' viability in a challenging global economy. The twelfth chapter reviews essential faults and key cost drivers in the U.S. healthcare system; specifies necessary practical initiatives to address critical flaws in cost containment efforts; and illustrates how integrated healthcare IT and widespread use of PHRs are fundamental to real, lasting, and effective long-term liability and risk-management solutions.

The first technical essay addresses PHR privacy and security. Extending the trust inherent in physician-patient relations to include the Internet requires an understanding of security components such as identity management, authentication, consents, authorizations, access control, etc. It is with a combination of these features, functions, and applications that a patient can securely import his or her health data into their Personal Health Record and export components of such sensitive data to his or her physician and other healthcare professionals. The potential value of this secure electronic exchange and sharing of confidentially protected information can be both cost- and time-efficient and increase compliance in managing acute or chronic conditions and/or health maintenance activities to stay on track with preventive health programs.

As patients receive medical care, their clinical histories may be tracked and recorded by multiple electronic systems developed by independent vendors. The second technical chapter identifies and considers the key interoperability issues associated with the information exchange between provider-facing electronic health record (EHR) systems and patient-facing personal health record (PHR) systems and offers an approach for enhancing interoperability. The author proposes the creation of a technical implementation guide to document, incent, and administer the use of system integration best. The proposed technical implementation guide would address issues of
vocabulary mismatches, identity resolution, security and privacy, among others, by relying on specific guidelines including the use of standards, and shared solution sets.

The third technical chapter addresses challenges of PHR unique to the healthcare of persons with disabilities. Electronic and communication technology design standards for accessibility, such as Section 508, help minimize health disparities.

We invite you to read each of these essays as they summarize the current landscape of PHRs today and outline their potential for improving healthcare in the future.

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DESCRIPTION OF PERSONAL HEALTH RECORDS

This chapter provides an overview of electronic personal health records (PHRs) and the technology that supports them. We will describe personal health records in several ways, emphasizing the technology and the end users who interact with the technology.

WHAT IS A PHR?

One could argue that personal health records technology has failed to mature to a level for a widely accepted published definition. We offer the following technical definition developed by the National Alliance for Health Information Technology:

“An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.”

One could also make the argument that paper personal health records have been in existence for years, but they may be known via other labels. Most parents keep “baby books” for their children. Medication lists kept on personal computers or haphazardly recorded on paper and kept in the wallet are representative of another kind-of elementary PHR. Explanations of Benefits (EOB) from insurance carriers could even be considered part of a PHR. They contain little clinical information, yet most readers have referred to an Explanation of Benefits to find the name of a provider who performed a procedure and when. Children of elderly parents frequently keep copies of advance directives for their parents and eventually for themselves. These are elements of a PHR. Even a personal calendar for women who track their menstrual cycles, can function as a PHR. What makes the PHRs of today and the future so different from those of the past is that they are much more comprehensive, electronic, and interoperable. Interoperability refers to the ability of different computer systems or applications to share and use data. Traditionally, a person’s medical records have been archived and maintained at hospitals and physicians’ offices. A PHR is owned and maintained by a patient, who controls access to it.

There are several ways to evaluate and define PHRs, including a listing of core data elements that are captured by a PHR, technical aspects of PHRs, and answers to key questions that should be considered when evaluating a particular PHR and the purpose for which it is designed.

CORE DATA IN A PHR

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The following list gives an overview of the types of information and functions that may be present in PHRs. For a more detailed listing of PHR functions, we recommend the Markle Foundation’s PHR Function List.2

**BASIC ELEMENTS**
- Name and demographic information
- Names, addresses, and phone numbers of healthcare providers
- Insurance information
- Emergency contacts and next of kin
- Family medical history
- Allergies and reactions
- Problem list (diseases and conditions)
- Medications (Rx, over-the-counter [OTC], vitamins, herbals, and other alternative therapies)
- Immunizations
- Hospitalizations/surgeries
- Spiritual affiliations/considerations
- Links to patient education, self-care content, and consensus guidelines

**ADVANCED FEATURES**
- Healthcare providers’ exams and notes including primary care, specialists, and dental
- Scanned images, such as CT scans or dental images
- Test results
- Electronic prescription refill capability
- Drug interaction check
- Other therapeutic modalities (counseling, occupational therapy, alternative, etc.)
- Advance directive forms and living wills
- Organ donor authorization
- Signed Release of Information Forms
- Way to correspond with healthcare providers in a secure fashion (e.g., e-mail)
- Goals, next steps, or disease-management plans
- Appointment scheduling and reminders
- Preventive service reminders
- Patient diaries (pain, symptoms, side effects)
- Longitudinal health tracking tools (charts, graphs)
- Financial information, such as Explanation of Benefits

TECHNICAL ASPECTS OF PERSONAL HEALTH RECORDS

The Robert Wood Johnson foundation, as part of Project Health Design, has described Common Platform Services for PHRs, a set of software components that are common to most PHRs. A “platform” refers to software used as a base on which to build something else. For example, Microsoft Windows serves as a platform for many software applications.

Common Platform Services of PHRs include:
- User Authentication—Verifying the identity of the user or computer software programs seeking access to the personal health record
- Access Control—The means to allow and specify rights to access the personal health record to those persons or computer software programs that have been granted permission.
- Storage of structured and coded clinical data—The ability to display and retrieve health information such as problems, medications, health observations in a meaningful way.

In order to allow the sharing of data among participants in Project Health Design, the Project Health Design grantees collaborated and designed architecture for Common Platform Services based on open, platform-independent Web-services technologies.

An open computer architecture is one in which details are made public so that other organizations can create clones and compatible accessories.

Platform-Independent Web-services technologies refers to the use of a standard computer language known as XML to exchange data between computers. The computers can run on the same or different platforms, but as long as they are connected to the Internet and using web services and a standard way to format requests, they will be able to share data.

The components that make up the common platform for PHRs include:
- Registry Service—The registry service includes a list of those applications and users that may access the platforms, as well as a listing of the patients whose data is being managed.
- Authentication Service—The authentication service validates the identities of the users and applications seeking access to the PHR.
- Access Control Service—The access control service stores and enforces rules regarding which users may access patient data, which data may be accessed, and what operations may be performed by the user on the data.
- Medications Service—The medications service is a data repository for managing all prescribed and over-the-counter medications.

5 Ibid.
6 Ibid.
7 Sujansky, pg 3.
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- Observations Service—The observation service is a data repository for managing health-related observations such as blood pressure, home glucose results, signs or symptoms, journal entries, etc.

In addition, Project Health Design systematically reviewed deficiencies in clinical data standards in current PHRs that need to be corrected for optimal use of PHR technology. Organizations that are contemplating interacting with external personal health records are encouraged to refer to both of these publications for an in-depth review of the design and infrastructure behind Personal Health Records.

MODERN ERA OF PHRS

The modern era of PHRs could be accredited to an IT-savvy consumer. Henry Frankel, a retired engineer, may have been the first to use a stand-alone “homegrown PHR”, which was a digitized filing system he created for scanned images and documents of his healthcare encounters, treatments, and test results using desktop software applications. Commercial Internet personal health record tools began appearing in the nineties. Many of these early applications failed due to the lack of a sound and sustainable business model. Personal health records in 2008 include both desktop programs, such as the one used by Henry Frankel, and Internet-based programs, such as those offered by health plans and some large healthcare organizations. For a complete listing of existing PHRs, see Appendix 3.

According to the Markle Foundation, an estimated 6.1 million people have PHRs in the United States in 2008. This number will likely increase in the next few years as a result of recent media attention focused on high profile PRH data repositories such as Microsoft’s Health Vault, Google Health, and Dossia.

Google Health and Microsoft Health Vault are free Internet-based PHRs that include many of the basic core features listed above. Both allow computer programmers to write special programs or applications to interface with the PHR, such as medical devices (heart rate monitors, scales, etc.), and both allow the sharing of data with healthcare providers. CVS pharmacy, for example, has agreed to share pharmacy information with both Google Health and Microsoft Health Vault.

Dossia is an employer sponsored nonprofit initiative whose goal is to offer a lifelong, personally controlled PHR to employees of member companies. Some of the member companies include

8 Sujansky W. Meeting the requirements of Project HealthDesign: comparative analysis with respect to existing and emerging clinical data standards and commercial PHR data repositories. Madison, WI: Project HealthDesign; 2008, pg 4.
http://www.projecthealthdesign.org/media/file/Meeting_the_PHD_Req_Comp_Analysis_8-15.pdf

http://www.astm.org/SNEWS/MA_2008/enright_ma08.html


Intel, Wal-Mart, AT&T, British Petroleum-and Pitney Bowes to name a few. Dossia provides a systems integration approach which is comprised of PHR applications (inclusive of devices) for viewing and input of personal data: data sources inclusive of claims, pharma, clinical data forms as well as providing the repository that is managed by Dossia for aggregation and distribution of these data types for and to individuals that are Dossia members. Dossia provides services for the interfacing of these services for employers inclusive of deployment of such to large and diverse population groups as defined by the employer or representative organizations.

Although not true PHRs by definition, Internet-accessible PHR tools offered by large integrated delivery systems and teaching hospitals are the largest segment of PHR-like applications being used in the United States. These software applications, also called patient portals, allow patients to view portions of their electronic medical records created by their healthcare providers. The information in a patient portal, unlike that in a patient-controlled PHR, is owned by and resides within the domain of the healthcare delivery organization. Today’s patient portals increase a patient’s access to parts of his or her medical record, such as lab test results, and provide links to medical knowledge endorsed by the healthcare delivery system. Patient portals are “covered entities” under HIPAA, and, thus, healthcare providers can be held accountable if their portals do not comply with HIPAA privacy and security rules.

Examples of Patient Portals in Illinois:
- InteGreat: Christie Clinic—Champaign
- DMH Patient Portal-Decatur Memorial Hospital—Decatur, Illinois
- Geonetric- Methodist Medical Center—Peoria, Illinois
- Heart Health by Intervent-Rush University Medical Center—Chicago, Illinois
- MyChart -Evanston Northwestern Healthcare—Evanston, Illinois
- My Chart-Northwestern Memorial Hospital— Chicago, Illinois

Examples of Patient Portals offered by medical systems across the United States include the following:
- MyChart -Palo Alto Medical Clinic
- Patientsite -Beth Israel Deaconess Medical Center
- MyChart -Cleveland Clinic
- Indivo Health -Childrens Hospital Boston
- Patient Connect -PeaceHealth Eugene, Oregon
- MedSeek -Henry Ford Health System Detroit

Example of a Patient Portal offered by the United States federal government:
- Myhealthyvet -Veterans Health Administration Hospitals and Clinics

Example of a Patient Controlled Gateway offered by a Regional Health Organization:
- Indivo: Massachusetts SHARE RHIO

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IMPLICATIONS FOR BETTER HEALTHCARE AND BETTER OUTCOMES

The following section outlines the potential benefits to patients and to society of a patient-centered approach to healthcare based on secure, standards-based Personal Health Records that allow patients and their healthcare providers access to common healthcare records. The use of the word “potential” needs to be emphasized, as a minimal amount of research has been conducted on the use of personal health records to improve quality of care. The use of ambulatory computerized physician order entry (CPOE) and the use of electronic health records (EHRs) has, however, been shown by a systematic review of 257 articles to improve quality of care. This improvement is primarily due to increasing adherence to guidelines and protocols, enhanced preventive care, reducing medication errors, and decreasing redundancy of testing. The majority of research has been done by four benchmark institutions 1) Regenstrief Institute, 2) Brigham and Women’s Hospital/Partners Healthcare, 3) the Department of Veterans Affairs, and 4) LDS Hospital/Intermountain Health Care. As pointed out by the Chaudhry et al. in their review of CPOE and the use of EHRs, “the effectiveness of these technologies in the practice settings where most healthcare is delivered remains less clear.”

Another systematic review of 109 studies evaluating information systems used in the care of chronic illness indicated that 67 percent had positive results. Core components of information systems related to success included connection to an EHR system; order entry when focused on specific disease and longitudinal care planning; population-based reporting and feedback (such as reporting that elements of a care plan had not been completed); and decision support in the form of computerized prompts.

Despite the lack of research demonstrating the benefits of Personal Health Records, Federal Agencies are actively studying PHR tools including the CMS “MyPHRSC”, an Internet-based PHR pilot project in South Carolina for Medicare beneficiaries, and The Veteran’s Health Administration’s PHR called “MyHealthyvet”. Hopefully, as these projects mature, study data will confirm that the following list of potential care improvements results in better patient outcomes.

1. Improved patient adherence to physician treatment plans for drug regimens and reduction of medication errors.

If patients keep up-to-date medication lists in their PHRs and share them with their healthcare providers, there is a higher likelihood that discrepancies will be noted and corrected. Alternatively, a patient may bring a printed version of the medication list to each healthcare encounter. Both of these methods have the potential to increase compliance with medication regimens and to reduce errors in prescription medications.

14 Ibid, pg 742.
2. Improved availability of healthcare data where and when it is needed for decision-making and better data-sharing among healthcare providers and patients.

The technology currently exists to upload test results and procedures that have been ordered by one healthcare provider to a patient’s PHR, which can then be accessed by another provider. In addition to sharing individual test results, healthcare providers who have implemented an EMR can share summary records with their patients (this is discussed in greater detail in the Private Practice Chapter). Under the direction of the patient, these results could be printed and brought in a paper format to share with other healthcare providers. This sharing of test results could help reduce unnecessary duplication of tests and procedures.

Use of an online PHR linked to a provider EMR has been shown to increase rates of medication adjustment for patients with diabetes.\(^\text{16}\) Although the intervention did not improve control of risk factors (due to low rate of use and good baseline control of blood glucose levels among participants), this study showed that data-sharing among healthcare providers and patients made a real difference in the plan of care of participants as compared to controls. Further research is likely to demonstrate that having all relevant data available at the point of care will improve quality and efficiency of the care that is delivered.


Only half of U.S. adults receive all recommended clinical screening tests and preventive care.\(^\text{17}\) A listing of preventative medicine guidelines is displayed prominently in many PHRs. If decision-support tools have been enabled in the PHR, a patient may be prompted when he or she is due for screening and preventative tests. Automated PHR reminders will hopefully spur discussions between a patient and his or her care provider(s) as to whether these tests or procedures are needed, which will increase shared decision-making and compliance.


Currently, 133 million Americans have a chronic medical condition, and many of these have more than one chronic condition.\(^\text{18}\) Chronic Disease Management based on ambulatory healthcare technology and care coordinators in complex medical/chronic disease populations reduces emergency room visits, hospital admissions, and length of hospitalizations.\(^\text{19}\) Patients with chronic diseases often acknowledge their difficulties with self-care, which is a key driver in preventing long-term complications. According to a recent survey of California consumers, 56

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\(^\text{16}\) Grant RW, Wald JS, Schipper JL, Gandhi TK, Poon EG, Orav EJ, Williams DH, Volk LA, Middleton B. Practice-linked online personal health records for Type 2 diabetes mellitus. *Archiv Intern Med.* 2008(Sep 8);168 (16):1776-1782.


percent of respondents went online to find specific information about medical conditions or prescription drugs.\textsuperscript{20} Personal Health Records can help patients improve self-care by providing peer-reviewed educational materials on specific diseases and explaining current clinical practice guidelines.

**IMPORTANT QUESTIONS TO ASK ABOUT PERSONAL HEALTH RECORD PRODUCTS**

In order to give the reader a frame of reference for understanding the various types of personal health records tools and applications, we have provided a preliminary list of questions that can be applied to each PHR:

1. Who is the owner or steward of the data?
2. Where is the data stored?
3. How is the data entered?
4. How is access to the PHR granted?
5. Who is responsible for monitoring privacy and security breaches?
6. How portable is the data?
7. How is data shared with healthcare providers?
8. Who pays for the technology?
9. How are discrepancies in contact corrected?

In the following text, we will discuss each of these questions in more detail. A more extensive discussion of questions #4 and #5 can be found in the Privacy and Security Chapter and question #7 in the Technology chapter.

In our research, the question of utmost importance to many consumers is who owns the data? The term “tethered” PHR was coined to classify PHRs in which the data is owned by a healthcare provider delivery system. The terms “stand-alone” or “untethered” refer to PHRs that are not integrated with a particular healthcare delivery system. There are many instances of untethered PHRs offered to the general public by private companies (Appendix 3). There are pros and cons to both tethered and untethered PHRs. The most significant disadvantage to a tethered PHR is that consumers are not the data owner and are, therefore, unlikely to be able to share the data with healthcare providers outside of the sponsoring organization. An obvious advantage to using a tethered PHR is that it is free to the consumer. A disadvantage of using an untethered PHR is that it may be difficult for the consumer to integrate some sources of their healthcare data such as clinical encounters, laboratory and pharmacy data with their PHR. In addition to healthcare providers owning the data, there are instances of tethered PHRs being hosted by insurance companies and employers.

The question of data storage can be broadly defined as either being Internet-based or software-based. With Internet-based applications, the database for the PHR is stored on a server or a server farm, with or without duplication. The physical location of the server must be kept secure from predators and natural disasters, and the messaging protocols used to exchange data also

must be secure. Security is also an issue for software-based applications. A consumer who uses a software-based PHR, whether it be at home or at work, needs to understand how to implement privacy and security measures in order to prevent unauthorized access to his or her health data by family members, co-workers, or voyeurs.

There are potentially multiple methods of entering data into the PHR, including direct data-entry by the consumer; automated downloading from data sources such as laboratory or pharmacy or claims data; or even summary clinical data from healthcare providers who use interoperable standards such as the CCR or CCD. The advantage of feeding data from data sources to a PHR is that the use of authoritative data can prevent errors in data-entry caused by spelling errors, dosing errors, or entering the wrong values for laboratory tests. The disadvantage to using Web-based applications, such as those sponsored by insurance companies or employers, is that PHRs that are data-driven are less likely to offer a full complement of services a disease-specific software application offers to the consumer. For example, consider the patient with a chronic disease such as diabetes. The patient’s ability to journal food and exercise the way they correlate with daily home glucose readings may be more important to the consumer than a claims data problem list. For a more in-depth discussion of the ability to populate PHRs using summary data from healthcare providers’ EMRs, please read the Private Practice Chapter.

Access controls allowing healthcare providers or family members to view PHRs can vary from application to application. In a complex or granular approach, the application allows the consumer to choose types of providers, specific providers, or family members identified by name or NPI; and the types of data that can be accessed, such as medication list, problem list, health observations, etc. In contrast, a simplistic approach, such as physically giving a printed health summary or handing over a portable electronic device to a provider or administrator, is much more straightforward but less conducive to taking advantage of current technologies. A disadvantage to a granular access policy is the cost of overseeing access. Access control, along with authentication of users and confidentiality, will be discussed in the Privacy and Security Chapter.

The question of who is responsible for monitoring privacy and security breaches depends on whether the PHR sponsor has identified the application as being a covered entity under HIPAA law. Please refer to the Privacy and Security chapter for an in depth discussion of the advantages of using a PHR that is a covered entity. The bottom line is that only those PHRs that are certified as covered entities under HIPAA law can be prosecuted for lapses in privacy and security. Consumers should be wary of using PHRs that are not covered entities.

Portability refers to the ability of the consumer to download the information stored in the PHR and carry it on their person. Options for portability include printing a paper version of PHR summary data; copying the information to a CD; accessing the PHR on a PDA or cell phone; or using portable electronic devices such as a USB flash drive, smart card, or thumb drive. Not all PHRs are portable, and even if a PHR offers a portable solution, there is no guarantee that a healthcare provider will accept the data. The issue of portability is complex. Limiting factors include the reluctance of healthcare providers to accept information in a format that does not fit into their customary work-flow; lack of reimbursement to healthcare providers for accepting
electronic personal health records; and the fear of the transmission of viruses, worms, and other malware when allowing a portable device to be inserted into a workstation.

The means for the sharing of data with healthcare providers does not necessarily depend on the portability of the PHR. The technical chapter and the independent chapter discuss other ways data can be shared between a patient’s PHR and a healthcare provider’s EMR. The means to share healthcare data electronically is dependent on the implementation of interoperable standards such as the CCR, the CCD, and the use of secure messaging protocols. Unfortunately, not all PHRs are based on interoperable standards. We strongly encourage consumers to use PHRs that are standards-based.

The question of who pays for PHRs is still evolving. As described below potential payment options include consumers, healthcare delivery organizations, employers, insurance companies, Regional Health Information Organizations, and State or Federal Government. Regardless of whom finances the PHR, digital data sharing between healthcare providers and patients would optimize the potential of the new technology. Reviewing information in a patient’s PHR is not currently reimbursed by 3rd party payers, despite the potential to improve chronic care and proactive care. A policy change at the federal level has been introduced by Rep. Patrick Kennedy, known as the Personalized Health Information Act, H.R. 1368. This legislation seeks to create enhanced financial incentives to healthcare providers who interact with Personal Health Records. We believe that passage of this or a similar legislation will lead to increased physician acceptance of and interaction with Personal Health Records. Unfortunately, the majority of healthcare providers are likely to await healthcare delivery payment reform before interacting with PHR applications as part of normal business operations.

There are existing business models for PHRs that do not depended on physician acceptance and/or interaction:

- A consumer can pay a subscription fee to a private company or vendor who offers PHRs directly to consumers. See Appendix 3. There are free PHRs, such as the CEND PHR that was developed by AAFP. A healthcare delivery organization pays an information technology company to implement and maintain a patient portal. Northwestern Hospital in Chicago is an example of a healthcare institution that has chosen to absorb the costs of a patient portal.
- An employer or consortium of employers pays an information technology company to implement a PHR or medical record data bank for their employees. Dossia is an example of an employer-consortium-sponsored PHR. [http://www.dossia.org/](http://www.dossia.org/)
- An insurance company pays an information technology vendor to implement a PHR for its members. United Health Care offers a PHR portal for its insured.
- A Regional Health Information Organization (RHIO) pays an information technology company to create a community PHR or health databank. Care Entrust, based out of Kansas City, Missouri, is an example of an employer-funded RHIO offering a medical record data bank. [http://www.careentrust.org/faqs.php](http://www.careentrust.org/faqs.php)

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• An example of a government-sponsored PHR is myhealthyvet, which is part of the federal government’s healthcare system for veterans. [http://www.myhealth.va.gov/](http://www.myhealth.va.gov/)

The final question pertaining to the resolution discrepancies in the content of a shared medical record is one that is applicable to all PHRs. Because the patient owns the PHR, we believe it is the patient’s responsibility to initiate the corrections. The exception to this rule is patient portals that are tightly integrated with electronic health records: in this case we believe the healthcare organization should be responsible. A likely scenario is that a patient who notices a discrepancy, for example, in the date of a surgical procedure or the medication list, will need to contact his or her healthcare provider and discuss the discrepancy via e-mail or phone or during an office visit. We believe consumer guidelines should be circulated by all organizations that offer PHRs instructing the patient on how to approach his or her healthcare provider after noticing a discrepancy in the content of a shared medical record.

In summary, electronic PHRs are a group of variable and emerging technologies that have the potential to improve healthcare and outcomes. Interoperability, portability, privacy and security, and lack of reimbursement are current challenges in the way of widespread adoption in the year 2008. Future challenges include automating the way data is entered into PHRs and defining policies and procedures for resolving discrepancies in the content of a shared medical record.

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VIEWPOINTS OF PERSONAL HEALTH RECORDS

PRIVATE PRACTICE VIEWPOINT ON PERSONAL HEALTH RECORDS

INTRODUCTION

This chapter will focus on the ability of a private practice to engage its patients with personal health tools while at the same time searching for ways to exchange either demographic and/or clinic data electronically with the patients. This chapter will describe two models of data exchange, including data flowing from PHR to EMR or from EMR to PHR, and the obstacles to implementing data exchange with patients. The pros and cons of each method will be discussed. The authors of this chapter believe that a private practice that implements an EMR, engages patients in personal health tools, and exchanges data with its patients will move toward an optimally functioning, patient-centric healthcare system.

DEFINITIONS

An EMR is an application environment composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications. This environment supports the patient’s EMR across inpatient and outpatient environments, and is used by healthcare practitioners to document, monitor, and manage healthcare delivery within a healthcare delivery organization.22

An EHR is a subset of each healthcare delivery organization’s EMR and is owned by the patient; it has patient input and access that spans episodes of care across multiple healthcare delivery organizations within a community, region, or state (or is some cases, the entire country).23

PHR is defined as “an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.”24 According to the Robert Wood Johnson Foundation less than 10% of physicians are working within a fully operational system, which they define as a system “that collects patient information, displays test results, allows providers to enter medical orders and prescriptions, and helps doctors make treatment decisions.”25 We would like to expand the definition of a fully

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23 Ibid, pg 2.
25 Electronic health records still not routine part of medical practice, says new study: multiple barriers keeping...
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operational optimally functioning, patient centric healthcare system as having the following attributes:

- Consumer centric
- Adapt at treating acute and chronic conditions as well as fostering wellness
- Has a sustainable business model
- Achieves harmony in work flow
- Ensures that relevant health information is available at the point of care
- Implements technology wisely
- Acts on plans of care for individuals and is proactive in improving care for populations of patients
- Allows consumers to access their clinical data
- Is interoperable with healthcare institutions with which they share protected healthcare information.

In the authors’ opinion, implementing an EMR is one of the major stepping stones on the path of achieving a fully operational healthcare system. There are financial and time management issues that arise in all care delivery models with the implementation of an EMR and care delivery organizations vary in their willingness to contribute to a patient’s EHR. We will use the term EMR to refer to the legal medical record of what happened to patients during their encounters with a particular healthcare delivery organization and is owned by the organization.

**CASE STUDY**

Pregnant patients seek prenatal care from obstetricians (OB) and midwives by seeing these health care providers in a clinic setting. Most patients will then deliver their babies in a hospital setting with their OB in attendance. Some physicians have a business association with the hospital (their practices are owned by the hospital, for instance); other physicians own their own practices (also known as a private practice). When a patient has a problem with her pregnancy or if she feels like she is in labor, the patient will present to the hospital’s maternity ward for evaluation, and a nurse will assess the patient and call the patient’s doctor. In assessing the patient, the nurse ideally will have access to and refer to the patient’s prenatal record, which details important information about the patient’s prenatal care. Ideally, physicians provide the prenatal record to the hospital’s maternity ward before the patient presents to the hospital, usually at around 36 weeks gestation, well in advance of the patient’s due date (defined as 40 weeks gestation). Currently, many physician offices will fax or hand-deliver a copy of the prenatal record to the hospital maternity ward. In the maternity ward, the receiving secretary will make up a file folder for that patient to store the prenatal record until needed. For hospitals with an inpatient EMR, the secretary will use a scanner to scan the prenatal record to attach the scanned record to the inpatient record. However, if a patient presents to a hospital where her physician is not on staff, there will be no prenatal record available, and the nurse will have to try to contact

http://www.rwjf.org/newsroom/newsreleasesdetail.jsp?productid=21882
the non-staff doctor’s office to obtain the prenatal record. Obviously, if the patient presents after business hours, there may be no way to obtain the prenatal record until the next day. In the instance that the prenatal record is not available, the nurse is left to utilize the patient’s memory and the nurse’s history taking and physical assessment skills. Though adequate care can be provided in this manner, it is far from ideal particularly for those patients who have complicated obstetrical or medical histories as will be demonstrated in the case study.

Mary had been particularly dedicated about getting her prenatal care at the local city clinic. She had not been so careful with her first pregnancy, and it had resulted in complications with her pregnancy and a subsequent C-section. She was determined that this time, she would be more diligent with her care and not let what happened to her before happen again. She had had bleeding earlier in this current pregnancy and was put on bed rest. She didn’t understand exactly why she had bled, but her doctor assured her that the reason for her bleeding had recently resolved, and she was taken off of bed rest. She was happy for this, since her best friend in the suburbs wanted to throw her a baby shower, and she was anxious to attend. Just three more weeks, she thought, and she would finally see her second child – a boy – in person. She planned on delivering by a repeat C-section.

Her friend lived an hour away, and given her doctor’s reassurances, Mary didn’t think there would be any problem in attending her baby shower. She had a good time at the baby shower, and there were several surprise visits by family and friends that she had not seen in several years. Everyone fussed over her, telling her to rest and sit down, but she was feeling good, and she was having fun. Later that evening, however, she started to feel some contractions, so she finally did take everyone’s advice and sat down. But the contractions didn’t stop, and when she excused herself to go to the restroom, she was alarmed to see that she was bleeding. Frantically, she called her friend to bring her to the nearest hospital, though her doctor was not on staff there.

Arriving at the nearby suburban hospital’s Labor and Delivery floor, Mary was first seen by Doris, a seasoned labor and delivery nurse. Doris quickly did her assessment. The baby’s heart rate pattern looked good, but the patient’s bleeding and history of a prior C-section troubled Doris. Doris pressed Mary for more details about her prior C-section, her most recent ultrasound, and why she had bleeding earlier in her pregnancy, but Mary didn’t know these details. By this point, it was clear that Mary had to be delivered soon because of her contractions and bleeding. Doris called the covering OB attending physician, Dr. Curtis, and as she waited for Dr. Curtis to arrive, she accessed the region’s health information network and was able to pull up Mary’s medical record from the city clinic.

When Dr. Curtis arrived, she looked over the records and found that Mary’s condition was more complicated than preterm labor. Mary’s earlier bleeding was due to a placenta previa, a condition in which the placenta is in front of the baby’s head and covering the cervix. And though her placenta previa had resolved as the pregnancy progressed, the placenta was still located in the front part of the uterus under her prior C-section scar. This location can result in a condition called placenta accreta in which the placenta actually grows into the prior C-section scar. This greatly complicates the repeat C-section and increases the chance for a catastrophic amount of blood loss. Dr. Curtis prepared for this possibility by arranging for blood to be immediately...
available and having a specialist in pelvic surgery on hand in case help was needed in surgery. Thankfully, Mary’s C-section was accomplished without any major incident mainly because the operating team was prepared for a much worse situation. Though Mary did not deliver at the hospital at which she had intended to deliver, she received excellent care and was thankful to bring home a healthy newborn

**FEATURES UNIQUE TO A PRIVATE PRACTICE**

This section will discuss factors that way heavily on an independent practice when it implements an EMR.

First, implementation of an EMR requires a significant investment of at least one provider’s time. A provider that is not seeing patients is less productive. In addition to lost income, a practice that implements an EMR will be required to invest in software licensing fees and hardware. The cost per provider to implement an EHR has been estimated at $33,000 per physician. An independent practice is unlikely to have additional sources of income other than patient care and thus will be highly dependent on reaping a return on their investment. This last statement is attested to by the two physician authors for this chapter, one who has implemented an EMR and the other who has not.

The high cost of purchasing and implementing healthcare information technology necessarily means that the owners of an independent practice, who are physicians, will be intimately involved in the purchase, implementation and upkeep of their technology. Having physicians vested in the long term success of the EMR we believe contributes to the likelihood that the technology will be utilized fully. We believe that full utility of an EMR is another major stepping stone on the path to a fully operational, optimally functioning, patient-centric healthcare system.

The third feature that distinguishes independent practices from other care delivery models is the ability to achieve buy-in from both management and physicians on the use of technology. This is due to the fact that physicians are in management positions in independent practices. There is less bureaucracy in an independent practice and thus an independent practice is able to adapt to change more quickly. Full utilization of an EMR is largely dependent on the providers' ability to adapt to change quickly.

A forth feature that may negatively impact an independent practice that implements an EMR, is lack of sufficient capital to hire information technology and informatics experts to work side by side with physicians during implementation and maintenance.

**RATIONALE FOR IMPLEMENTING AN EMR**

Briefly we will outline key rationale for an independent practice to implement an EMR.

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A digital office is more efficient than a paper office because of access to ICD9 and CPT codes within a clinical encounter, immediate access to patient charts by clinical and administrative staff, legible medical records that substantiate higher levels of coding, more efficient charge capture using Computerized Provider Order Entry (CPOE), and electronically stored patient education materials that can be printed and handed out to the patient.

Patient safety is markedly improved with the use of a pharmacy model that tracks medications longitudinally, alerts providers to drug interactions and drug allergies and reduces errors in transcription at the pharmacy due to legibility. If ePrescribing is used, patient safety is further improved by eliminating errors due to data entry at the pharmacy.

Care quality can be improved through the use of patient-specific, disease-specific dashboards which track needed health maintenance and disease prevention activities and provide reminders to both providers and patients when certain actions are due. This also has financial implications given the Pay for Performance initiative.

An EMR can lower overhead including decreasing transcription costs, reducing supplies used in a paper chart, reducing the square footage needed to store paper charts, and reducing the time spent filing paper charts. Malpractice premiums may also be reduced if a practice utilizes an EMR.

Once a practice moves beyond implementation and is comfortable with the basic functionality of their EMR, the providers will be motivated to look for ways to import electronic sources of clinical data, while minimizing paper data coming into the practice and find creative ways to export data to all customers including other healthcare providers, diagnostic facilities, pharmacies, and patients. Few practices are able to achieve a fully operational healthcare system as we have described. The following section lists resources available to healthcare providers who wish to move towards higher levels of functionality.

**INFORMATION RESOURCES AVAILABLE FOR IMPLEMENTATION OF TECHNOLOGY**

There is sufficient guidance and information available for an independent private practice to purchase, implement, and maintain technology successfully. Examples of resources include printed and electronic educational materials published by organizations whose purpose is to help physicians improve healthcare through information technology.

A partial list of such resources follows:
- American Health Information Management Association (AHIMA) [http://www.ahima.org/](http://www.ahima.org/)
• Medical Records Institute [http://www.medrecinst.com/](http://www.medrecinst.com/)
• American Health Information Community (AHIC) also known as the “Community” [http://www.hhs.gov/healthit/community/background/](http://www.hhs.gov/healthit/community/background/)
• American Medical Informatics Association [http://www.amia.org/](http://www.amia.org/)
• MGMA [http://www.mgma.com/](http://www.mgma.com/)
• Doctor’s Office Quality Information Technology (DOQ-IT) This program is administered through each state’s Quality Improvement Organization (QIO)

**RATIONALE FOR UTILIZATION OF PERSONAL HEALTH RECORDS**

Personal Health Records can have a direct and significant impact on patient care. Engaging a patient in self-management, even if the patient is healthy and rarely sees a healthcare provider, has merit. Forerunners of today’s Personal Health Records are baby books kept by parents for their children, which include dates of well baby checks and immunizations. Also, calendars kept by women of childbearing age to track their menstrual periods (now sometimes kept on cell phones) and medication lists kept in wallets are additional examples of Personal Health Records that benefit individuals and families. Even though it would be difficult to measure these benefits, it is logical that there would be cost savings from avoiding duplication of adult immunizations such as tetanus shots, performing unnecessary pregnancy tests on young adult females who can’t remember the last date of menstrual period, or medications errors made because a patient can’t remember the antibiotic that caused a rash prescribed by an out of state provider when the patient required emergency treatment. Despite the difficulty of proving a business model for PHRs for healthy patients, there are studies that demonstrate the benefit of consumer involvement in those persons that have chronic diseases. One such study showed that Chronic Disease Management based on ambulatory healthcare technology and care coordinators in complex medical/chronic disease populations has been shown to reduce emergency room visits, reduce hospital admissions, and reduce length of hospitalizations.27 Chronic conditions are defined by Johns Hopkins University as those that “last a year or longer, limit what one can do, and/or may require ongoing medical care.”28 According to Dr. Sophia Change, an expert in Chronic Disease Management, there is evidence that providing good chronic disease care will not only improve patient outcomes but will also save money.29 Patient support tools that Dr. Chang believes improve quality care include home monitoring devices, personal health records, and web-based education and support. We agree with her supposition and propose that a healthcare provider has four functions with regards to a patient’s Personal Health Record (PHR).

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• First, the practice can support a patient portal and allow their patients to view portions of their electronic medical record. Please refer to the Academic Chapter for a discussion of patient portals.
• Second, they can advocate PHR adoption
• Third, they can refer patients to disease specific websites. These last two functions can be accomplished with minimal capital expenditure and also have the advantage of not requiring a change in workflow.
• Lastly, a provider can update a PHR on behalf of their patient’s through the use of two new standards, the CCR and CCD.

Each of these options requires different levels of technology awareness and implementation. We will discuss these options in order of complexity.

Patient Portal

This option requires additional expenses above and beyond the usual per provider licensing fees negotiated by independent practices with their electronic medical record software vendor. This option is discussed in the Academic Chapter.

Advocate PHR Adoption

An independent practice that is in transition towards implementing an EMR can play a crucial role in engaging patients to utilize personal health records tools. According to a 2006 survey by Health Industry Insights, roughly half of patients surveyed had never heard of a PHR. Physicians are in a unique position to educate patients about the benefits of PHRs as well as assist patients in setting up their own PHR. Given the time constraints of a typical medical office visit, physicians who have not implemented their own EMR may introduce the concept of a PHR and then direct the patient to further information either via distributing literature on PHR options or directing patients to a website such as http://www.myphr.com/ or http://www.google.com/health/.

Referral to Disease Specific Web Sites

A provider group that is exclusively involved in the care of certain diseases—for example, obesity or diabetes—may find it beneficial to engage their patients by referring them to specific URLs such as http://www.fitday.com/ for tracking calories and exercise or http://www.medicompass.com/, an online diabetes-management software program. Another option is to participate in a registry. Examples of diabetes registries include the New York City HgA1c reporting and the Vermont Diabetes Information System. To be efficient, the mechanism of entering data into a registry should be simultaneous to the entry of data into the EMR. For providers that do not practice in an area of the country that has an organized registry

or who are working in a paper office there are free registry systems such as one for diabetes tracking.\textsuperscript{33}

Advocating a specific PHR would require someone in the practice to investigate PHRs that are available and supported in the region of the county that the practice is located. A complete listing of PHRs by cost and format in the United States can be obtained at www.MyPHR.com, a consumer Web site supported by the American Health Information Management Association (AHIMA). An independent practice that chooses to work exclusively with one PHR vendor is accepting a high degree of responsibility for the PHR. At a minimum, someone in the practice should investigate the privacy and security policies and procedures that have been implemented by the PHR vendor and make certain they are in compliance with regulatory requirements. Issues of Privacy and Security will be thoroughly discussed in the Privacy and Security Chapter.

**Updating Patient’s PHR**

A provider group that has reached the highest level of functionality may be in a position to start exporting clinical data elements from their EMR to their patients PHR. Until recently, this was not feasible due to issues of interoperability. Recent breakthroughs have now made it possible for a provider group that has reached the highest level of functionality to export clinical data elements from their EMR to patients.

The Continuity of Care Record (CCR) was sponsored and balloted June 2005 in a consensus ballot as approved by a standards-development organization (SDO) known as the American Society for Testing and Materials (ASTM).\textsuperscript{34} The CCR was created by clinicians to solve a clinical problem that has plagued providers for years: how to collect a core set of patient information in a standardized format that can be transferred to other healthcare institutions. Like many successful digital healthcare templates, the CCR was based on a paper form. The Massachusetts Department of Public Health designed a Patient Care Referral Form, and required a healthcare provider to complete the form when discharging a patient from a hospital to a long-term care facility. The content of the Patient Care Referral Form was refined by physicians with a deep understanding of the data elements that are present in both paper and electronic medical records to become the CCR. A complete CCR has 16 data elements. Demographic information appears in the top of the document, followed by clinical information, and then a plan of care. Strict rules must be followed in the use of the CCR, which include following a predefined vocabulary and implementation guide. If these rules are followed, the CCR will validate and be interpretable by other computer systems.

Another standards organization, Health Level Seven (HL7), worked together with ASTM to harmonize the CCR with a standard known as the Clinical Document Architecture (CDA), which has been around since 2000. The CDA enables the electronic transfer of multiple types of medical data from one healthcare institution to another. The new standard, the Continuity of Care

\textsuperscript{33} Ortiz DD. Using a simple patient registry to improve your chronic disease care: who needs an EHR? software you already have can help you make sure your patients get the care they need. *Fam Pract Manag*. 2006 (Apr);13(4):47ff.

Document, (CCD) will allow institutions that have successfully implemented the CDA to aggregate the data sets defined by the CCR and share this information electronically using HL7 messaging. The CCD was successfully balloted by HL7 in January 2007. The CCD has been implemented as part of IHE profiles for 2006 and 2007.

The most recent healthcare technology breakthrough is PDF Healthcare, based on the PDF file format. Many of the same people and organizations that came together to create the CCR have worked together to improve it. The crux of PDF Healthcare is that it allows healthcare providers and/or patients to add attachments to the clinical data present within a CCR or CCD. These attachments could include radiology images or reports, EKGs or legal documents. PDF Healthcare also allows patients to decide which portions of their CCR or CCD they are willing to share, and with whom. Two industry giants, Intel and Adobe, have supported PDF/Healthcare. A best-practices guide was released in March of 2008, and provides a blueprint for computer programmers on how to implement the PDF Healthcare in a computer system, whether it is a hospital information system, ambulatory medical record, or even a personal health record owned by an individual or family. As long as the sending and receiving systems have implemented the necessary standards, the PDF/Healthcare offers a scalable, affordable, and secure communication medium for exchange of protected health information.

In one possible solution, a healthcare provider would be able to generate a patient’s CCR or CCD within their EMR software at the time of an office visit. See figure one.

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**Figure 1 Data Export from EMR**

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36 [Link](http://www.ask.com/bar?q=HL7+Continuity+of+Care+Document+and+HIE&page=2&qsrc=2106&zoom=%3CKW%3EHl7%3CKW%3E+for+Dummies%7C%3CKW%3EHl7%3C%2FKW%3E+Specifications%7C%3CKW%3EHl7%3C%2FKW%3E+Exam&ab=2&u=http%3A%2F%2Fwww.ihe.net%2FParticipation%2Fupload%2Fitil3_ihewkshp07_content_profiles_boone.pdf)  
[Link](http://www.fortherecordmag.com/archives/ftr_10152007p22.shtml)
Having created the CCR or CCD, the provider would be able to click a send button and the CCR/CCD would automatically be forwarded to temporary data storage. The originator of the CCR/CCD and the recipients would need to agree that the CCR/CCD would be accessed within a specified time frame. This oversimplification assumes the presence of a neutral third party that has agreed to be a temporary data store. Possible candidates for this third party include a regional health information organization (RHIO), also known as a Health Information Exchange (HIE), or a health record bank. Northern Illinois Physicians For Connectivity is an example of a RHIO that intends to implement transient data storage for both CCRs and/or PDF/Healthcares. Kansas City plans to implement a Health Record Bank for its citizens. A non-profit corporation called Health Record Banking Alliance has come together to help communities across the United States operate secure repositories for electronic health records.

If a provider works in a region without community support for health information exchange, it is still possible for a provider to export data from an EHR to third parties, but it is does require both the provider and the recipient to be highly motivated to do so. MedCommons is a company that facilitates point-to-point CCR transport between individuals.

In each of the scenarios described above, the transfer of protected health information must occur in a secure fashion, with encryption. As mentioned before, access to the CCR or CCD must be controlled, so that only authorized individuals can view the data. There must be policies and procedures in place to identify and take action against both malicious and unintended breaches of privacy and security.

**Data Flow from PHR to EMR based on a Clipboard Model of PHR**

The concept of exporting clinical data elements from a provider's EMR is in contrast to the "Clipboard" model that iHealth and others have been promoting. While both models advocate the acquisition and use of EMR systems by healthcare providers, the clipboard model takes a more market-driven approach to accomplishing that goal. The clipboard model takes its name from HHS Secretary Leavitt's Initial challenge: "elimination of the annoying medical clipboard upon which patients repeatedly create paper-based PHRs." The technology adoption curve for EMR systems can be understood / explained via the same fundamental 'rule' that explains the adoption of other technologies: they must provide value to the consumer in excess of their cost. Independent practices will adopt EMRs when there is sufficient demand for their use among the practices' patients.

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38 Northern Illinois Physicians For Connectivity - [http://www.niphysiciansforconnectivity.org](http://www.niphysiciansforconnectivity.org)
39 Health Record Banking: A Practical Approach to the National Health Information Infrastructure. Yasnoff on eHealth; June 21, 2006. [http://williamyasnoff.com/?m=200606](http://williamyasnoff.com/?m=200606)
40 Health Record Banking Alliance - [http://www.healthbanking.org](http://www.healthbanking.org)
Demand for new technologies among consumers is based on the extent to which a product/service embodying a new technology delivers value relative to competing products in one of three categories: cool, convenient, or cheap. Markets progress, to the extent that they do, through these three distinct phases which, in turn, provide three distinct value propositions. The initial phase of adoption is characterized by the technology's use by those who value its "coolness." The EMR systems market is currently 'stuck' in this phase. To move to mainstream adoption, EMR systems must be perceived to be the most convenient way to transfer medical information among the parties to a healthcare transaction. Convenient is the hallmark of the clipboard model for both patients and providers.

Patients have long complained about the necessity of filling out paper forms containing the same information for every new healthcare provider they visit. By allowing patients to utilize a PHR as the means to communicate their demographic, medical, and medication history at registration, the clipboard model addresses this complaint directly.

Providers, especially independent practitioners, have complained about the cost and lack of direct financial return of EMR systems. The clipboard model addresses this complaint and offers independent practitioners choices not available under competing models. Practitioners have at least two options with respect to allowing patients to utilize their PHR for registration that do not require the acquisition / use of an EMR system.

Practitioners can accept standard, paper-based representations of the information in patients' PHRs. Medem, Inc., for example, currently allows patients to print the PHR they create on iHealthrecord.org. There is no charge to the patient for creating the PHR, and there is no charge to print it. It is, however, important to recognize that there is a "cost" to the practices that pursue this option. The practice's workflow will be impacted by the utilization of more than one form for patient information. Moreover, the quality of services delivered may be negatively impacted by the use of more than one form as the probability that important information will be missed increases in direct proportion to the need to search for it.

Practitioners can also take advantage of services that, for a fee, allow the information in the patient's PHR to be printed to a practice's existing forms. This answers the workflow and potential quality issue. Additionally, the practice can choose to import the relevant contents of the electronic version of the PHR into its Practice Management and Billing system. In most cases, this import in-lieu-of manual entry of registration information will offset the cost of the service. In some cases, this approach can even result in a small profit to the practice on every registration.

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The specific words used by the author (Cool, Convenient, and Cheap) to characterize the value propositions to which consumers respond differ slightly from the terminology used by Treacy and Wiersema. The choice to use different words was based on a belief that those chosen are easier for the reader to relate to and remember.

44 [YourTimeMatters.com](http://www.yourtimematters.com), for example, offers such a service.
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In economics, value is defined in the context of an exchange. The utilization of patients' PHRs for registration provides the exchange. It is the ability of the clipboard model to provide value to both patient and provider with minimal investment on the part of either that some believe makes this model superior in terms of advancing the adoption of EMR systems. See Figure Two demonstrating manual data entry of PHR information into EMR and Figure Three demonstrating direct mapping of PHR information into EMR. See Figure Two demonstrating manual data entry of PHR information into EMR and Figure Three demonstrating direct mapping of PHR information into EMR.

Figure 2 Manual Data Entry of PHR Data into EMR

Figure 3 Direct Mapping of PHR Data into EMR

**LEGAL MEDICAL RECORD**

If a practice agrees to export data elements from an EHR into a PHR or import data elements from a PHR to an EMR, the practice will need to have additional policies and procedures in place to ensure a legally sound medical record. An office that exports data elements to their patient or allows their patients to view portions of their EHR should expect requests from patients to modify their medical record. Policies should be implemented to allow for valid requests to alter the medical record. Authors of disputed entries in an EHR should expect these types of requests as a natural side effect of transparency rather than a challenge to their ability. Similarly, a practice that accepts electronic protected health information from their patients will need patient access management policies to include authentication and tracking the source of each patient entry longitudinally. The same security measures that are required for data exchange between healthcare providers need to be followed for the exchange of patient generated data. The Electronic Health Record-System Records Management and Evidentiary Support Functional Profile is an excellent legal resource for healthcare providers to follow when venturing into the

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relatively uncharted territory of patient centric healthcare exchange. Additional concerns that need to be addressed in order for data sharing from patient to physician to become widespread include compensating physicians for reviewing personal health records and liability issues if a physician who is asked to review a PHR by their patient overlooks something important and there is a bad outcome.

CONCLUSION
The use of healthcare technology can have a direct positive impact on patient outcomes and utilization of healthcare resources alike. In order for multiple independent practices across the United States to achieve a fully operational, optimally functioning, patient centric healthcare system and engage consumers in the use of Personal health record tools, several obstacles need to be overcome. First, providers need to be educated on personal health tools outlined in this chapter including patient portals, disease specific websites, PHRs, or the standards that allow a provider to update a patient’s PHR by exporting data from an EMR. A widespread educational campaign should also include language that helps providers adopt that technology that best suits their business needs. This chapter outlined two distinct options for the direction of the data flow and the content of the data being exchanged between healthcare providers and patients. The first option allows providers to share multiple types of clinical data by using the CCR, CCD, and/or PDF/Healthcare. This model is not yet in widespread use but is technologically possible and has been piloted by the author since 2005 (CCR exchange) and 2007 (PDF/Healthcare exchange). The second option automates the registration process and allows patient to share demographic and in some cases medication history when they register at physician’s office.

Once a sufficient numbers of providers have been educated on emerging PHR technology, policies pertaining to the legal medical record will need to be circulated to physicians including how to modify disputed entries in an EMR, how to track the source of entries made by patients and the liability of physicians who agree to accept large quantities of patient generated data.

Finally, neutral data storage options need to be available to both consumers and healthcare providers across the country. It remains to be seen whether Regional Health Information Organizations will be successful at filling this need, or whether independent point-to point subscription agents such as MedCommons will fill this void.

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A systems thinker, Bill Walton believes the open-source model is our best route to a system of systems capable of accommodating and accelerating the learning inherent to the laboratory called Healthcare.
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CASE STUDY

The following is the true case of a nineteen-year-old male patient with Crohn’s disease. We present the true process of events and what might have happened had a PHR been employed.

Process Without a PHR

The patient had been treated for the last seven years since the time of diagnosis at a major teaching hospital (Hospital A), which had a renowned practice in pediatric gastroenterology and was outfitted with fully-functional EHR. In March of 2007, the patient was stable and very responsive to the drug therapy he was receiving, so the pediatric gastroenterologist (Doctor A) decided to graduate him from the pediatric gastroenterology clinic to an adult practice. A referral was made to an adult gastroenterologist physician (Doctor B) near the patient’s home. The patient was never admitted for his condition.

The family requested that a copy of the patient’s medical record be forwarded to the new physician, Doctor B. This process took several months.

In June 2007, the patient began to have a series of troublesome symptoms and his new Doctor B decided to do a series of diagnostic tests. These were completed at the suburban hospital (Hospital B) where Doctor B has privileges. All the results were electronically photographed and produced.

In early August after a number of days of chronic pain, the patient’s parents took him to the ER of the local suburban hospital near their home (Hospital C). Some of the diagnostic tests that had been completed in June were repeated because it was not possible to get the results in the middle of the night. These repeated tests were also captured electronically and in fact this hospital had an extensive EMR with CPOE and nurse documentation. The CPOE was optional for the physicians and augmented by clerical entry if the physician did not want to enter orders himself. After a week’s stay, the patient appeared to be responding well to drug treatment and was sent home. Since Doctor B did not have attending privileges at the second suburban hospital (Hospital C), the patient saw a new gastroenterologist (Doctor C), primary care physician (Doctor D) and surgeon (Doctor E). While the diagnostic test results from June were requested, they did not arrive before the patient was discharged.

After two days, the patient was again in severe pain. On the advice of Doctor B, the patient and his family drove 40 miles to the ER of Academic Medical Center (Hospital A) where the patient had previously been treated. Again tests were repeated in the ER and the patient admitted. The morning after admission, a new primary care physician, Doctor F, stated that is would be good if the hospital could see the test results from suburban hospitals B and C. So the patient’s father, with a note from the patient, drove to both hospitals and tried to have the results faxed to the nursing unit of Hospital A. After putting about 200 miles on his car, he was successful in getting the information faxed and also obtained CDs of the pictures. He drove the CDs back to Hospital A. After reviewing all the previous tests it was decided that the patient needed surgery. While
Hospital A the patient saw many attending, residents and house-staff. He did however, have one primary surgeon, Doctor G.

This surgery was successfully performed and the patient is doing well and has returned to his adult gastroenterologist Doctor B for follow up. The surgeon, Doctor G, sent Doctor B a follow-up letter outlining the results of the surgery.

**Process With a PHR**

Instead of waiting months for the transfer of the patient’s records from Doctor A, the use of a PHR would have enabled Doctor B to access the patient’s health information immediately. By using a networked PHR (i.e., one with the ability to automatically pull in information from other systems), the patient’s previous diagnostic test results would have been available to clinicians on both visits to the ER, obviating the need for redundant tests. Unlike doctors’ offices, PHRs are “open” 24 hours a day, making it possible to pull up test results in the middle of the night. With regard to the patient’s experience before his surgery, it certainly would have been in his best interest to have his father nearby instead of driving around gathering test results. In terms of quality of care and cost, since it took an entire day for the patient’s father to obtain the records, the use of a PHR could have enabled the surgery to have been performed a day earlier, which may have been safer for the patient and may have shortened the length of stay.

**THE ACADEMIC INSTITUTION PERSPECTIVE: PERSONAL HEALTH RECORDS POTENTIAL AND CAVEATS**

Personal health records (PHRs) embody many of today’s developing healthcare trends (e.g., patient-centeredness and autonomy) and will enable accurate, shared, efficient delivery of health care focused on an individual. The definition of a PHR proposed by the Markle Foundation’s Connecting for Health\(^\text{46}\) collaborative and supported at the 2005 symposium of the American Medical Informatics Association is:

> “An electronic application through which individuals can access, maintain, and share their health information, and that of others for whom they are acquainted, in a private, secure, and confidential environment.”\(^\text{47}\)

In short, a PHR refers to a repository for a patient’s pertinent health information. Unlike an electronic health record (EHR), it is more narrowly focused and owned by the patient. It is the position of this chapter that the adoption and integration of PHRs may benefit both academic institutions and their patients, although there are currently significant barriers to their effective implementation.

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\(^\text{46}\) Markle Foundation: Connecting for Health: \(\text{http://www.connectingforhealth.org/}\) (Accessed 10 July 2009)

POTENTIAL BENEFITS OF PHRS IN ACADEMIC HEALTH CENTERS

Academic health centers provide mainly tertiary and quaternary care. This emphasis on referred care increases the need for timely access to accurate health information about a patient. However, in most cases today, academic institutions contact a patient’s outside providers by fax or require family members to go on last-minute, information-gathering quests. In light of the widespread availability of communication technologies (e.g., the Internet), these widespread practices are perceived by many to be inadequate for the provision of safe and effective care.

Those who discuss the potential values of PHRs focus first on the clinical value to an individual. Since patients often see numerous providers, it seems intuitive that allowing those providing care to know all about the patient would be helpful. That is, such information could enable clinicians to make better-informed decisions. It also seems intuitive that the patient would like those caring for him or her to know all about his or her health care needs.

The additional ability of academic centers to update patients’ PHRs would also be required in order for patients to continue to receive benefits from their PHRs. This scenario, in which content becomes automatically populated and accessible to subsequent caregivers, appears likely to facilitate increased access to accurate information, leading to more effective care and more efficient use of resources.

By their nature, academic institutions are highly involved with research but face inefficiencies in identifying and enrolling patients in studies. A PHR database, including patient preferences regarding being contacted for research, could either be used for automatic patient notification regarding studies for which the patient may be eligible, or could, if patient preferences permitted, enable researchers to contact the patient directly. The cross-provider information contained in a PHR provides the clearest picture of a patient’s health situation, making it a potentially invaluable tool for medical research.

COMPLICATIONS AND LIMITS OF PHRS IN ACADEMIC HEALTH CENTERS

The multiple concepts involved in the PHR definition show us that there is work to do to make the PHR even a partial solution to better health care for all. There are significant functionality questions still unanswered, and, even with perfect functionality, there are technical and socioeconomic concepts, mixed and misaligned goals of who owns and is able to share information, unclear ideas about what is meant by “individual,” concerns about who reaps the benefits in terms of health and/or income, and the conundrums of finding ways to assure privacy, legal protections, and security.

A significant risk of PHRs is that they can pass along bad information. The potential benefits discussed above work under the assumption that information contained in a PHR will be accurate and can be automatically updated by academic centers, but this is unproven.

A recent case study highlights the potential harm that can arise from an inaccurate PHR: A patient transferred an academic medical center came with a written information sheet maintained by the patient’s wife. The patient, when asked for his medical history, pointed to his wife and the health care document (a paper version of the PHR). We compared the paper version
to electronic data from the past hospital and ours, and we found numerous discrepancies. The patient’s written comments in the PHR did not coincide with the history or the physical data from any of his providers. Reconciling such discrepancies may have improved care. In this case, the inaccuracies were introduced by the patient, causing concern over ownership and maintenance of PHRs.

While the potential to improve clinical care with a PHR probably does exist, it has not been shown to be so. We don’t even have a common definition of what the PHR should be. There is a spectrum of technical complexity; some suggest patient subjective data should be included; some suggest including only objective data. Others expand on the idea of the PHR to include not only a repository of clinical information, but would like them to serve as “alerts” for clinical trials, or knowledge delivery systems for specific types of patients and conditions, or use them to allow the public to take a more active role in health care decisions.

If we are going to maximize the clinical value, and, subsequently, the academic value of the PHR, some common definition of what should/should not be in a PHR is a first step to realizing the potential. *Hence, a first role for the academic community is to develop the studies to assess the options, and the benefits and harms of the options, for those developing or hoping to support the PHR. However, this must include an assessment of how the PHR fits with our disparate models of health care delivery (consider the number of proprietary PHRs such as MyChart, PatientSite, or Indivo, for example, will the PHR fall into a business model where patients can be sent advertisements about products?)*

There are no studies showing improved patient outcomes with a PHR, although observations offer preliminary findings on its potential to improve the healthcare delivery process and patient satisfaction (see below “PHR: Preliminary Implementation Observations”). The second role of the academic community should be to find important clinical outcome measures that will elucidate the marginal benefits and harms of providing universal access to a PHR. It is hard to imagine that the PHR will flourish without clear goals for use; or proof that they matter to patients.

Several studies have tried to measure the value of the PHR, or components, in specific clinical contexts. Some have assessed patients’ willingness to be involved and recruited for clinical research studies via electronic sources. Others have surveyed patient attitudes about access to a PHR. Unfortunately, only 33% of those surveyed responded, leaving any assessment of attitudes precarious. *This is a third issue for academic relationships with PHRs. Who uses them and are they similar enough in clinical terms to those people who don’t use them so that meaningful extrapolations can be made? Unless PHRs are universal and universally accessible, they will have little to offer academic researchers.*

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48 Ibid.
So far, we have ignored the academic relationships with the technical development companies that grapple with semantics, presentation of information, and interoperability issues. While academics are involved with early product development, and there will always be the need for clinicians to define the technical requirements, this may not be where we need to focus our academic efforts.

As illustrated by the case study, patients clearly deserve to have one medical record instead of multiple incomplete charts with conflicting information. PHRs offer one approach to realizing this goal, but research in support of steps necessary to achieve this goal coupled with more pilot initiatives by major medical centers will likely be needed before large-scale adoption of PHRs can be justifiably recommended. Indeed, the academic community may presently have more to offer the PHR than the PHR has to offer the academic community. There is an urgent need to systematically and academically review the existing literature, focused on clinical outcomes that may be associated with the use of a PHR. This review may, then, allow the academic communities to hypothesize some of the trade-offs between valued outcomes and those not so valuable that result from different models of deploying the PHR. We need to understand what clinical outcomes will be affected by using a PHR before we study their use. The academic community, also, must advocate for universal definitions and universal access. Partial use or partial, disparate data included in one person’s PHR versus another’s will lead to poor information. We also need ways to reconcile differences in data that will be evident in a PHR and that arise from, for example, differences in laboratory performance or differences in interpretations from multiple providers which may differ from the data that is entered by the patients themselves. We have a daunting academic task, indeed.

**PHR: PRELIMINARY IMPLEMENTATION OBSERVATIONS**

An important goal of patient portals is to facilitate interaction between patients and their physicians and patients with their health records. Our experience at the Northwestern Medical Faculty Foundation with an interactive patient portal at an academic medical center is pending more rigorous assessment; however, a few initial observations may be helpful:

1. A significant number of patients must be encouraged to sign-up. Once registered; many become active users. A seemingly effective approach is to encourage patients to sign up the same day of a visit in order to access upcoming test results. Signing up at the visit with the promise of providing test results has been an effective (albeit incremental) way of signing up patients.

2. Open-ended questions from patients tend to be brief, indicating that concerns of physicians regarding being overwhelmed with online questions appear to be unfounded. Handling online queries in a manner similar to those placed over the phone through a triage process facilitates responses in many cases before the physician is involved. However, there continues to be concern about providing unreimbursed care.

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3. Shortcuts for “releasing” normal labs online are highly valued by physicians. Some practices have adopted automatic release of normal tests. Other sites still ensure viewing by the physician first. Any unexpected results are deemed inappropriate for initial transmission online and physicians make phone calls first and follow-up with online release of the results.

4. Despite the complexity of many test reports (CT scans, e.g.), patients are typically content viewing the complete report accompanied by the attached explanation of their physicians. An identified downside here is that such explanations take longer to articulate in writing and are not infrequently met with return questions.

5. Refills, referrals, and appointment scheduling are highly used features.

6. Upcoming enhancements will include ensuring patients are aware of pending health maintenance activities. Additional untapped opportunities include questionnaires, inputting of glucose levels, blood pressure readings recently made available, and other chronic disease management tools.

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Dr. David Liebovitz is a practicing internist and the Chief Medical Information Officer for the Northwestern Medical Faculty Foundation, the full-time academic medical practice affiliated with the Feinberg School of Medicine at Northwestern University. In this role he works to advance development of the outpatient medical records system and optimize information exchange with Northwestern Memorial Hospital where he also serves as Medical Director for Clinical Information Systems. Within the hospital, Dr. Liebovitz is the physician leader for initial implementation and now optimization of CPOE and online documentation. Northwestern Memorial Hospital has successfully adopted online physician entry of orders and notes for all inpatient services and has entered its maintenance phase in which Dr. Liebovitz is now working to complement existing basic decision support with advanced and anticipatory enhancements for high risk areas. Leveraging this experience, Dr. Liebovitz is a program director and course instructor for the Northwestern University Masters in Medical Informatics Program. In addition, Dr. Liebovitz is participating on several funded research projects, works 6 weeks on the inpatient general medical service, sees outpatients in his clinical practice, and supervises residents' inpatient and outpatient clinical experiences.
PRIVATE HOSPITALS WITH AFFILIATED PHYSICIANS AND THE PHR

SECTION 1 - IDENTIFYING THE BENEFITS OF A PHR

In this section, we will provide a brief review of the literature and identify the various definitions and benefits of a Personal Health Record (PHR). In reviewing the literature, it is important to understand the various PHR definitions and dimensions that exist today. These issues will impact a community hospital environment, the community, the medical staff, and their ability to effectively interact with a Personal Health Record.

Connecting for Health Common Framework (December 2006) defines a PHR as “a variety of emerging technologies that enable people to manage their health information and health care transactions electronically.”

Furthermore, the Connecting for Health Personal Health Working Group described the PHR as an electronic tool that enables individuals or their authorized representatives to control personal health information, supports them in managing their health and well-being, and enhances their interactions with health care professionals.

There are seven attributes of an ideal PHR:
1. Each person controls his or her own PHR.
2. PHRs contain information from one’s entire lifetime.
3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure
6. PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it.
7. PHRs permit easy exchange or information across health care systems.

The American Health Information Management Association has a similar definition: “the personal health record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers and the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.”

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In the marketplace today, over 24 PHR sites were noted by an April 2006 AARP study – Personal Health Records: An Overview of What is Available to the Public\textsuperscript{58}. Each of these companies could be defined as a PHR in their own definition, but still in keeping with the overall definitions previously cited. These sites offer a variety of offerings such as Internet-based, PC-based, portable, or a combination of the above. However, six dimensions are emerging to classify a PHR in today’s marketplace.

- **Population** – a PHR either serves the general public or a selected population based on select criteria, i.e., age, disability or service provider.
- **Integration** – a PHR is tightly integrated with a health system, commonly referred to as a tethered offering which is an outgrowth of service to a provider. The other option is a standalone version, which leaves integration of data at varying levels.
- **Data** – a PHR may have several sources of data, but can be categorized into consumer-based, professional-based, or device-based, e.g., biomedical monitoring tools.
- **Platform** – a PHR can be delivered to the consumer in three main platforms or a combination of the three. These are mainly Web- or Internet-based, portable device-based or PC-based applications.
- **Sponsors** – a PHR can be distinguished by the sponsoring entity of its products. These could include, but are not limited to employers, integrated health systems, small practice doctors, insurance companies, disease management companies, pharmacies, etc.
- **Business Foundation** – a PHR must have a business model for the sponsoring organizations. These are either direct-revenue-based or indirect-based through a form of sponsorship.\textsuperscript{59}

Overall, a PHR is a patient-centric model which improves a patient’s and his or her caregivers’ access to the patient’s medical information. Even though the various models and dimensions can have an influence on the PHR components, the underlying theme remains a patient-centric model. Americans are learning to take control of their health information and, in many ways, will be forced to become better consumers of health care. However, the patient is becoming very privacy-savvy and realizes the implications of an electronic means to tracking health information. This is further supported by the statement made to the Subcommittee on Oversight of Government Management by Carol C. Diamond, MD, that “Americans see electronic access to their medical information as a way to improve quality and reduce health care costs if their significant privacy concerns can be addressed.”\textsuperscript{60} Access to information and improving the quality


\textsuperscript{60} Prepared Statement of Carol C. Diamond, MD, MPH Managing Director, Markle Foundation; Chair, Connecting For Health, to the Subcommittee on Oversight of Government Management, the Federal Workforce, and the District of Columbia Committee on Homeland Security and Governmental Affairs of the Senate of the United States. Private Health Records: Privacy Implications of the Federal Government’s Health Information Technology Initiative. Feb 1, 2007.
of care are driving forces for PHRs; however, a more significant concern related to privacy needs to be addressed as well.

All of these issues and dimensions need to be taken into consideration when a PHR enters the hospital environment. The next section will address the characteristics of a community hospital and its effects on a PHR capability.

SECTION 2 - BACKGROUND – CHARACTERISTICS OF A COMMUNITY HOSPITAL WITH INDEPENDENT PHYSICIAN PRACTICES

For this section, we must first define a not-for-profit community hospital as it relates to implementing a Personal Health Record.

The goal of a community hospital is to provide quality health care to the community through several points of care throughout the patient care continuum. In addition, the community hospital serves not only the community, but its medical staff and employees. The community hospital is often the largest single employer in the area. A community hospital may have additional service lines, such as home care, hospice, durable medical equipment, or reference lab services. These service lines are primarily set up to provide a continuity of care to patients and additional revenues to the overall business unit which contains the community hospital. In some cases, rather than the hospital owning them, the same service lines are made available through affiliations with other hospitals or health care service providers. These affiliations can be loosely defined with a simple agreement to utilize services or refer services or they can be contractually bound with revenue and/or utilization guarantees.

Another characteristic of a community hospital is the varying degree of affiliation with the physician groups which admit or utilize services to the hospital. Some community hospitals own practices and are responsible for all aspects of office management, staffing, billing, and patient care, along with employing the physicians and care providers. Some hospitals will lease office space to physicians and provide billing services through contractual agreements with independent physicians. Community hospitals are beginning to employ or contract with hospitalists and intensivists. In this way, these specialists can work closely with affiliated physicians to address the ongoing quality assurance initiatives during the hospital stay. Community hospitals may have medical residents in areas of Family and Emergency Medicine, but this is not the norm. To summarize, community medical staff affiliation includes multiple relationships between physicians, their patients, and the hospital.

Information systems in a community hospital can be as varied as the medical staff. Some hospitals have taken a best-of-breed approach and implemented systems which meet the current need of the department, business requirements, or strategy. In contrast, some have focused on one major vendor which provides the majority of system functionality. There are tradeoffs to both strategies. However, one common trait that exists in all community hospitals has been the ability to implement systems which enable registration, order processing, and billing to a degree which allows financial stability to the organization. Without being able to bill and collect payment through the insurers, government (Medicare and Medicaid), and patient,
the hospital would not exist. This strategy has been refined over the years to the point where many hospitals have now moved on to improving clinical data collection through clinical system implementations. Not only does this have an impact on improved patient care and documentation, but it supports the current billing practices of today.

The next tier of information systems which have evolved in a community hospital are ancillary systems. See figure four. Ancillary systems are focused on supporting the processing and functions of key clinical departments and are usually integrated into the order-processing and billing processes of the hospital information system. Examples of these would include laboratory systems, radiology systems, and pharmacy systems. These systems came from a growing need for automation and quality computer functionality to support the diverse needs of the department, clinicians, and patients. These needs were not typically met through the core HIS vendor. The ancillary systems diagram identifies the key ancillary systems and other ancillary systems which have grown out of a departmental need. In a community hospital, it is important to identify the level of implementation with ancillary systems and their integration with advanced clinical functions, such as nursing documentation or computerized practitioner order entry (CPOE). These core ancillary systems are feeding much of the advanced clinical systems with data necessary to treat the patient.

![Figure 4 Ancillary Systems Diagram](image-url)
Another computer system which has evolved in the community hospital is the Electronic Medical Record (EMR). By HIMSSanalytics 2006 definition, the EMR is:

An application environment composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications. This environment supports the patient’s electronic medical record across inpatient and outpatient environments, and is used by healthcare practitioners to document, monitor, and manage health care delivery within a care delivery organization (CDO). The data in the EMR is the legal record of what happened to the patient during their encounter at the CDO and is owned by the CDO.61

The definition of an EMR is quite broad and encompassing. A community hospital could be at varying levels of implementation for an EMR. The adoption model is further defined through the AHIMA and the HIMSS analytics EMR Adoption Mode62 demonstrated by Figure Five.

![Figure 5 EMR Adoption Model](image)

The stages range from a Stage 0, with no ancillary systems in place, to a Stage 3, which contains clinical documentation, error-checking, and PACs, to a Stage 4, which is CPOE, to a Stage 7, with full electronic capability of the EMR to populate the Electronic Health Record (EHR). It is important to pay special note to the percentage of hospitals that are in each stage, with approximately 74% not reaching beyond Stage 2. This is extremely important to note when trying

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to integrate with a PHR. Because of these varying EMR implementation levels, a community hospital will experience several barriers to information- and data-sharing.

A key system imbedded within the integration of the various systems within the community hospital is an integration engine or interface engine. These systems allow communication from one system to another, minimize the need for duplicate data entry, and improve the quality and timeliness of the data. If a community hospital has chosen to implement its systems without interfaces or in silos, the establishment of the EMR does not exceed stage 1. The interface engines also become increasingly important when departmental systems or best-of-breed systems are purchased which differ from the core HIS. The interface engine is the vehicle for integration between disparate systems. Data standards are set, and unidirectional or bidirectional interfaces are created.

The Connecting for Health Common Framework identified the key steps necessary for a community hospital to begin its transformation and acceptance of a PHR. These steps are as follow:

1. **Widespread use of digital data systems**
   This is focused on bringing systems into tighter integration beyond the HIS. As mentioned before, if the hospital has implemented a more comprehensive HIS, this integration is the foundation for the next steps.

2. **Adoption of EMR/EHRs**
   The use of an EMR and familiarity with its form and features are key elements to clinician acceptance. Without this familiarity and willingness to explore EMR use, the foundation cannot be built for future growth.

3. **Interoperability of EMR/EHRs**
   This begins to focus on standards development among varying systems and the openness that may exist for data integration. The community hospital will have to work through the issues of proprietary versus non-proprietary systems.

4. **Proliferation of PHRs**
   The consumer now becomes engaged in obtaining copies of his or her own health records and begins to own his or her own health care data.

5. **Distribution of technology to the patient and family**
   Personal health data collection can come from multiple sources, such as weight monitoring tools or cardiac care management. These tools become a source of data for the PHR.

6. **Reallocation of roles, responsibilities, and money to the patient and family**
   The shift begins to move from episodic care to a continuity of care model. The patient begins to own his or her data and manage it effectively with his or her care takers.63

The overall steps for a community hospital to integrate with a PHR are very dependent on the characteristics which have been discussed. If the community hospital strategy does not integrate information technology and health care data strategy, the option of integrating with a PHR because small. Only when a community hospital has begun the journey beyond stage 2 of the EMR enablement model are the criteria set for future integration with a PHR.

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SECTION 3 - BARRIERS TO A PHR IN A COMMUNITY HOSPITAL

Once we have understood the evolution of systems and the EMR in the community hospital, the strategy for utilizing or integrating with a PHR begins to take form. Many community hospitals can identify with the benefits and needs of a PHR, but first we must define the types of PHRs a community hospital may come in contact with. For purposes of this chapter we will focus on electronic PHRs (ePHRs) versus a paper transfer from one source to another.

“The current forms of ePHRs in the market mainly involve three basic models:

- Software utilized by individuals to enter and maintain their personal health information,
- Web sites that are maintained by third parties which allow patients to enter and access their information, and
- Web sites that allow patients to view information from other applications, such as an institutional EMR/EHR, or from an application that maintains the individual’s health insurance claims data.”

These forms also provide another classification called tethered or untethered PHRs. A tethered PHR may be linked directly to a provider, insurance company, or employer. It may allow updates to occur from other sources, but this is at the discretion of the PHR owner. In this situation, the PHR is owned by the creator or sponsor of the PHR and is not necessarily patient-owned. An untethered or unconnected PHR can only be updated by the patient, or those having the approval of the patient, to update the PHR. Both categories offer concerns or barriers for the community hospital.

A tethered PHR requires the community hospital to maintain standards within its own systems to transfer data to the PHR format. Without clear data standards, a community hospital could be faced with maintaining several PHR standards based on the owner. If the PHR is owned by the community hospital, the data transfer becomes more within the hospital controls. However, most community hospitals have not begun even an EMR strategy, as previously stated, and would struggle with data flow to a PHR.

The untethered PHR offers similar issues to the tethered version. If the patient provides approval or access, the transfer of data can occur from the community hospital to the patient-centric PHR. However, as was the case with the tethered PHR, multiple standards could exist, in addition to multiple PHR formats and requests. The complexity of the data request sits with the community hospital to decipher. A community hospital might provide the data to the patient and place the data integration responsibility on the patient’s shoulders. This creates several questions, then, as to whether data transfer occurred correctly and as to the completeness of the PHR. If the data transfer becomes too cumbersome for the patient, will they leave out critical information?

Another, less direct, barrier to successful PHR use in a community hospital is the complexity of the relationships, which exist between the medical staff and hospital. Most community hospitals

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provide a view-only access into the patient record for the physician of practice. These views are primarily Internet-based applications, such as a portal or Web service tool. These tools are not providing integration of data to the practice management systems of the entire medical staff. The practice management and EMR systems, owned by a physician group, may have a PHR capability designed within their systems. In this case, the community hospital might be able to work directly with a practice who has implemented a PHR to establish a standard format to exchange data. A community hospital is at a disadvantage when a wide variety of practice management and EMR systems have been implemented by the medical staff.

The need for a common data set standard to populate a PHR becomes a critical issue for the community hospital. By having a common standard, the community hospital can begin to support one standard versus multiple standards. Three Healthcare Information Technology (HIT) industry associations, the American Health Information Management Association (AHIMA), the Healthcare Information and Management Systems Society (HIMSS), and the National Alliance for Health Information Technology (The Alliance), joined forces in 2004 to launch the Certification Commission for Healthcare Information Technology (CCHIT). In September of 2005, the U.S. Department of Health and Human Services (HHS) awarded a three year contract with CCHIT to develop and evaluate certification criteria and create an inspection process for health IT. 65

CCHIT is now a recognized certification body (RCB) and has developed a modular approach to system certification. In the last three years, the focus has been on ambulatory EHR certification and inpatient EHR certification. Under the domain of CCHIT are ten active workgroups: EHR Foundation, Ambulatory EHR, Inpatient EHR, Emergency Department EHR, Network, Child Health Expert Panel, Cardiovascular Medicine Expert Panel, Security Expert Panel, Inter-operability Expert Panel, and Privacy & Compliance Expert Panel. These workgroups provide the testing and certification processes for each area. The expansion roadmap places the PHR market research to start in 2008, with development and launch to take place during 2009 and 2010. 66 To date, no consistent standard or data format exists to assist a community hospital, although much work and planning will be taking place in the next few years.

Medical liability concerning the content of PHR data becomes another issue for the community hospital. If the hospital accepts PHR data into the medical record or as legitimate clinical data for treatment purposes and the data is not correct or incomplete, the liability to the community hospital begins to grow. In addition, the medical staff utilizing this data would also be liable. Also, a PHR that has data from multiple state health care locations begins to identify inter-state liability issues. It is not to say that real time communication with the patient and family is also not fraught with incompleteness and inaccuracies, but do we hold the electronic PHR to a different standard? These issues become financial liability and risk issues for the community hospital to address.

Security and privacy issues are another concern as it relates to PHRs. How secure are the PHR Internet sites and who has access to the data? Has the patient provided full access to all


information in the PHR or only selected individuals or providers have selected access to specific data? Does the PHR fall under the HIPAA privacy provisions as electronic PHI? If a PHR has portability, is the data encrypted in that only proper individuals can open the files and read the information? These are all questions which need to be addressed for a community hospital to work through.

All of these issues become barriers for the community hospital in utilizing or interacting with multiple forms of a PHR. This can be especially difficult when a community hospital may be struggling with issues of developing an EMR strategy in addition to the PHR issues.

SECTION 4 – PHR STRATEGIES FOR A COMMUNITY HOSPITAL

Based on the discussion so far, what are the options for a community hospital to begin to move into a PHR strategy? If the hospital is in its beginning journey of implementing an EMR, can participation in a PHR even be possible? This section will focus on potential initiatives a community hospital could begin as it relates to a PHR.

For a community hospital to begin a strategy of transformation, the first step must be to establish a strong foundation of data capture and data warehousing. This then leads to the capability to data share with other systems internally and externally from the organization. As mentioned in the barriers, a community hospital must first address the HIS and ancillary system integration. A strategy must exist to provide strong transaction systems, which are well integrated and can demonstrate good data quantity, quality, and effectiveness. This strategy must also be supported by the medical staff and executive leadership of the hospital. In order to enable this strategy, a community hospital will need to minimize a best-of-breed approach and begin to focus on key information systems which can support a clear data integration model. This may mean eliminating systems which are strongly entrenched in a department and replacing that system with a more integrated system. By minimizing independent stand-alone systems and emphasizing a data integration model, the foundation becomes established for future data sharing.

A strong data quantity strategy can be supported in a community hospital by inventoring all systems and understanding their role in the community and IT strategy. It is not a strategy of perpetuating more systems, but should focus on reviewing systems for what is the point of data capture they are performing and what role they play in the hospital for that data capture. For example, a community hospital could start with a review of how many patient registration systems exist, whether they are automated or manual, what functions/role they have in the overall operations of the facility, and what systems are within the control of the hospital. Once this is established, a clear review of the quantity of data collection can be done with the intention of minimizing points of entry and further automating these entry points.

If several registration programs or processes do exist, not only is this frustrating for the patient in the community which interacts with this hospital, but a single data source does not exist for basic patient demographics. This is often demonstrated by patient comments such as, “I just provided that information to my physician’s office staff, why do I need to provide it again to the hospital
admissions staff?” Or a similar comment could be, “I was just in the Emergency Department last week, why doesn’t the hospital have my address and phone number from that encounter?” Both of these examples are demonstrating concerns with data collection at the point of encounter. In these examples, the data may be collected, but a review of automation should take place and processes aligned to support a more automated approach. For a community hospital, it is important to limit the number of systems which can be the initial data collection point for the processes which exist and creating a stronger data quantity strategy that supports overall transformation.

Data quality is another step the community hospital must take to streamline its functions. Previously, we stated that data quantity should be reviewed with a strategy towards automation. This must also be supported by a strong data quality strategy. Take the examples of the registration encounters. If the registration collection points are automated, but quality checks are not performed on the data, the systems may be collecting and storing data, but future retrieval and usage is not being considered. As a registration clerk pulls forward stored data for a new registration encounter, what are the alerts to make sure the basic demographic data is currently in the system? Are appropriate search criteria questions being asked to identify the correct patient? Can this step be streamlined to minimize duplication, but also provide quality checks on the current data? In this situation, if the registration clerk does not employ good data retrieval techniques from the system, the demographic data could be duplicated and the data quantity continues to grow. Without a good quality standard to maintain and establish its growth, the database continues to grow with no consideration to receiving systems and future integration.

Another concern with data quality is, who is responsible for the data? During the system inventory, it is important to understand who owns certain elements of the data and takes responsibility for its quality. In the registration encounters, how many departments are able to register a patient should be addressed, but more importantly, who is reviewing this data for accuracy, duplication, and thoroughness? A community hospital may be driven by establishing a quick registration process on the front end, with no consideration of receiving systems on the back end. A process should be put in place to regularly audit the data quality and put measures in place to clean up data duplication and errors. This process should be incorporated into the data owner’s responsibility and can become a benchmark standard for this area. Streamlining all of these features becomes critical to a strong data quality strategy.

Once the strategies of data quantity and quality have been established, then a strategy of data effectiveness can be implemented. Data effectiveness is based on an integrated strategy with information systems and the deployment of interfaces or integration where appropriate. Acceptance and use of data standards must also be deployed for not only internal integration within the community hospital systems, but future integration with external systems to the community hospital.

One standard present today is Health Level 7 (HL7). Founded in 1987, HL7 was created to develop standards for the electronic interchange of clinical, financial, and administrative
information among independent healthcare-oriented computer systems\textsuperscript{67}. In 1994, HL7 was designated an ANSI approved standard. This provided developers with accredited development standards for integration of health systems. Data effectiveness is dependent on utilizing these standards to improve integration among health care systems. If a community hospital and its implemented systems implement these standards, they are then complying with future integration capabilities and are developing the foundation for data integration to the hospital.

Along with standards being accepted by the community hospital, another component to data effectiveness is a data warehousing roadmap for the future. The data warehouse is based on an integration model for systems, but it creates a separate staging and storage area for data which can be utilized for information access purposes. A data warehouse takes the data from transaction-based systems and stores them in a separate system for later retrieval or reporting purposes. This strategy is built on data quantity and quality, because it identifies where the data originated, how the data are extracted, how the data are transformed, how the systems are linked via interfaces or middleware, and where the data will be stored.

Information access is also critical to the data warehouse strategy. Retrieval needs are identified by identifying key data elements and how the end user would locate the correct data and access it effectively. This is a very different strategy from populating demographic data during the registration process; it is a strategy of adding additional value to data storage and delivery of data to various users. With this strategy, a strong infrastructure is needed to manage the data warehouse process in conjunction with the source systems, track the flow of data, and audit its utilization.

Once a strong quantity, quality, and effectiveness strategy is built for the community hospital, the next steps enable data sharing such as populating a PHR.

\textbf{SECTION 5 – COMMUNITY HOSPITAL PHR ADOPTION STRATEGIES}

The last few sections have focused on what is needed in a community hospital for a successful PHR strategy. Before a hospital can establish this integration, it has to achieve other levels of automation success. However, is there anything that a community hospital could be doing to support the future of PHRs? Could a community hospital be in support of smaller elements of the PHR in order to familiarize its staff with the concept and stay linked into other organizations leading the way?

One area a community hospital can review or implement is the Continuity of Care Record (CCR) for the Long-Term Care industry. Standards experts have identified a core data set which will be utilized when a patient is transferred or referred from one provider to another. In some cases, the community hospital may already be providing this information in a manual or partial manual format to its physicians or service providers. The data standards have been developed with several other health care organizations which represent more than 500,000 practitioners, 13,000

\textsuperscript{67} HL7: http://www.hl7.org/ (Accessed 9 July 2009)
IT professionals, and 12,000 institutions in the long-term care community. Not only is this a strong standard to support information sharing outside of the organization, but it can improve the quality of care, reduce costs, and medical errors.

Community hospitals should also become aware of the nine projects currently being funded through the Robert Wood Johnson Foundation’s PHR initiative program. This has been a project based on innovation and collaboration between hospitals, providers, and allied health professionals. The nine projects follow:

1. **A Customized Care Plan for Breast Cancer Patients**: This project aims to build a customized care plan that allows patients to play a more active role in their health, including helping them find decision-support tools available on the Internet.

2. **Personal Health Management Assistant**: This tool will include a software system to help heart failure and heart disease patients manage their conditions from home.

3. **Personal Health Application for Diabetes Self-Management**: Patients with diabetes will use a personal health application that combines a variety of data to help patients better manage their conditions.

4. **Chronic Disease Medication Management between Office Visits**: This program will use technology such as cell phones to monitor overweight patients’ conditions and send information such as blood pressure readings to their electronic health records.

5. **My-Medi-Health: A Vision for a Child-Focused Personal Medication Management System**: This three-part program aims to help children, schools, and caregivers manage children’s chronic diseases via personal medication management devices and text messages.

6. **Supporting Patient and Provider Management of Chronic Pain with PDA Applications Linked to PHRs**: Chronic pain patients will use a PDA that links to their PHRs to track physician appointments, pain logs, and stress reduction strategies.

7. **ActivHealth: A PHR System for At-Risk Sedentary Adults**: Adults at risk for chronic diseases will use devices and biomonitoring systems to help physicians monitor their health.

8. **Living Profiles: Transmedia Personal Health Record Systems for Young Adults**: This project will use various mobile devices and Internet applications to help teens take an active role in maintaining their personal health.

9. **Assisting Older Adults with Transitions of Care**: This team will create an interoperable PHR prototype that is tailored to the information management issues that older patients and their caregivers face as they deal with multiple chronic diseases.

These nine projects are diverse in scope, but have a central theme of data-sharing outside of the organization and working directly with patients, families, and the community to identify the needs. A community hospital can familiarize itself with these projects and ideally identify a strategy it could potentially enable within its own transformation. In addition, a hospital may be

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at a point in its own transformation to pilot a similar project with its systems, medical staff, and community. By isolating a smaller subset and in a controlled setting, the hospital becomes familiar with PHR functionality.

In summary, the PHR may currently be a long-term strategy for the community hospital, but is possible by laying a strong foundation for transformation. This transformation takes the form of a strong data management direction with a focus on the quantity, quality, and effectiveness of data. Medical staff and community support must also be part of the strategy to enable an effective PHR. A community hospital can be positioned effectively for a PHR by working with all levels of the healthcare community to ensure success.

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INTEGRATED DELIVERY SYSTEM VIEWPOINT ON PERSONAL HEALTH RECORDS

INTRODUCTION

Accompanying the change in administration with the recent election of Barack Obama is a mandate for healthcare reform. While there are a number of controversial aspects of the president’s plan, there is universal agreement that the backbone of this reform will depend on the ability to establish a nationwide medical information system. Part of this plan includes the establishment of a Personal Health Record (PHR), allowing patients to have their own easily accessible and portable snapshot of their medical information. However, the PHR will need to be more than an individual’s blog of his or her medical information which the individual can access and edit at will; it will need to be a vehicle which is linked to the individual’s personal physician and through which accurate and real-time health information will be entered by the patient’s healthcare providers and will be available to share with whomever the patient feels needs that information.

Thus, it becomes imperative that the PHR combines the patient’s health impressions and priorities with provider information gathered through encounters with the healthcare system. This will require a fully integrated and transparent system of medical information and exchange. It will require the foundation of a fully integrated Electronic Health Record (EHR) able to communicate freely with the patient’s PHR. Without the EHR, the Personal Health Record becomes relegated to a personal diary of patients’ health impressions. Without the fully integrated EHR linking provider information and communication to the patient’s PHR, the full potential of this powerful tool will fall short of the goal that our leaders envision.

This paper describes the steps that an Integrated Health System has taken to build the infrastructure necessary to support a robust Electronic Health Record. It also describes how this is interfaced to the patient’s Personal Health Record, transitioning a Personal Health Blackboard into a medical instrument as important and integral to the patient’s healthcare as the stethoscope was in the last century or the MRI is today. The patient’s front door to this new medical model is the PHR. The opportunity to open this door into a patient-centric medical home resides in the ability to coordinate and communicate the patient’s medical information in a transparent, secure, and portable fashion.

BACKGROUND-INTEGRATED DELIVERY SYSTEM AND THE EHR (THE BACKBONE OF THE PHR)

An integrated delivery system (IDS), in the true sense of the phrase, combines the continuum of healthcare from finance to clinical delivery at the community level. An IDS integrates the providers (primary care and specialists), the facilities (hospitals and ambulatory sites), and the payer side of the house (Health Plan) into a unified structure linked together by a common information system.

The Sisters of Mercy (Mercy) presently have two such integrated systems within the State of Missouri. Located in St. Louis and Springfield are St. John’s Mercy Medical Center and Mercy Medical Group and St. John’s Hospital and the St. John’s Medical Clinic respectively St. John’s
Health System in Springfield, Mo., topped the list of integrated health networks in the United States in the 2009 SDI assessment of integrated healthcare networks (IHN).

Both groups offer the full array of insurance options through the Sisters Insurance Plan – Mercy Health Plan. The Sisters of Mercy presently have Electronic Medical Records in varying stages of implementation. Through their implementation of Epic across 300 medical and surgical practices, they have created digital access to inpatient medical records, test results, H&P/discharge summaries, and consultations which are available in-house or over the Internet through a Citrix farm of servers.

In the winter of 2006, the leadership of Mercy presented a courageous proposal to their board which represented a significant change in strategic direction. Mercy elected to change its clinical and financial information systems to one software partner – Epic. In addition to consolidating 14 disparate systems distributed throughout 17 hospitals and 1,000 integrated physicians, Mercy made the commitment to implement a fully integrated Electronic Health Record for its patients and communities. The reason behind this drastic shift in direction was determined by the strategic vision of their leadership to establish “one patient, one record” across their continuum of health services. This EHR represented a seamless integration of clinical and financial information which will be centered around the patient and will be available to all providers of the patient’s healthcare through a secure Web-based portal. Through the use of “affiliate link Epic copyright “ and “Care Everywhere Epic copyright,” providers who are not part of the integrated delivery system will be able to access the medical record, if they have established a clinical relationship with the patient and have the patient’s consent.

As part of this commitment, Mercy will be implementing a PHR for its patients, which will be interfaced to the patient’s electronic medical record and available through a secure Internet portal. This PHR (Personal Health Record) will have the functionality to allow patients to communicate with their providers, through secure e-mail, concerning questions about their health or to request information about medical conditions, schedule their own appointments, or request referrals to specialists and/or refills of medications.

Functionality will include the ability to send attachments including JPG encoded pictures, articles, or PDF files, either from the patient to the physician or from the physician to the patient. This information will be available to the patient’s relatives or providers if the patient allows these healthcare surrogates entry into this space utilizing their personal secure password or proxy access. The patient’s Personal Health Record will maintain portability through its Web-based application or by being printed to paper for the patient to utilize as needed (immunization records, medication lists, problem lists). There will also be the ability to interface the PHR with provider information outside of the Mercy Integrated System.

Mercy, through their Rogers Hospital and Medical Group, will be working with Wal-Mart to further develop the Wal-Mart PHR Dossier, which they are building in partnership with Intel. The hope is to integrate the EHR with this PHR to allow for a seamless exchange of patient clinical information in order to populate the patient’s PHR with accurate and timely clinical information.

This project represents a 4-year effort at the budgeted cost of $750 million. While, intuitively, the return on investment seems obvious, the lack of other health systems venturing into such a
sweeping change in their integrated medical informatics made it difficult to build the business model definitively. Interestingly, the Return on Investment (ROI) was difficult to justify from a financial standpoint. Basing their decision on the support of clinicians and patients for this project, it was the decision of the board and Mercy leadership (under the direction of their CEO Ron Ashworth) to proceed with this medical information systems transition at its hefty price. After a year and a half of systems build, hardware build (including a $65,000,000 data center not included in the budget above), and physician and employee buy-in and participation, the first implementation began in February of 2008 with the ambulatory piece of the project scheduled to be complete by June 2009, and all 17 hospitals fully implemented by December 2010. The MyChart Epic® PHR will begin rolling out to Mercy’s patients March of 2009, after the initial implementation of the ambulatory record, and will be completed by January 2010.

OBSTACLES

The obstacles to the success of this project come from several areas.

ADMINISTRATIVE/EXECUTIVE

It is one thing to commit to a project of this magnitude in the boardroom, amidst the excitement and inherent high level view of the overall strategy. It is quite another to stay the course when the times get tough and local budgets are stressed. Within every one of the integrated systems of Mercy, there are a multitude of competing priorities. There is a continuing need for growth and expansion through new structures, updating infrastructure, and purchasing equipment and there are financial pressures caused by nursing shortages, improving patient and physician satisfaction, and the increased costs associated with increasing government regulations and oversight. Additionally, there continues to be a constant financial challenge, derived from almost every sector of the economy, in trying to find ways to lower healthcare cost. Fifty-four months is a long time to watch 50-to-75% of your capital budget spent on something that is not likely to change market share for 3 to 5 years.

The senior leadership has to make the implementation of the clinical systems the number one (and two and three) priority of the organization all the way through its complete implementation.

PHYSICIANS AND MEDICAL STAFF-INPATIENT

Implementation of Clinical Physician Order Entry (CPOE) and digital documentation is a sea-change in the workflow of a physician. This represents the single largest change a physician will experience in his/her career. Change is always difficult. There have been suggestions that a "hybrid" model of paper and electronic systems may be an interim step to a fully developed clinical information model. Our experience would not support this. When digital order entry is introduced, paper has to end: anything short of this will lead to significantly increased risk of clinical errors and confusion, to the detriment of patient care. It would be impossible and self-
defeating to run parallel systems within a hospital clinical setting. More importantly, it would significantly and negatively affect patient care. The duplication of tests and errors in delivery due to missed information and ambivalent communication would be astronomical. Thus, it is the responsibility of the hospital CEO and medical leadership to mandate use of the EMR within the hospital setting by its medical staff and licensed healthcare providers. This group of leaders will need to be resolute, as there will inevitably be pushback from the medical staff, which may result in a negative economic impact to the facility, as well as to the practices of the medical leaders who are dependent on referral business. Historically, when having to make a decision between what the “big admitter” demands and what is the right thing to do, the “big admitter” more often wins out. Quality patient care and service need to be at the center of the decision-making process. Our experience has been that, when faced with a choice between patient-centric care and their self-interest the physician always chooses the patient.

PHYSICIAN-AMBULATORY

There are a number of obstacles that face the implementation of an EMR in the physician’s office. Many physicians fear that the computer represents an intrusion in the patient-physician relationship that has always been a sacrosanct part of the clinical space. Physicians are fearful that:

- Patients will resent and be fearful of having a computer in the exam room.
- Physicians will appear clumsy with the computer in front of their patients, and thus lose credibility.
- The computer will slow physicians down and cause decreased productivity.

Interestingly, experience has shown that these concerns are unfounded. Our experience with over 3 million patient visits utilizing a computer and an Electronic Medical Record over the last 5 years (90 providers on Misys-supported EMR) has shown that patient satisfaction increases and physician productivity is unchanged (although in many instances there is an increase in revenue). Patients are very supportive of the EMR and view their physicians as progressive, with an increased feeling of better care, due to the availability of information to the provider. This was also the finding of Dr. Marshal at Kaiser, which he expressed in his 1999 report in AIM.\textsuperscript{71} Comments such as the one listed below are fairly representative.

“When patients feel that you are informed, they feel amazingly secure. When you know what happened in their primary care visit that morning, or if you have a complex case, they like to know that there is a team approach to taking care of them. We don’t hear ‘God, why don’t you guys talk to each other?’ any more.”\textsuperscript{72}

Workflow changes are necessary in the transition from paper to digital. This can be difficult for physicians who have become comfortable to their paper world. With the EMR, it is necessary for


\textsuperscript{72} Ibid, pg 154.
physicians to enter more information and personally order tests and procedures which may have been the responsibility of others within the office in the paper world. Thus, some physicians will, for the first time, code the patient visit or enter orders as well as complete detailed documentation. It is necessary to communicate with physicians, early and often, to let them know that their clinical workflows will be changing. Additionally, it is helpful if the physicians are included in designing this change process. Once again, allowing physicians (and patients) to be part of the change will lead to early acceptance and better resolve when difficult and inevitable bumps appear in the implementation road.

Another obstacle, which we found to be fairly common, is the fear of the computer itself. Some physicians have never or infrequently used a computer (staff would print out e-mails, which they would respond to by hand and give back to their staff to enter into the e-mail server). Many physicians don’t know how to type and a significantly large number have little understanding of how a computer works. Physicians will immediately think that this change will slow them down and negatively impact their compensation. We did not find this to be true with our Misys implementation, nor did Kaiser with its Epic implementation. In general, we found that physicians who were slow before the EMR were slow after, and fast physicians remained fast.

Physicians in the organization have expressed that their biggest concern is that their income will suffer, secondary to decreased productivity. Medicine remains a volume business, and while quality is assumed, it is not reimbursed. The majority of physicians agree that the EMR will improve their ability to provide care for their patients. The ready availability of accurate patient information and clinical data is a Rosetta stone that physicians have been seeking for years. Despite the widely accepted view of improved quality, there remains the concern that the time it takes to populate the EMR will decrease the time spent on patients.

PATIENT RESPONSE

As noted previously, the patient’s response has been positive. The clinician is viewed as being progressive, “smarter,” and more interested in the clinical aspects of the patient’s care. However, there is a natural fear that the relationship between the physician and patient will degenerate into a “mechanical and robotic” interaction. It remains tantamount that the physician is aware of this fear and is cognizant of the time spent interacting with the patient and not the computer.

The other prevalent feedback from the patient is the desire to have access to this EHR clinical information over the Web and to be able to also access the physician over the Web. Thus, the move to an integrated PHR becomes a natural response to the implementation of an integrated EHR.

AMBULATORY ACCESS

The dissolution of the caregiver’s ties to the paper record allows for a significant improvement in access to care for the insured and uninsured. Once the provider is freed from a physical location
(where the chart resides), the ability to provide multiple points of access to care increases. These include, but are not limited to the following:

- Small smart clinics which are completely clinical in their design. They can be supported by a central communication and business office. Then, the clinician can “bring the office to the patient.”
- Use of strategically placed kiosks allowing secure communication with providers.
- Utilization of ancillary providers—Nurse Practitioners (NPs) and Physician Assistants (PA’s)—remotely from physicians. This care model is enhanced through the communication between the NP and the physician through the EHR, as well as the availability of the patient’s medical record.
- Provision of electronically linked clinics within business and schools.
- The ability to economically staff indigent clinics with rotating physicians, directed by NPs/PAs, without loss of continuity, as the record follows the patient.
- Home visits by NPs who are linked to the Internet wirelessly, allowing for real-time communication with physicians, as well as the availability of the record at the fingertips of the NP providing care in the home.

**PHR ADOPTION STRATEGIES**

In order to increase the adoption of the PHR, all parties involved in the integrated delivery systems care delivery model need to step up their efforts. These include clinicians/providers, insurance/payers, and patients. The government remains a key stakeholder with the ability to support the development of the infrastructure, which would allow for the development of data and interchange standards for the key content areas. This has already begun through the establishment of CCHIT, HITSP, and AHIC. ASTM (American Society for Testing and Material), CCR (Continuity of Care Record), and HL-7 CDA (Clinical Document Architecture) are a few examples which can be adopted as a standard language for all the transactions running across the interfaces. These are standards that have been adopted within the “Care Everywhere” model referred to in previous paragraphs.

In order to make a PHR practical, consistent and universally accepted guidelines, language, and regulations need to be accepted, allowing for a reasonable interface and exchange of information among disparate systems. The technical chapter of this document discusses how data can be exchanged between EMR and PHR, allowing the interfacing of disparate systems to a common PHR platform.

Funding agencies, like the Agency for Healthcare Research and Quality (AHRQ) and the National Library of Medicine (NLM), etc., should promote funding for researchers who are willing to invest time and resources in this direction. There will need to be legislative relief which will remove barriers among providers, allowing all members of the integrated delivery system to work together without fear of Medicare fraud and abuse.

The signing of the Medicare Modernization Act in 2003 by President Bush gave the impetus to the adoption of Health Information Technology (HIT) by both rural and suburban physician practices and, further, laid down the plans for development of the Doctor’s Office Quality
Information Technology (DOQIT) project across multiple states. Policy initiatives like these are necessary for the development of a planned initiative on the PHR front as well. Additional governmental support should be directed toward the promotion of PHR and could take the form of tax deductions and credits for EHR-PHR related expenses incurred by the providers and payers who are taking initiatives to provide their patients a health record. The Center for Medicare and Medicaid Services (CMS) should sponsor demonstration projects promoting these types of funding innovations. As stated earlier, the cost of building the infrastructure to support EHR-PHR implementation is prohibitive without governmental support. Another area that is gaining support within both the physician world and CMS is the Medical Home as a model of care delivery. The availability and integration of the Personal Health Record with provider networks is a natural extension of the Medical Home coordination of care model.

Allowing patients to participate in their care via the PHR and integrating patient information through the continuity of care model has the potential to decrease redundant tests and procedures. To that end, payers should explore the option of providing incentives to providers and practices to implement integrated EHR-PHR models. This can be structured through reimbursement differentiation for EHR practices and for those that use a PHR based Medical Home model. Management of benefit design, providing incentives for patients to utilize the EHR-PHR, would encourage increased adoption. One example of promotion through benefit design change could be through the promotion of home-monitoring instruments which could integrate into the PHR, the expenses of which can be taken by the payers. This increased use of home monitoring has the potential not only to improve the community’s overall healthcare status, but it would also guide researchers to investigate the different platforms for PHR access, such as cell phones and PDAs. Payers can also increase funding and direct resources to promote research in different facets of PHR.

Recently, there have been instances of this type of collaboration. As of June 3, 2007, there were four plans that participated in the PHR Registration Summary & Medication History study. These included HIP USA (The largest Health Plan in New York), Humana, Kaiser Permanente, and University of Pittsburgh Medical Center. As of July 21, 2006, CMS awarded two contracts to test the transfer of Medicare claims data into PHRs. The six-month contracts were awarded to ViPS and Capstone Government Solutions, and the total cost of the project was $500,000. The goals of the project are as follows:

- Test the feasibility of using Medicare claims data in personal health records.
- Assess how to best communicate data from an existing CMS system to PHR tools.
- Evaluate the information included in existing PHRs and how they would best help Medicare beneficiaries’ care.
- Evaluate how existing PHRs address security and privacy issues.

The results of the above-mentioned pilots are still pending, but are exemplary in their spirit of participation and support.

There have also been some early efforts at Internet information availability. Medicare beneficiaries are currently able to receive personalized information about their Medicare benefits and services at MyMedicare.Gov. Although this is not a true PHR, users can save and
update a record of their self-entered prescription drug and pharmacy information, which can be retrieved at any time using a password, date, and confirmation number. This allows them to have their current drug list with them at all times. Enhancements are being made to further improve usability. The MyMedicare.gov Internet portal is now available to beneficiaries nationwide and has over 140,000 registered users. Similar initiatives would guide patients and the general population toward making informed decisions regarding their personal health information and create a road map to the development of PHRs.

THE RESPONSIBILITY OF THE INTEGRATED DELIVERY SYSTEMS

In order for the PHR to be widely adopted and utilized to its fullest potential there will need to be strong physician support as well as cooperation with will all aspects of the healthcare system. Physicians should assist in PHR development by being a part of research models which evaluate the experiences of PHRs, including analyzing and documenting how PHR use can change the way clinicians interact with patients. Providers and payers should work together to develop pay-for-performance programs that provide incentives for PHR use by patients and physicians.

Integrated delivery systems have already established some of the infrastructure changes that allow for an EHR- PHR platform support. Large, multi-specialty group practices associated with integrated healthcare organizations should take the initiative to provide resources and guidelines for integrating their EHRs within their own network and with other networks. This will allow patients to have the most up-to-date health information. The traditional parochial and nontransparent relationship between competing health systems has no place in the seamless exchange of information through the PHR.

As mentioned previously, CMS is the greatest patron, and aligning incentives to support the patient-centric Medical Home utilizing the PHR/EHR platform would stimulate the investment into these systems by the medical community.

Using the power of the integrated network, the PHR/EHR would allow for a more sophisticated and real-time case management system. Allowing for health maintenance reminders and easy access to providers communication through the PHR would intuitively lead to decreased use of resources. It becomes important to promote the use of the PHR through education of patients and providers. This could begin in elementary school and extend into the long term care facilities.

Following is a schematic which represents the Mercy strategic vision of the Medical Home utilizing and integrated EHR/PHR information systems approach. See Figure Six.
SECURITY

Security will remain a daunting task. It places patients in a position of being the stewards of their health information. Therefore, a Web-based strategy, which is the option that the IDS has built, presents a better option than device storage (such as a flash drive), while still allowing for portability and transparency. That is not to say that Web-based applications don’t have their security issues, but this type of access is far less cumbersome and more ubiquitous in its availability than physical access technologies such as smart cards and flash drives.

Authentication of both the healthcare provider and patient are important security concerns. The Privacy, Security, and Authorization Chapter, discussed multifactor authentication as a way for consumers to identify themselves so they may participate in secure electronic communication with their healthcare providers.

Authentication at the provider level will need to be structured and consistent throughout the integrated health system.

Proxy access (parent-child, caregiver-elderly) will need to be flushed out in greater detail.

Role-based access by providers and care-givers will need to be consistent. Authorizing provider and caregiver access to protected information based on roles needs to be consistent across all facilities.
Solutions to these issues are already being addressed within the integrated delivery systems. The IDS could provide a framework for other, less integrated, healthcare delivery organizations to follow, including the following:

- Monitoring security
- Auditing use and content
- Structuring compliance procedures and strategies

CONCLUSION

The Personal Health Record has been a long time in creation. Most would agree that our health system needs to evolve into a patient-centric model that allows patients to freely access their medical information, as well as to be able to provide the information to their physicians and caregivers. This information needs to be accurate, clear, concise, and portable. In order for that to happen, the PHR must be an extension of the patient’s medical record.

“The American healthcare delivery system is in need of fundamental change….What is perhaps most disturbing is the absence of real progress toward restructuring healthcare systems to address both quality and cost concerns, or toward applying advances in information technology to improve administrative and clinical processes.”

The Integrated Delivery System, as defined earlier, is in a unique position to provide the framework necessary to accomplish the goals as stated by the IOM, allowing for the interface of the PHR into the patient’s medical record. The clinical and operational infrastructure to create a digital patient record that allows for the seamless transfer of patient medical information is daunting at best. However, the strategic nature of the IDS is to build and support this type of seamless information. It is the responsibility of the IDS (as well as their opportunity) to integrate the Personal Health Record into this continuum of care model so that the patient becomes a true participant in management of their health. Anything less would not fulfill the charge of the IOM – Safe, Equitable, Timely, Efficient, Effective, and Patient-Centered Care.

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Dr. Thomas H. Hale received his Ph.D. in pharmacology in 1977. He attended the University of Missouri-Columbia Medical School and is board certified in Internal Medicine. Dr. Hale is presently the President and CEO of Mercy Medical Group in St. Louis.

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FEDERALLY FUNDED HEALTHCARE CENTERS - THE ELECTRONIC HEALTHCARE ENVIRONMENT

INTRODUCTION

In the fall of 2005, Hurricanes Katrina and Rita brought the importance of electronic, portable personal health records starkly to light. With most paper records destroyed and evacuees forced to seek care in new environments, many faced medical crises. A large percentage of the population was vulnerable, such as the elderly, low-income, and ethnic minority groups.

The objective of this chapter will be to look at the barriers to adoption of personal health records (PHRs) in a federally qualified healthcare center (FQHC). It will also review current thoughts on and alternative scenarios for culturally effective PHRs. Finally, this chapter will examine the role of American health agencies in promoting healthcare information technology adoption in federally funded healthcare centers.

PHR PERSPECTIVE IN A FEDERALLY FUNDED HEALTHCARE CENTER

What information is relevant to include in a PHR? Who should be responsible for the content of a PHR? Dr. Fred Rachman, CEO of the Alliance of Chicago Community Health Centers, views PHRs as an “out of the box approach.” Rachman leads the Alliance Clinicians Committee and particularly focuses on health center EHRs and clinical quality improvement activities. The centers in the alliance deliver primary care to low-income and underserved populations with multiple, complex needs, including minorities, the homeless, refugees, and HIV-infected individuals. Dr. Rachman views the PHR similar to the military, EHR to PHR, “the patient is responsible for their own health record.” The Veterans Administration designed a system whereby veterans can access their personal health information within the VA's EHR and maintain this information in their own PHR. The veteran is responsible for maintaining the PHR through a My HealtheVet electronic health information system. According to Rachman, he would like to see the personal health record, in a federally funded environment, “occur at birth, similar to a receipt of a birth certificate, a passport, or a license. Payer status should not be a consideration.”

My HealtheVet is an online personal health record available to veterans. In the VA system, a patient seeking access to his or her health information would go to any VA medical center to be identified in person by the facility’s Release of Information (ROI) office. The ROI staff confirms the patient’s identity with appropriate identification and documents it in the patient’s record in VistA, the Veterans Hospital Association's (VHA) electronic health record. This authentication process is only necessary once. After the patient has been identified and authenticated, he or she is granted permission to request copies of his or her EHR through My HealtheVet. In the future,

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75 Personal communication, 2008.
76 Personal communication, 2008.
users will be able to view appointments, co-pay balances, and key portions of their VA health records online.  

This arrangement is in contrast to private sector healthcare delivery models, in which few patients exchange or have, access to the healthcare information owned by their healthcare providers. EHRs are considered paramount in the FQHC setting, where frequently changing staff and inconsistent patient visits can stymie the best-laid care continuity plans. Jeff Sexton, Project Manager at the Tennessee Department of Health, Office of Information Technology Services, recommends that, “Overall, the HIT community should do whatever it takes to ensure the interactions with a patient become part of a person’s PHR (in whatever form).”  

Sexton and Rachman have both noted that our understanding of what comprises “personal health information” is changing. Today, more and more clinicians are viewing lifestyle and social and economic information relevant to preventive medicine and case management. Privacy and security must be very strict and safe, and patients should be advised of the intended use of the information they provide. Otherwise, patients would not give information freely to their providers. Rachman raises the question, “Should the PHR contain medical diagnoses only, or is it a comprehensive health record which needs to take domains such as health behaviors, social issues, education, and caregiver databases into account?”  

THE ROLE OF AMERICAN HEALTH AGENCIES IN PROMOTING HEALTHCARE INFORMATION TECHNOLOGY ADOPTION IN FEDERALLY FUNDED HEALTHCARE CENTERS

State and federal government, as the largest payer of indigent care, must increase reimbursement to those FQHCs that utilize healthcare information technology such as EHRs, PHRs, and health information exchanges.  

As of July 2008, the United States Senate gained support for its approval of legislation that provides financial incentives for physicians to adopt electronic prescribing, or "e-prescribing," and requires adoption by 2011. These types of legislative initiatives, such as the current economic stimulus package, will support continued investments in adoption of the electronic health record. As President Obama has stated, “to improve the quality of our health care while lowering its cost, we will make the immediate investments necessary to ensure that within five years, all of America’s medical records are computerized. This will cut waste, eliminate red tape, and reduce the need to repeat expensive medical tests. But it just won’t save billions of dollars and thousands of jobs - it will save lives by reducing the deadly but preventable medical errors that pervade our health care system.”  

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78 Personal communication, 2008.  

79 Personal communication, 2008.  

Another trend on the horizon is greater access to telemedicine, the provision of remote clinical services and patient-tracking, thereby reaching rural populations. The Telemedicine and Telehealth News[^81], reported in June 2008 that new legislation introduced by Congressmen Mike Thompson (D-CA) and Kenny Hulshof (R-MO) would increase the number of health facilities that offer telehealth services to Medicare recipients. "Telehealth has the potential to make the best treatments and medical professionals available to any American," said Hulshof. "This legislation has broad support from the medical community, as we all share the same goal: to take full advantage of medical and technological advances to save lives and keep people healthy. Telehealth also has great potential to save billions of taxpayer dollars, so this bill is truly a win-win."[^82] The legislation also provides $30 million in grant funding to help health facilities pay for the telehealth equipment and to expand telehealth support services.[^83] This could be a positive incentive for FQHCs, allowing additional revenue, preventive healthcare, and mitigating physician shortages and the notorious patient-scheduling burdens.

Today, the Health Information Technology Standards Panel (HITSP)[^84] receives from the Office of the National Coordinator (ONCHIT)[^85] healthcare priorities by requesting harmonization standards for interoperability, such as Consumer Empowerment and Clinical Access via Networks and Media.[^86] Consumer Empowerment was defined with the primary goal of helping individuals manage their healthcare and advocate for themselves as they use healthcare services. The ONC specifies four areas to achieve this goal: Personal Health Record, Medication History, Health Record Locator, and Registration Information.[^87]

**PHRS AND THE MEDICAL HOME**

Frank Castillo, M.D., Medical Director of Erie Family Health Center, Humboldt Park, Illinois, is on the Diabetes Call to Action Task Force. This Task Force reported in December 2006 that diabetes is extracting an enormous toll on the people of Humboldt Park, most notably Puerto Ricans. Among Puerto Ricans in this community, the prevalence of diabetes is 21%--almost three times

[^83]: Ibid.
[^87]: ISO5: Consumer Empowerment and Access to Clinical Information via Media
higher than the U.S. rate. Diabetes increases a patient’s risk for kidney disease, blindness, and amputation, among other problems.88

From his position trying to mitigate this crisis, Dr. Castillo feels “that the 'Medical Home' is the next future step in patient care.”89 The Medical Home is a model of patient-centered care that incorporates primary care services in the everyday lives of patients through patient partnership with medical and community resources. The patient is enabled to better manage chronic and life-altering conditions through continuous care that is cultural effective and family oriented. The “Medical Home” concept dates back to the 1960’s and was originally intended to address children with special healthcare needs. However, it is now regarded as a means to serve diverse underserved populations.90 The widespread adoption of information technology for care management and quality improvement, along with adequate payment methods, would be important steps toward implementing the Medical Home, with possible better health outcomes that could result in long-run savings to patients, employers, and health plans.

The author of this chapter believes the Medical Home philosophy, together with an interoperable PHR, has the potential to empower the vulnerable consumer.

The Medical Home identifies promising models by creating mobile medical units, school-based health centers, and telemedicine. In the author's opinion, nursing programs and medical schools need to include curricula on the Medical Home and consumer-centric healthcare, such as defining policies and procedures that will facilitate the sharing of healthcare data and instruction on how to engage patients in using PHRs.

**PHR TOOLS AND EDUCATION**

Educating patients both underserved and the general population, about the potential uses of healthcare IT is essential to creating a market environment that is ready for PHR adoption.

Organizations like the Healthcare Information and Management Systems Society (HIMSS)91 are assisting in the growth of HIT interoperability through harmonization of standards as a partner in HITSP92, for a National Health Information Network (NHIN). The American Health Information Community (AHIC)93 has prioritized Use Cases for HITSP to harmonize standards that assure interoperability.

The Use Cases are areas that will benefit the clinician and patients, such as the following:

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89 Personal communication, 2008.
• Clinicians will benefit from having the ability to respond to (or initiate) secure communications to facilitate the care process and promote better patient health. This communication will be done in a manner which provides appropriate information to the patient and meets existing needs for clinical documentation.

• Clinicians will have the ability to securely communicate reminders to patients and their family members to promote preventive healthcare. These reminders could include items such as annual check-ups, cancer screenings (e.g., mammograms and colonoscopies), and immunizations.

• Personalized Healthcare Use Case will focus on the exchange of genetic/genomic test information, personal and family health history, and the use of analytical tools in the electronic health record (EHR) to support clinical decision-making.

• Remote Monitoring Use Case will focus on the communication of interoperable remote monitoring information from applications or devices to the EHR and the PHR.  

In short, FQHC patients and clinicians may benefit from the ability of the patient to gather and communicate remote monitoring information electronically from measurement devices in a home or other non-clinical setting to a clinician’s EHR system and/or to the patient’s PHR. Remote monitoring could include, but is not limited to, communication of physiologic measurements (e.g., weight, blood pressure, heart rate and rhythm, pulse oximetry, glucose, etc.), diagnostic measurements (e.g., transthoracic impedance, etc.), medication tracking device information (e.g., medication pumps, infusion devices, electronic pillboxes, etc.), and activities of daily living measurements (e.g., ADL biosensors, pedometers, sleep actigraphy, etc.). Interoperable, user-friendly technologies are needed to enable the flow of information to EHRs and PHRs utilized by clinicians, care coordinators, and patients.

However technologically enabled a particular clinic is, healthcare providers must seek solutions to provide consumers with assistance in creating a PHR. The American Health Information Management Association (AHIMA) has created a website, www.myPHR.com, which provides forms that consumers can complete. In addition, AHIMA has created a free educational seminar for anyone interested. AHIMA representatives will present this information to any group or organization throughout the United States as requested. One relatively easy step forward would be to provide these forms, with clear instructions, at the clinic during the discharge process.

**PHR CASE STUDIES**

**A paper PHR Case Study**

The scenario below describes the case of Maria Alvarez, a single mother of four, and her solution to create and maintain a PHR.

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Maria recently came to the United States from Mexico. She works as a waitress part-time. Even though health insurance is available, Maria cannot afford coverage for herself. Maria has severe asthma and visits the free clinic in her neighborhood for treatment of asthma attacks. When the clinic is closed, she seeks treatment at the hospital emergency room. Maria is on a multitude of medications for her asthma and other health conditions. Maria keeps detailed records of her clinic and ER visits as well as a list of medications, including the dosage of each. She keeps this information on a single sheet of paper (because she does not have access to a computer) and updates it after each visit. Maria is taking charge of her health care by having a personal health record.

However, Maria is a rarity. Most adults, especially those who are uninsured and with limited means, do not keep a PHR. There are many reasons why consumers with or without insurance do not have a PHR, but one of the most common reasons is that most adults have not taken the time, nor seen the benefit, to keeping a personal health record.

Keeping a PHR is beneficial to all consumers as a communication tool to and from their providers. This is especially beneficial to those who frequent clinics and emergency rooms. However, the barriers to creating and maintaining a PHR for that population are great.

First, there is often a language barrier between the healthcare provider and the patient. This includes the forms that are provided and other literature given to the patient. Medication information, including dosages, treatments, procedures, and follow-up, is extremely important to document and is often not provided in a language or competency level that is understood. Interpreters and forms written in the patient’s first language should be available in order to properly provide information to the patient and vice-versa.

Second, the information needed in order for someone to create a PHR is often difficult to obtain. Most hospitals and clinics do not automatically share health information with each other. Hospitals and clinics usually do not have the same information storage system, so paper is still the medium of choice to give the patient or provider. HIPAA allows for patients to access their personal health information. However, there may be fees involved, which can deter patients with limited ability to pay.

Third, much of the information provided to the patient is written at a reading level much higher than the typical patient can read, interpret, and understand. Verbal language and written documents must be written at no higher than a sixth-grade reading level. Time must be taken with patients to assure they understand the diagnosis, treatment, medication, and follow-up needed.

As mentioned earlier, many patients do not understand the need for a PHR, nor do they have a desire to take control over their own healthcare. Taking the time to explain the benefits will create the desire. A few examples of benefits to explain are 1) assuring that contradictory drugs are not prescribed, thus assuring that they will not be harmed or encounter additional illness if taken; 2) unnecessary or duplicative tests and procedures are not performed, thus eliminating additional time and hardship on the patient, both mentally and physically, and 3) potential to confirm diagnosis and proper treatment more readily knowing patient history, current meds, and the like, leading to sooner healing.
An Electronic PHR Case Study

Finger Lakes Migrant Health, an FQHC in upstate New York, is using the "MiVia Personal Health Record" for migrant workers who are seen at their clinics and at clinics in Florida.

The MiVia Web site\(^6\) allows the patient to give any clinician access to his or her data by providing a name and password. Clinicians are not required to subscribe to MiVia to access or update the patient’s information. The site is available in Spanish and English.

By using this PHR, along with telehealth links to regional hospitals and specialists, Finger Lakes Migrant Health has enabled clinicians to have timely access to health information to care for occupational injuries and illnesses. They have reduced high costs and liability of travel to metropolitan hospitals and patient transport, made more efficient use of case-worker and clinician time, and achieved better coordination between care partners, while creating proper and portable documentation of patient care. At the same time, they have kept a comfortable environment for their migrant patients.

**SUMMARY**

This chapter has explored current expert opinions, government initiatives, Web tools, and recommendations of merging the Medical Home concepts with the PHR. It has discussed the barriers to high-quality care that currently exist in the FQHC setting, including transient populations, language gaps, and a lack of awareness.

The PHR, achieved through electronic or paper means, has the potential to overcome many of these barriers by engaging patients in documenting their own care. While PHRs would be optimized by EHRs, they can be implemented in a paper format as an important first step. PHRs, increasingly more accessible to many providers, can help establish a new paradigm of patient involvement.

As covered elsewhere in this paper, barriers exist for any provider seeking to adopt health information technology. In addition to issues of standards and connectivity, the FQHC may face additional hurdles seeking funding or other incentives for adoption. However, an electronic system is not necessary to coach patients and provide them with a tool to take charge of their own care. While the FQHC waits out the legislation, budget determinations, and standardization debates, they might realize benefits tomorrow by implementing a hard copy PHR today.

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\(^6\) MiVia: https://www.mivia.org/ (Accessed 10 July 2009)
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PERSONAL HEALTH RECORDS AND ELECTRONIC HEALTH RECORDS FOR LONG-TERM CARE FACILITIES

The nation is currently in a health care crisis, with 77 million baby boomers coming online for care. They are all prone to have 4 to 5 chronic diseases upon reaching the Medicare benefit age of 65. To avoid national bankruptcy, the nation must lower the rate of increase in health care costs by eliminating wasteful clinical practices, improving quality controls, balancing the budget, and, most importantly, pursuing restorative outcomes. At the current rate of spending, health care costs in the nation will escalate to 30% of GNP by the year 2010 (compared to 16% at the present time). To avert the impending crisis, there needs to be a paradigm shift from crisis care to “health preservation of America.”

This shift promotes three basic principles:
1. Health care is a privilege, and each American must take personal responsibility, which includes the sharing of their personal health records - nationwide health information exchange - for continuity of care and care planning.
2. The billions of dollars of waste in the current system must be eliminated through the use of Health Information Technology (HIT) that will facilitate information-sharing in a secure environment across multiple approved providers of health care, thereby improving outcomes and efficiency.
3. There must be a universal benefit package that insures all Americans and uses automated best-practice models focused on outcomes as the basis for payment.

To address the health care crisis, President Bush set a goal of electronic health records for most Americans by 2014. To meet this ambitious goal, many states are employing a variety of strategies to encourage the use of electronic health records and other innovations. In 2005 Illinois passed House Bill 2345 instituting Public Health Act 94-646 which created the Illinois Health Records Task Force, who have been given the assignment to develop a mechanism for collecting data from providers. The underlying Task Force Electronic Health Record and Plan is 129 pages of bureaucratic details primarily on privacy and some information on costs, but NO plan on standardizing content.

The document states “there are not standardized forms to request or disclose patient information.” After reading this document, it is my opinion that the general lack of

98 Ibid.
standardization of data has created silos of information that will impede the transition from paper to a shared electronic health record. Before interoperability can be attained the information must be in a standardized format using standardized terminology. An example where the health care industry must first be ISO 9000 certified before it can be Six Sigma efficient.

The philosophy of HIPAA—that health information is private between the patient and provider—also contributes to the formation of these private silos. A change in mentality that health information should be accessible to other than the physician and patient is occurring, albeit slowly. This change is a prerequisite to a use of such information for a technical infrastructure development that leads to standardization of policy, procedures, and practices.

Achieving the vision of nationwide health information exchange first requires interoperability: the ability of disparate health information systems to be able to talk to each other and share data in a safe and secure manner. Interoperability and standards are often mistaken as one. Standards are much narrower and specify technical details. Interoperability, on the other hand is a much broader concept that involves both the technical and business context.

Currently, content is stored in a variety of disparate formats such as the following:
- Physicians handwritten medical history, prescription and treatment notes
- Hospital medical records that include electronic demographics, handwritten history, treatment notes and laboratory results
- Nursing home medical records that include handwritten history, treatment phone orders and narrative notes
- Home care medical records that include handwritten history, treatment and narrative notes
- Hospice medical records that include handwritten history, social service and narrative notes
- Assisted living is handwritten social histories

This information would be more usable and easily transferred to electronic format if there was **standardized terminology** for care maps and care plans. **Standardized terminology** would also facilitate the generation of outcome measures and the development of standardized problem assessment instruments that would assist in physician diagnosis for defining the following:
- Medical necessity
- Severity of illness
- Intensity of service
- Desired outcome

In addition, care models can be developed by clinical staff based on the assessments. The care models could define the following:
- Interventions
- Schedule of care onset, start and stop dates
- Estimated minutes of care attached to the interventions
- Outcome goal for each problem
• Standardized measurable scales or statistics attached to the goals for measuring progress or decline in patient functioning and cognition.

Once the care models are built, the appropriate clinical discipline intervenes and charts the goals by problem, measures improvement or declines the information used to revise or update the plan as the patient’s condition changes.

Standardized content will allow accumulation of information that is currently not available for analysis. We have the processing power for managing and analyzing massive amounts of content but are lacking content. In addition to standardizing and harmonizing terminology, there is a need for developing standardized forms and processes for capturing information. Forms and processes must be deductive in nature and not inductive; that is, there must be an outcome measured for each problem which would allow the measurement of performance. Performance measurements would allow pay for performance based on evidence presented on the medical, emotional, and social problems addressed in the discharge plan and activated in the care plan.

Standardized terminology, processes and forms will drive the integration of the disparate data sources into a single source that will be accessible to the patient, caregivers, and physicians. This will allow for better patient care and management of outcomes. The adoption of Electronic Health Records can be accelerated by the creation of Point of Care Systems that can improve the quality of care and reimbursement. Standardized information will also spur the adoption of Personal Health Records and a new paradigm of consumer-centric healthcare.

Electronic Health Records (EHRs) in this context are defined as digital information captured electronically of the care plans, interventions and outcomes for each patient episode for communication from providers and clinicians to patients, patient families, payers, regulatory agencies, and enforcement bureaus.

Personal health records (PHRs) in this context are the patient’s medical, psychological, and social histories including care plans, interventions, and outcomes for each episode, along with clinical outcomes.

HOW ELECTRONIC POINT OF CARE SYSTEMS CAN IMPROVE QUALITY AND REIMBURSEMENT

Adoption of computerized EHR systems in the future would be greatly enhanced if the systems provide processes and tools that assist the physician at the point of care. These care-planning tools should be embedded in portable devices so the clinician can record outcomes and measure results. These tools need to be carefully designed so the processes are deductively thought through and programmed into the devices. The current tools that are available do not provide assessment data and linkage to a care planning and tracking process. Care planning is imperative for many functions when it comes to quality control and reimbursement.

The point of care tools developed must include the following features:
• Integrate pertinent clinical protocols with appropriate interventions and time factors. It is the time element that will calculate costs, efficiency, and productivity. Using the care plans for
measuring quality, cost and profit margins is a function of deductive care mapping into the technology.
• Integrate what Medicare, Medicaid, insurance, and private resources will pay for protocols so the patients get their entitled benefits and are not decertified too soon and put on private spend down or public assistance too soon. Using the Medicare regulations and transmittal 262 will enable the staff to know what to do and capture the reimbursable data as they are doing it.

Developing point of care technology will provide usable tools for the clinician to pursue outcomes and improve cost reimbursement. In addition, it will eliminate the unreadable, unusable handwritten documentation that does not allow the measurement of quality and outcome.

PERSONAL HEALTH RECORDS
The PHR is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual. (The National Alliance for Health Information Technology Report: Defining Key Health Information Technology Terms; April, 2008).

The PHR does not replace the legal record of any provider. In a long-term care facility, the PHR can serve an important role as an application that gathers, stores, and shares the essential health data of the patient. Aggregating data from multiple providers, systems, and data sources in the PHR will support improved treatment, help inform the provider and enhance communication with health care providers through secure messaging. The PHR is a vehicle of consumer choice and a bridge across a fragmented health care system.
Following are examples of PHR and EHR technology sponsored by the long-term Care users that are fully operational in Illinois and the U.S.
• Caregiver Management Systems, Inc.
• American Health Tech
• Computdata
• Answers on Demand
• Acu-Med
• PointClickCare
• Quickcare
• Health Care Software, Inc.
• Health Data Systems
• American Health Care Software
• HealthMedX
• Momentum
• MDI Technologies
• Lintech
• Achieve Healthcare Technologies
These systems offer demographic, medication management, care planning, charting, and billing databases. The common language is driven by the Resident Assessment Instrument, ICD-9 codes and medication listings. Most of these systems are web based and operate on wide area networks.

**BARRIERS TO ADOPTION OF PHRS**

1. **Patient Acceptance**: Currently, the data in the PHR is not shared information. It is confined to the local network and password protected. It is the patient families who will be the obstacle to sharing personal medical records. It is only when there is a care issue that the family agrees to share the records. Most of the patients are Medicaid recipients who are medically indigent and do not want that fact known.
2. **Provider Acceptance**: The providers don’t even share the PHR with the families on a regular basis. Doctors and pharmaceuticals also do not have electronic access to PHR. The data bases are there but not accessible for sharing data.

**STRATEGIES TO ENGAGE LTC FACILITIES IN OFFERING USE OF PHRS**

Health information technology (HIT) has become an important vehicle for providing health information to consumers and is increasingly being used by consumers for other functions, including self-care, informed and shared decision-making, connecting with health care providers, communicating with others with similar health issues, and storing and accessing personal health records. HIT has the potential to significantly increase the efficiency of the health sector by helping providers manage information. It could also improve the quality of health care and, ultimately, the outcomes of that care for patients.

With the health care environment’s increasing emphasis on engaging consumers in their care, the market for HIT has been expanding. To support the new paradigm health plans are providing consumers with information and tools to enhance their decision making ability. Adoption of PHRs in Long term Care (LTC) facilities requires the following criteria:

1. **Interoperability and Portability** -- Personal health data can be exchanged among PHRs and sources of personal health information (e.g., electronic medical records, payer or pharmacy systems). Interoperability and portability require the standardization of data so that information can be shared between multiple providers and specialties. The development of an ISO 9000 effort needs to be instituted to standardize processes in health care. The benefits of interoperability are reduced cost of care, improved ability for a correct diagnoses, and development of an appropriate care plan. Evidence based medicine and pay-for-performance are all contingent upon standardizing processes and converting an art form to a science. The old school of inductive “rule out” approach must be replaced by the deductive “pursuit of an outcome.

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2. **Privacy and Security** -- Privacy protection and security safeguards are paramount, and timely access for all consumers and their proxies to their personal health information should be ensured.

3. **Education and Outreach** -- Effective messages for consumers and providers should guide broad educational efforts to engage them. PHRs may become important tools for disease management. Enhancing a patient’s ability to routinely access his or her own medical information could dramatically improve the success of disease management programs. Patients with more self-care resources are better equipped to reduce costly complications from chronic illness. The result of this would be a paradigm shift from crisis care to “health preservation of America.”

**Health preservation** is defined as a proactive set of life style principles that will change the cultural bias towards self-preservation. These preservation principles include a holistic lifestyle for each American based on fitness, nutritional values, avoidance of harmful chemicals, positive relationships, meaningful family values, and spiritual commitment to self and others. The objective of health preservation is to improve the quality of life in American for an aging population. The goal is to pursue this lifestyle in an effort to preserve personal health and lower the cost to society for these areas:

1. Chronic Diseases  
2. Re-hospitalization  
3. Over medication  
4. Redundant and unnecessary crisis testing  
5. Turnover of health care staff  
6. Injury to staff and patients  
7. Pursuit of treatment based on symptoms  
8. Waste due to lack of focus on causation and well defined outcomes  
9. Payment is for treatment and housing  
10. Waste due to lack of focus on restorative services and reintegration back to community based programming

**PHRS AND EHRS AS A TOOL FOR MANAGING AND PRESERVING HEALTH**

The focus on treatment of illness is already at its peak and driving the payment system into bankruptcy. HIT is the ultimate resource for reducing the cost per episode by preventing the occurrence and preserving health and fitness as a lifestyle change for Americans. In this endeavor, we need to take the employer out of the middle since it cannot control the cost of health care, nor the cause of chronic disease. Commercial insurance billing records do not provide a practical solution to determining over utilization nor effective savings, this must be a function of controlling inputs not an analysis of outputs.

Lastly, health care providers (especially primary care physicians) are key partners in realizing widespread adoption of PHRs. Surveys of consumers have identified their health care providers

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103 Rhodes, 1.
104 Ibid.
as the most trusted sources of health data. It is important that incentives are properly aligned so that providers realize benefits from encouraging PHR adoption among their patients and that portability of data between PHRs and EHRs is encouraged.

In conclusion, EHRs and PHRs will be the key technologies over the next several years that will enable the transformation in health care. Economic incentives will motivate LTC Facilities to utilize PHRs and EHRs, the incentives can be in cost savings or added revenue streams. Health care costs reductions are realized by reducing inefficiency through incomplete information resulting in inappropriate care. In addition, there are moral incentives for improving continuity and quality of care through the availability of information to guide medical decisions at the time and place of care, reducing medical errors, and advancing the delivery of appropriate evidence based medical care producing better outcomes. Other benefits are off-site use of specialists for performing tests and ordering restorative programs, as well as medication orders and treatment regimens. The emergence of new PHRs and EHRs in the marketplace will provide the needed momentum for change and accelerate adoption.

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105 Davenport-Ennis N, Robertson RM, 7.
CHAIN PHARMACY VIEWPOINT ON PERSONAL HEALTH RECORDS

Chain pharmacies have always been leaders in the health care industry in regards to Health Information Technology (HIT). Pharmacies were the first health care entities to do real-time electronic billing, send and receive electronic prescriptions and provide online services to their patients. For this reason, pharmacies will likely have an active role in the development of Personal Health Records (PHR) as well.

Chain pharmacy websites are currently the closest thing to PHRs in use today. From these websites, patients can view and print their medication history, refill prescriptions and ask a pharmacist a question. The limitation of these sites is that each one is its own silo, only providing information from that particular pharmacy chain. A true PHR would have information fed to it from all pharmacies, as well as physician EMR systems.

There are three main ways a pharmacy can interact with a patient’s PHR. Individual pharmacies could choose to act as one or all of the following:

• Data Provider
• Clinical Care Provider
• PHR Owner

As a data provider, the pharmacy would have a more indirect role in the patient’s PHR. It would merely be providing a data feed directly to the PHR, or to a central repository to which the PHR connects.

As a clinical care provider, the pharmacy, or more specifically the pharmacist, would use the information from the PHR to provide various clinical services, such as poly-pharmacy, or a drug utilization review of all the patient’s medications or other Medication Therapy Management (MTM) services.

As a PHR owner, the pharmacy would build and maintain the PHR. It is likely that the PHR would be web-based and branded based on pharmacy ownership. The pharmacy-owned PHR would still be fully integrated and have all the features of a non-pharmacy owned PHR. The question that remains to be answered is that of the economic model behind the pharmacy-owned PHR.

One can assume that most pharmacies will play at least one of the above roles with regard to their patients’ PHRs. In order for PHRs to become successful, it is imperative that pharmacies, at minimum, become data providers to ensure complete and accurate medication history within the PHR. One can argue that Pharmacy Benefit Management systems (PBMs) could provide the same medication history data; however, only the pharmacy data will show the complete picture. A PBMs is generally responsible for administrating prescription drug programs for employers and insurance plans. Primarily, they process and pay prescription drug claims, but are also responsible for developing and maintaining their formulary and contracting with pharmacies.106

PBM data will not have non-covered medications (e.g. erectile dysfunction medications), workers

compensation prescriptions, or prescriptions paid for with cash or manufacturer’s coupons. Also, PBM data does not include prescription directions, which are another important component for a complete PHR.

Pharmacy medication history is currently available through SureScripts\textsuperscript{107} for prescribers using certified software. SureScripts operates the Pharmacy Health Information Exchange, which allows doctors to send and receive electronic prescription messages to 95\% of the nation’s pharmacies\textsuperscript{108}. This connection to pharmacies means that SureScripts also has access to medication history data, which could potentially be fed into a PHR. However, a PHR with only pharmacy data does not provide much more benefit to a patient than a pharmacy website. In order to have a fully integrated PHR, physicians must adopt and utilize electronic medical record (EMR) systems of their own. Since many of these EMR systems also connect to the SureScripts Health Information Exchange, it makes sense to utilize this data to populate the patient’s PHR.

RxHub\textsuperscript{109} provides medication history information to prescribers using PBM data. Both SureScripts and RxHub send this data using National Council for Prescription Drug Programs, Inc. (NCPDP)\textsuperscript{110} SCRIPT Standard format. (The NCPDP SCRIPT standard is designed to facilitate the electronic transfer of prescription data between pharmacies and prescribers\textsuperscript{111}) It would make sense for a PHR to utilize the same format for medication history data. Although the data would have to be formatted in a way that is understandable to the patient, utilizing the existing infrastructure is the easiest and most cost effective way to provide medication history to a patient.

A pharmacy can use data from a patient’s PHR to enhance clinical services. For instance, having a complete medication history for a patient would allow the pharmacist to do a full Drug Utilization Review (DUR) as well as provide MTM services. Having a complete patient record, including lab values and diagnosis, allows the pharmacist to provide the best clinical services possible. Pharmacists are expanding their roles as health care providers with services such as MTM, immunizations, compliance counseling, and poly-pharmacy reviews. The results of these interventions can be valuable information for the physician to have. Alternately, it is important for the pharmacist to be notified by the physician if a medication has been discontinued or if a dosage has changed. A fully integrated PHR could open up the doors of communication between the physician and pharmacist and set a higher standard for overall patient care.

MTM Services would undoubtedly see the greatest benefit from consumers having a PHR. Using the PHR as a reference, a pharmacist could schedule a poly-pharmacy medication review with the patient or alert the patient of non-compliance. A pharmacist could also monitor and suggest

\textsuperscript{107} Surescripts: http://www.surescripts.net/ (Accessed 9 July 2009)
\textsuperscript{110} National Council for Prescription Drug Programs: http://www.ncpdp.org/ (Accessed 9 July 2009)
changes in drug therapy to the physician based on information from the PHR. For instance, if two different doctors are prescribing conflicting medications, and the patient is having these prescriptions filled at different pharmacies, neither pharmacist would know that the other prescription exists, and therefore the interaction would go unnoticed. However, if the patient utilized a fully integrated PHR, both pharmacists would have access to a complete medication history and would be able to see the issue and take action.

Alternately, the patient can enter information into the PHR, such as blood pressure or blood glucose levels, which can help the physician and pharmacist in assessing whether the patient’s current drug therapy is appropriate. For instance, a patient on a blood pressure medication may be logging higher than normal blood pressure readings. If the pharmacist sees this, they could intervene and have a discussion with the patient. Perhaps the current therapy is no longer sufficient, or there are other external factors that have led to the increase in blood pressure. Either way, having patient-entered data can help improve care. This sort of data could also be obtained from a physician’s EMR system. By having the patient’s lab values as well as the related diagnosis, the pharmacist could better evaluate the drug therapy prescribed, and suggest changes if needed.

It is very important that pharmacies, doctors, and other health care providers serve as both data and clinical care providers. Only then will both the patient and the provider see the full benefits of a PHR. This continuity of care is perhaps the largest advantage of a PHR. However, let us not assume that that continuity of care will be understood by patients as a whole. Although a recent study showed that 65% of the public is interested in accessing their own personal health records that does not mean that they will just because a PHR is available. Most patients are disengaged when it comes to PHRs. They’d like one, but they are not well-informed on how to obtain one or what the benefits are. There must be a driver to get the patient to sign up and use a PHR. This is where the pharmacy as a PHR owner comes in.

Imagine if your pharmacy told you that in order to fill your prescription, you had to fill out an online form and register with the pharmacy. It sounds absurd, but the reality is, this is what is done on a daily basis in doctor’s offices. A clipboard is handed to the patient to fill out certain information for the office to start a chart. A similar process is also done today in pharmacies. The only difference is that instead of a clipboard, a pharmacy technician sits at a computer terminal and types in all of the patient’s information as the patient provides it. At this point in the registration process, using the information the pharmacy now has, a PHR could be created. By obtaining an email address from the patient, the online authentication process can begin and the patient can be signed up for their own PHR through the pharmacy. Alternately, if there is an integrated system, this process could be done at the doctor’s office as well. If the patient already has a PHR, the doctor could access the information directly. Either way, the “avoidance of the clipboard” may be a big enough benefit to engage patients.

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112 Survey finds Americans want electronic personal health information to improve own health care. [Press Release]
New York, NY: Markel Foundation; November 2006. Available at:
The biggest concern of consumers regarding PHRs is that their information may be used for purposes other than their own care. 80% of patients said they were very concerned about identity theft or fraud.\textsuperscript{113}

Authentication of the patient can be done in the pharmacy or in the doctor’s office. Since the patient is often present in the pharmacy, the authentication process can be done in person. Authentication can be as simple as putting an email address and mailing address in the patient’s account, and then mailing a letter to the patient at their home address with a PIN that can be used to unlock the PHR online. Alternate forms of authentication could include looking at the patient’s ID or having the patient call a phone number to verify information. Patient authentication could also be done in the doctor’s office, regardless of who owns or maintains the PHR. Whether the pharmacy or the doctor authenticates the patient, an interoperable PHR is essential in order to make the process work for all health care providers. Patients will not want to have separate PHRs for each provider.

Chain pharmacies have always been ahead of the curve when it comes to technology. Personal Health Records are the next step in the progression of that technology. For a PHR to have the most benefit to the patient and to pharmacy, it should do the following:

- Be web-based
- Have the ability to download onto a thumb drive or be printed
- Be accessible by any health-care provider (with patient consent) including pharmacists
- Have the ability for the patient to add information, such as Over-the-Counter (OTC) medications, allergies, health conditions, etc., but have that information clearly identified as patient-entered data.
- Include a patient health risk assessment that ties results into the PHR
- Have a clinical care engine that triggers action alerts to the patient (e.g. immunization is past due, etc.)
- Connect to all pharmacies and EMR systems as part of the SureScripts Network
- Display: Medication History
  - Benefits
  - Lab Results
  - Current paid claims
  - Diagnosis(es)
- Give the patient the ability to
  - Refill prescriptions
  - Email their Pharmacist or Physician a question
  - Schedule an appointment with their physician
  - Schedule an appointment for MTM services with their Pharmacist
  - View paid claims

Personal Health Records have the ability to change the way patients, pharmacists, and physicians see overall health care. By giving the patient visibility to his or her information, we create a sense

\textsuperscript{113} Ibid.
of ownership of that information, which will hopefully lead to patient empowerment. Long gone are the days of not putting drug names on a prescription bottle for fear of the patient knowing what disease they have. Today’s world demands that the patient take an active role in his or her disease state management and overall health. A PHR gives the patient the tools to do so.

Pharmacists can benefit from PHRs by having access to information that was previously only considered necessary for the physician. By having access to clinical patient data, they can make informed clinical decisions and collaborate with the physician to provide the best care possible for the patient.

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NURSING VIEWPOINT ON PERSONAL HEALTH RECORDS

In 1845, Florence Nightingale entered the field of nursing and established a high standard of compassion and commitment to quality patient care. Nursing has since evolved into an increasingly more complex field with greater reliance on other care team members. However, the compassion and commitment to patients’ health and well-being, coupled with the flexibility to evolve and adapt to a changing health care landscape, has remained central to nursing’s mission.

The number of consumers who have access to computers and the Internet has dramatically increased in recent years. There now exists immediate availability to a wealth of health information, and health care providers should take advantage of this opportunity to improve the quality of care. There is an unprecedented ability to shift emphasis from that of a reactive to proactive approach focusing on health promotion, disease prevention, and illness management as opposed to acute illness or chronic disease management.

To assure continuity of information through all stages of care: prevention, diagnosis, treatment, and rehabilitation, across time and all care settings (ambulatory, acute care, home care, and long-term care); health care systems should share information between patients and caregivers. These new technologies and applications offer healthcare providers and patient caregivers the opportunity to communicate and share valuable and timely health information on a “real-time” basis. Healthcare providers and patient caregivers will benefit from these new information-sharing tools and applications.

Nursing is essential to successful collaborative healthcare; as patient advocates and as the critically important primary care coordinator nurses. Access to relevant and timely health information provides nurses with the opportunity to improve clinical outcomes through early detection and prevention of costly and possibly avoidable chronic illnesses. Given the vital nature of the nurse’s role, having the tools necessary for increased collaboration between nursing and other care providers benefits the patient at the center of the team.

Nursing is one part of an interdisciplinary team responsible for the total care of patients. Ideally, the patient should be at the center of that team, taking an active part in the coordination of his or her own care and health decisions. The intricate challenge of managing patient care amid the multitude of disciplines, specialties, and sub-specialties is often left to the skills of the nurse. Information stored on paper and in disparate locations makes it difficult for the nurse to garner a consistent and longitudinal picture of the patient’s health status and accurately identify and address existing health risks.

Nursing itself is a multi-disciplined field. Many nursing specialties will benefit from PHR use in the future. Some specific nursing specialties that will benefit include, but are not limited to, home health nurses, long-term care nurses, case managers, and school nurses. These nurses are already caring for some patients who are engaged with various tools and applications to improve or maintain their health. For those who have not yet cared for patients who are currently utilizing PHRs, it will not be long until they encounter them or begin to receive questions from their patients about the use of PHRs.
PERSONAL HEALTH RECORDS AND THE NURSE AS ‘HEALTH COACH’

The advent of information sharing has ushered in a new type of electronic health records referred to as electronic personal health records, or PHRs. Sometimes referred to as Personal Health Applications (PHAs), these may include health tools and other resources for collaborating with the care provider team in addition to the records.

As mentioned in an earlier chapter, PHRs are one of several tools used within a health care information exchange. PHRs may also be used in conjunction with the electronic medical record (EMR) in the hospital setting or the electronic health record in the primary care physician office setting and are used directly by the consumer/patient to store, manage, and exchange information with his or her care provider team.

According to the Markle Foundation, “PHRs encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Although there are many variants, PHRs are based on the fundamental concept of facilitating an individual’s access and creation of personal health information in a usable computer application that the individual (or a designee) controls.”\(^\text{114}\) The word “facilitating” is key here, in that some patients and consumers will need assistance and motivation both to create a PHR and also to realize the benefits of continuous use. Given this, the field of nursing is evolving to include a “health coach” role, which some nurses, not all, will be a very good fit for.

Nearing the completion of my master’s degree in Medical Informatics, and being an R.N. myself, I decided to explore a new area of informatics which combines health and wellness tools as well as nurses as “health coaches.” I have been working for HealthString since February 2008 and am seeing the nursing role expand in some very positive and interesting ways. In addition to offering a Personal Health Application, HealthString also offers its members RN health coaching. We employ experienced RNs who work with our members one-on-one over the phone, in person, and via email to educate them about positive lifestyle changes. The nurses encourage and motivate our members to learn about their health and what they can do to take more ownership of their decisions and behaviors that ultimately affect their health.

The HealthString nurses are all trained in the Transtheoretical Model of Behavior Change (TTM) from Pro-Change Behavior Systems\(^\text{115}\). They work with our members and create individually tailored behavior change programs based on the member’s “readiness to change,” which is determined through the Pro-Change surveys within HealthString. These programs have achieved unprecedented results with entire at-risk populations—from those not thinking about changing, to those actively maintaining a new behavior. By helping individuals and populations adopt health behaviors like maintaining a healthy weight, exercising regularly, eating a healthy diet, managing depression, not smoking, and adhering to prescribed medications, they help our members to improve quality of life, reduce health care costs, and increase productivity at work.

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These RN health coaches have various backgrounds such as occupational health and hospice care. They all possess a common passion for education, wellness, disease prevention, coaching, and teaching members about technologies such as PHRs to improve their health and prevent disease. Some of the HealthString RN health coaches offer additional training and experience in such things as yoga, nutrition, and energy healing (e.g., Reiki). As we roll out our HealthString for Kids and Teens modules in the near future, we will be looking for RNs with backgrounds in pediatrics and working with children and teens to coach this specific population. Not every nurse is a perfect fit for this new role, but for those who are interested in working with a broad spectrum of patients (from the very healthy to those with multiple chronic diseases) and have the skills necessary to foster positive behavior change, this may be perfect.

The role of the nurse coach is varied, and some examples of what the nurse coach role would encompass are listed below:

- Initial program start-up, on-site (at an employer site), on-line, by phone
- On-site biometric testing (HR, BP, Height/Weight/BMI, Lipids, Glucose readings)
- Direct phone calls to promote survey completion
- Email reminders to support Health Risk Assessment and Quality Metric Survey completion
- One-to-one personal RN accessibility when it’s convenient for the members
- LifeStyle Plan reviews that encourage participation and behavior change
- RN coach calls dictated by risk level and member preference
- Assistance in helping employees get the most out of their health benefits; for example, if disease management is offered by their existing health plan, our nurses can discuss next steps for gaining DM and set expectations for optimal care
- “Prescribing” videos, workbooks, educational tools to learn more about conditions and health risks

It is likely that we will begin to see in the near future “RN Health Coaching” certification programs (either in-person or via the Internet), which will add some consistency in training and continuing education for RNs entering this new and exciting role. We may also begin to see more education and awareness around PHRs and other technologies to facilitate improved health and wellness in nursing schools around the country.

PATIENT-CENTERED COLLABORATIVE CARE

The patient and the nurse collaborate with other healthcare providers on the patient’s behalf. The physician no longer bears sole responsibility for maintenance of the patient’s health information and ultimately healthier outcomes. Given the nature of health care today, physicians have less time to effectively coordinate and address many of the patient’s care and educational needs. It is at this primary point of need that nurses can have a positive affect by using PHRs.

Education about a PHR has several facets; patients should be encouraged to be more proactive and increasingly accountable and responsible for their own health care. Patients should be encouraged to co-ordinate their care and share their history with multiple providers and should be instructed on how to use the software to their best advantage. The PHR should not be viewed
as another regulatory hurdle that further depletes already stressed nursing staff resources. The process of teaching patients how to maintain their own health records is an opportunity for nurses to capitalize on educational time spent with patients. It presents an opportunity to initiate conversation about health promotion and disease prevention.

It can be valuable to include family members in this educational process so that they can act as a support system to the patient in case the patient is unable to maintain his or her PHR for any reason. In order to do this, responsible family members must be identified early on in the course of treatment to ensure a smooth transition to self-directed health record-keeping. The nurse shares this responsibility with the rest of the care team.\textsuperscript{116}

**PATIENT’S HEALTH LITERACY**

PHR development requires consideration of patients’ health literacy. Involvement of family or other significant individuals may be warranted in cases where literacy concerns indicate that the patient may be incapable of maintaining the personal health record. The nurse’s early assessment and prompt initiation of education to address literacy concerns is essential in leveraging the benefits of a PHR.\textsuperscript{117}

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions about their health. Studies show that it is a strong predictor of health status. Inadequate health literacy can lead to numerous negative effects on an individual’s health and well-being, including poor self-care, increased utilization of health services, worse outcomes, and less likelihood of receiving preventive care and services.\textsuperscript{118} Nurses can and will play a significant role in improving the overall health literacy of consumers.

**A ‘TRANS-DISCIPLINARY’ APPROACH TO IMPROVING CARE**

The Physical Medicine and Rehabilitation Unit at the Hospital of the University of Pennsylvania in Philadelphia is one example of a team that has adopted a “trans-disciplinary” approach to the development and deployment of the patient PHR. The “Patient Care Committee,” composed of clinicians from nursing, physical therapy, occupational therapy, recreational therapy, speech, neuropsychology, medicine, and case management were all involved in the design and roll-out of this important project. The committee chose to begin with a simple preprinted envelope containing demographic information, medication, general health, and functional ability forms. Patients began by keeping their own records while on the rehabilitation unit and learned how to maintain their PHRs.

\textsuperscript{116} Kupchunas WR. Personal health record: new opportunity for patient education. Orthopedic Nursing. 2007 May/June; 26(3):186.
\textsuperscript{117} Ibid.
The Physical Medicine and Rehabilitation Unit is responsible for a portion of the PHR education, and the process is incorporated into the daily therapy schedule. Nursing provides the medication portion of the education and also reinforces the overall concept of medication record updates. Occupational and speech therapists provide much of the teaching regarding how to complete the information on the forms, adapting to the patient's functional abilities and health literacy. Physical therapy provides the functional status information. Physicians work with each patient to assist with the completion of the health problem section. Case managers assist the patient to record valuable information about insurance and develop lists of physicians and appointments. The patient benefits by possessing a comprehensive record of his or her current medical status, current medications, functional status, and future appointments.

It is critical for nurses to engage and assist in the development of PHRs in the community. Success may be maximized if the initial focus of PHR development is with specific regional community health concerns such as asthma, depression, or obesity. A group of pioneers studying PHRs from a nursing perspective at the University of Iowa College of Nursing are designing and developing the Iowa Personal Health Record (IowaPHR). They discovered that, although there are many PHRs on the market today, none of them included elements specific to nursing. Their goal is to develop a PHR that takes into account the unique elements of information specific to nursing, including nursing assessments, diagnosis, and plans of nursing care.

According to the Iowa group, PHRs have the potential to facilitate such interaction:
- By collecting, monitoring, and organizing daily health data.
- By gathering education and increasing health knowledge.
- By sharing and querying health information or their own personal data among individuals or between individual and healthcare providers.

The group suggested that Standardized Nursing Languages (SNLs) be built into the PHR so that nursing can be represented and visible in health records. SNLs are standardized vocabularies used to describe what nursing does. They are tools for systematically studying nursing interventions and determining which ones really work. They also provide the foundation for documentation in a computerized medical record.

For example, nurses have historically been responsible for taking and recording a patient’s health history upon admission to the hospital. In the new data-sharing and PHR model, a patient may fill out a questionnaire that uses nursing language, prior to admission, to capture historical information. A hospital that allows patient-entered summary data to be included as part of the legal medical record could potentially improve healthcare outcomes by allowing the nurse more time to focus on present health concerns, as opposed to simply entering historical data. The PHR

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119 Kupchunas, ibid.
could also provide educational materials focused on what individuals need to know about their condition(s) prior to admission and/or after discharge.\(^{122}\)

The key steps for developing the IowaPHR from a nursing perspective follow:

1. Identified main community health concerns and integrated them as key navigators
2. Installed common features of the PHR based on the literature including:
   a. Patient demographics
   b. Security and privacy policy
   c. Access
   d. Medical conditions
   e. Medications
   f. Laboratory tests
   g. Diagnostic tests
   h. Immunization
3. Developed and applied specific nursing fields with self-assessment questionnaires and feedback based on a SNL.

Experts’ evaluation of the usability of the IowaPHR for nursing specifically:
   a. Ease of navigation
   b. Ability to find desired information
   c. Site presentation
   d. Usefulness of information saved for healthcare providers in the future
   e. Time to complete tasks

LEVERAGING DATA FOR RISK/DISEASE IDENTIFICATION AND PREVENTION

The primary focus of many PHRs is information storage. Designing them to concisely record important health events or health-related behaviors plus the ability to calculate health risks beyond clinical healthcare events expands the PHR into an invaluable tool for addressing patients’ problems and planning interventions.

There are several PHR products available today for assessing health risk. By including additional tools and analytics, calculation of future risks of disease and other complications can be made at the individual patient level. Leveraging specific PHRs that combine health risk assessments (HRAs) with predictive modeling capabilities and supportive nurse coaching can be a powerful combination in the early identification and prevention of disease.

Use of a PHR to capture the patient’s history with predictive tools for assessing disease risk is valuable education processes for nurses. For example, metabolic syndrome is increasingly diagnosed as clinicians gain more knowledge about its etiology and treatment. Metabolic syndrome with interrelated risk factors of metabolic origin appear to directly promote the development of atherosclerotic cardiovascular disease (ASCVD). Patients with metabolic syndrome are also at increased risk for developing type 2 diabetes. Risk factors are a

\(^{122}\) Lee, 25.
combination of several disorders, including central obesity, elevated triglycerides and blood pressure readings, decreased HDL levels, and insulin resistance. Once a patient develops these disorders, there is a synergistic effect leading to an increased risk of heart disease and diabetes\textsuperscript{123}.

Early identification of disease risk factors is ideal in the prevention of any syndrome with its subsequent debilitating and expensive cardiac and diabetic risks. Sometimes, early diagnosis is hampered by patients’ tendency to visit multiple care providers or forego medical care entirely. PHRs, supported by nurse coach interventions, present the possibility of disrupting this inevitable downhill cycle at its onset.

For example, a 38-yr.-old patient named Mike has not been seen by a physician in over 10 years. He recently had blood tests completed at work as part of a health screening. He leverages the PHR with its health profile (history, meds, lab values, etc.) available to him through his employer and enters the recent blood test results. He also completes his HRA and schedules an appointment with his nurse coach to review the results of the HRA and develop a lifestyle plan.

During the health history phase of the discussion, the nurse discovers Mike has a higher than normal body mass index (BMI) of 31, he has a triglyceride level of 180 mg/dl, his HDL level is only 30 mg/dl, and his BP is 160/90 mmHg. The nurse also discovers that Mike has a family history of coronary artery disease and does not have a basic understanding of good nutrition to prevent CAD and diabetes. The nurse talks with Mike about his laboratory results explaining the normal ranges are using the opportunity to educate about the meaning of blood test values. The nurse recommends that Mike see his primary care physician to have a full physical and to ask his physician for a fasting glucose test.

Mike schedules his appointment and discovers from the exam and blood work that his fasting glucose level is within normal range (90 mg/dl) and that, despite having an elevated BMI, his central waist circumference is within the normal range. Fortunately, Mike is not diagnosed with metabolic syndrome but is told that he is at risk and could develop it if he does not make some lifestyle changes.

A follow-up call is made to the nurse coach and Mike works with the nurse to develop a plan to improve his BP, TG, and HDL levels and to keep his weight and blood sugar within normal limits through basic lifestyle changes. The nurse suggests several educational videos on preventing heart disease, diabetes, and nutrition that Mike can link to directly from the PHR and that he can watch at his convenience. In addition, the nurse makes an appointment for Mike to visit the dietician. While waiting for the appointment, the nurse refers Mike to reliable medical websites, sending him several educational handouts on diet, plus recommending a 3x/week exercise program. He is also referred to available behavioral modification programs designed to assess his readiness for change and assist in appropriately supporting his efforts. The nurse is available to provide additional support and motivation as necessary.

Ultimately, Mike follows the recommendations of his physician and of the nurse coach. He continues to work with the coach and is very determined to improve his health and prevent the onset of metabolic syndrome and diabetes. Since Mike is able to easily monitor his results and improvements in his PHR, he feels more educated and motivated to continue with his efforts than if he had just gone for a physical exam only and did not have the tools and resources to keep him informed of his progress on a long-term basis.

PROJECT HEALTHDESIGN

Funded by the Robert Wood Johnson Foundation (RWJF), with additional support from the California HealthCare Foundation, *Project HealthDesign* is a $4.4 million national program designed to support health and information technology pioneers to create a new generation of personal health record (PHR) systems. Administered by a national program office at the University of Wisconsin-Madison and lead by Patti Brennan, R.N., Ph.D., *Project HealthDesign’s* goal is to design and test a suite of PHR tools and applications that work together to help people achieve their various and specific health goals in an integrated fashion.

From among the applicants, nine interdisciplinary teams were selected to participate in the 18-month project. The teams feature innovations bringing a wide variety of backgrounds and expertise to this challenge, including nursing and medical informatics, medicine and community health, computer science, media design, human systems engineering, and psychology.

The various projects take into account nursing’s unique responsibilities and incorporate the nursing role in the design of the PHRs and PHAs. One PHR is designed for patients with diabetes and allows them to record blood glucose levels, HR & BP, food intake, and exercise levels. They can quickly upload these readings wirelessly over a cell phone to their health care provider. Providers review the information and sync it with the patient’s electronic medical record. In testing the concept of a health record shared between patients and healthcare providers, the team will develop and test the web-based application with extensions onto a cell phone, such as Apple’s iPhone. The nurse will play a role in providing feedback and counsel to the patients as needed.

Other PHRs, with the assistance of nursing intervention, will provide benefit to those with other chronic conditions such as asthma and chronic pain.

CONCLUSION

Nurses have a tremendous opportunity to assist and educate patients in establishing and leveraging personal health records and applications for more efficient care and improved clinical outcomes. Assisting patients in efforts to be more proactive in their own healthcare and personal health data record-keeping is a first step in establishing effective partnerships between patient...

and nurse. The hope is that nursing and nursing informatics will be actively involved in these regional and national health information exchange efforts, with PHRs as a key enabler to this new and improved model of health care.

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A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings


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PERSONAL HEALTH RECORDS FOR CONSUMERS OF HEALTHCARE

Personal health records (PHRs) consist of medical records that the consumer collects from each of their health care providers, plus any health information that the consumer adds. Sharing information from the PHR with providers enables the consumer and provider to work together. Use of data in the PHR can help reduce or eliminate duplicate procedures or processes. This helps save time and health care dollars. It can help the consumer receive better, more coordinated health care. In addition, PHRs will eventually have the impact of empowering consumers as never before to make informed health care choices and have a positive impact on the overall cost of health care.

1) CONSUMER EXPECTATIONS - A PHR PATIENT USER PERSPECTIVE

Like many baby boomers, Bob has had an increasing number or health issues over the last few years, including some chronic conditions. He is a frequent patient at his primary care physician or specialists, with a current treatment regimen including six ongoing prescription medications plus periodic testing, combined with treatment by specialists in five different medical specialty areas over the last two years. Recalling details correctly can be a challenge for him, and repeatedly giving the same basic information to hospitals and doctors in written and verbal form is source of frustration. This frustration is exacerbated by his knowing there is an easier and more accurate way to share this information.

The mix of providers he has used in the last 3 years includes the following:
- Two primary care physicians. After moving several years ago he switched from his long time personal physician to a new physician located near his new home.
- Two heart specialists. Upon his primary care physician’s discovery of an irregular heartbeat, he began seeing a Cardiologist, who in turn referred to a specialist in cardiac electrophysiology
- Gastroenterologist – for routine colonoscopy
- Orthopedic surgeon for knee problems
- Chiropractor for chronic back and neck pain
- Sleep specialist

Treatment by these doctors involved having tests and procedures done at four different hospitals.

Chronic conditions include the following:
- High cholesterol
- Allergic rhinitis
- Enlarged prostrate
- Sleep apnea
- Back and neck pain
In addition to six ongoing prescriptions for these conditions, he uses some over the counter drugs/treatments.

Having worked in the health care information technology (IT) arena for 30 years, it is probably not surprising that Bob was an early adopter of PHR. He has been using one for over four years. His relocation about three years was a motivation for him to use the PHR better since it necessitated changing his primary care physician and he wanted to have his health information well organized for his new doctor. His PHR experience has yielded mixed impressions. On the one hand, it has been personally positive and helpful. On the other hand – it is still far from fulfilling its potential.

Here is what he wants from a PHR:
• A helpful and easy way to organize his medical history.
• An easier and more accurate way to share it with physicians – both to avoid responding to the same questions/requests for information, and to share it accurately with health care providers. At the top of that list is prescription information – recalling precise name, spelling and dosage of drugs can be a challenge, as can simple information such as names and contact information.
• Do the same for other family members.

To date, his PHR has proven helpful in the following areas:
• Organizing key portions of his personal medical record – specifically medications, immunizations, provider contact information, and listing of conditions, diagnosis and major procedures.
• It is easier to share the information than relying solely upon his memory and writing or verbally responding to routine questions every visit. The current means of sharing information is to print it out and hand it to the provider during physician visits.
• He can carry a printed or electronic copy (such as a CD or a flash drive) of the record with him when he travels – especially for out of country travel where there may be a big language barrier and immunization records can be vitally important.

Bob clearly states he does not want to minimize the value and importance of these benefits – they are certainly worth the cost (none in his case, but there can be costs for other PHRs) and effort (manual entry via web site) – and he will continue using it. However, he feels it could do much more. Frustrations in using the PHR include the following:
• Information can only be manually entered - by him. There is no mechanism to scan data, import from other systems, or permit providers to enter data. Data sets are limited – for example he cannot enter test results, physician notes/recommendations, radiology transcriptions etc.
• It is not always easy or intuitive to enter data – and can be time consuming. There are no edits to validate accuracy of entered information, though, unlike when he is at a physician office, he has the luxury of having his prescriptions and other records in front of him, making the source of his information much more accurate than memory alone.
• Despite the PHR vendor claiming to have one of the largest physician user bases in the country, none of his personal physicians uses this PHR. To his knowledge none of them use any PHR. Hence, they are not interested in electronically accessing his records. All data is exchanged with them by printing out records from the PHR.
• There are certainly other products out there claim they can do these things, but there has been no compelling evidence to suggest they do it well enough to warrant the time, effort and possible cost of switching.
• Other family members do not share his enthusiasm for PHR, and are not currently taking advantage of it.

2) PATIENT CONTROL OF PHR INFORMATION

Who owns health information? While health care providers typically maintain health records, consumers must have the ability to control their own PHR. Consumers need to be aware of their rights regarding health information in general, regardless of whether they have a PHR. According to Lydia Washington, MS. RHIA, CPHIMSE in her 2007 article entitled Protecting the Privacy of Your Personal Health Record, Ms. Washington suggested the following\textsuperscript{125}:

• **Understand your rights as a health care consumer.** This includes the right to review and obtain copies of your medical information, the right to request amendments and corrections of information that may be erroneous, the right to know who has received copies and reviewed information and the right to complain about medical privacy practices or breach of privacy.

2. **Exercise information rights.** Consumers should obtain and maintain copies of their medical records and information so that personal care can be monitored and spot any errors in the information. Individuals are strongly encouraged to establish PHRs and monitoring the accuracy of the health information.

Once consumers decide to utilize a PHR, they should have the ultimate authority in deciding which sections of their PHR can be accessed, by whom, and for how long. This includes granting or retracting permission to view specific content by provider. The PHR must contain sufficient security features to authenticate users, their permitted level of access and their authorized purposes. For example, consumers must be assured that the data contained in the PHR will not be used for undisclosed purposes such as drug marketing or research, though they may elect to specifically permit such uses. Consumer health information should never be made available to an employer in the case of an employer-sponsored PHR.

Another important concern of consumers is the portability of their personal health data from insurer to insurer if they change plans. This is especially important if their PHR is sponsored by a health plan. There should be no restrictions (procedural or technical) imposed by the health

plan, or PHR vendor, on easily moving one's own data from one PHR to another. Indeed, the industry should strive to develop standards and tools to make portability fast, efficient and easy. As PHRs develop to empower consumers to make informed choices, consumers need to ensure that organizations protect their health information and ensure its privacy. Privacy and security are covered in more detail in the Privacy and Security Chapter of this white paper.

3) PHR SPONSORS
In the November 2007 Continua newsletter, Dr John Halamka describes four types of PHRs currently available.126

In the provider hosted patient portal to the clinician’s Electronic Health Record (EHR), consumers have secured access to health information from the hospital and/or clinician’s office. The payer hosted patient portal to the payer claims database allows for access to claims data such as discharge diagnoses and reimbursed medications. Lab data may or may not be available through this model. Employer sponsored PHRs typically utilize a third party vendor to provide consumer access to both claims and benefits information. Vendor hosted PHRs allow for consumers to store, retrieve and manipulate their own data.

Consumers also have a fifth PHR option. Vendor software is available for the consumer to maintain and control their own PHR on their own computer. This type of PHR is not remotely hosted or supported by any vendor, employer or provider.

An example of an employer sponsored PHR recently in the news includes the Dossia project sponsored by companies including Wal-Mart, AT&T, Sanofi-Aventis and Intel.127

There are close to 100 vendor hosted products on the market today including products such as MEDEM and Microsoft’s Health Vault.

The concern with any of these models except for the vendor hosted PHR, is portability. The consumer can lose access to a payer, employer or provider hosted PHR if they voluntarily or involuntarily change jobs, insurance companies, or providers for any of a number of reasons.

4) PATIENT PORTALS IN ILLINOIS
Patient portals are similar in concept to PHRs in that they offer an electronic means of sharing information between patient and provider. However, they do not necessarily include the key attribute of a PHR; e.g., the ability for a patient to maintain and store their own clinical information, and often have capabilities that individual PHR products do not. As of an Internet search in the winter of 2007, Illinois has several examples of provider- and payer-sponsored portals in existence. The portals vary in their offerings to consumers and may include some components of a true PHR.

127 Dossia; 2008. www.dossia.org
Decatur Memorial Hospital, Decatur, IL. The online portal (https://mydoctor.dmhhs.org/) allows patients to do the following:
- View and Update Their Medical Record
- Request Appointments
- Request Prescription Refills
- Email Their Physician Office

Christie Clinic, Champaign, IL, by InteGreat allows the following: (https://www.icmyhealthrecord.com/christieclinic/)
- View health Summary
- Request an Appointment

Methodist Medical Center, Peoria, IL by Geonetric (http://www.mymethodist.net/). The online portal “creates” a PHR for the consumer and allows patients to do the following:
- Request an Appointment
- Message their physician office
- Prescription refills
- Request/View Lab results
- Create a “web” visit for non-urgent medical questions that the physician replies to after the consumer completes a specific questionnaire
- Creates a PHR that includes patient medications, problem list, allergies

Rush University Medical Center, Chicago, IL, by Intervent, Heart Health Portal (https://www.interventathome.com/rush/) is available in Cook, DeKalb, DuPage, Grundy, Kane, Kankakee, Kendall, Lake, McHenry and Will County; specific to heart health.

BlueCross BlueShield of Illinois (http://www.bcbsil.com/) PHR is available to insurance subscribers.

IVF 1 (http://www.ivf1.com/), a fertility medicine clinic in Chicago and Naperville, provides both a patient and physician portal that allows patients to do the following:
- Enter or update their personal demographic information
- Review laboratory results
- Review treatment flow sheets and past treatments
- Review prescriptions
- Send messages to office staff
- Allow primary care and referring physicians access to medical data

Evanston Northwestern Healthcare, the online portal https://www.northshoreconnect.org/ allows patients to do the following:
- Schedule Appointments
- View Test Results
Renew Prescriptions
Secure Message Their Physicians
Pay Their Medical Bills
Manage Their Children’s Health
Review Their Medical Record

Northwestern Memorial Hospital is discussed in the Academic providers chapter.

5) PHR CONTENT

Ideally, a PHR will serve the health care needs of both the patient and provider community. Most providers of health care collect certain elements of a patient’s history almost universally at the time of an initial encounter and at subsequent visits to the same provider. Consumers of health care are repeatedly asked to respond to the same questions. As a result, errors of omission in recollection can result. A PHR can readily serve as a source of information assisting patients in collecting and presenting health information easily.

Components commonly requested by providers during patient encounters that are also important to the consumer, and should be included in a PHR include:

- Health History, including surgical, family, psychiatric, social history. Part of most new patient visits to primary care providers and specialists include delineating a basic medical, surgical and psychiatric history. A history is important even if a medical condition is no longer current. By recording a list of active and past medical, surgical and psychiatric problems within a PHR, the patient does not need to continually recall this information with every new provider. The patient can make additions and modifications to the PHR.
- Allergies – every provider of health care requires this element. Once recorded within a PHR, it helps to prevent omissions due to recall.
- Medication list (current and past/inactive) – Who best to record what medications they are taking than the patient? The PHR serves as a central record for prescribed and over the counter medications. JCAHO has mandated medication reconciliation across all patient care encounters. Consumers could facilitate this process by furnishing this information from their PHR to providers of health care. The PHR in turn could assist patients by making drug information and interaction checking available.
- Immunizations and preventive care – A listing of completed and pending routine vaccinations and preventive care screenings.
- Insurance information – Consumers know when this information changes and can readily track modifications within a PHR.
- An emergency contact section

What is the difference between an EHR and a PHR? A basic PHR could be merely an extract of EHR data or a summary from multiple provider EHRs and other sources of data. To personalize its use beyond that of an EHR, it needs to include components that would benefit the consumer in managing their own personal care plan. The following components that would benefit the consumer, and are typically not part of a single EHR:
A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings

- Health maintenance and preventive care reminders geared toward the patient – To encourage consumer participation in health care management the PHR needs to be “smart” enough to recommend goals and provide tools unique to that patient. For example, a PHR could be used to track peak flow readings for asthmatics, and make recommendations based on values entered.
- The ability to track information for family members in addition to themselves.
- Tools for journaling activities such as recording an exercise log or food diary.
- A schedule of past and future appointments – what better place for a consumer to keep track of their own appointment history across the health care system than in a PHR.
- A listing of current and past providers – the consumer is the best source for knowing the names of health care providers. The PHR can serve as a central source for recording the contact information of providers and facilities visited.
- Dental and eye records
- Store medical data from multiple providers in a single place, making it easier for the consumer to access and easier to share with other providers when the consumer wishes to
- Living wills and advance directives – the actual content of a living will or advance directive is appropriate to store within a PHR.

6) DISEASE MANAGEMENT TOOLS

Without the incorporation of disease management tools, the PHR serves only as a static repository of consumer data. To be truly beneficial to the patient it must also be interactive, allowing for self-management of diseases.

In order to effectively manage diabetes, patients need to record and track home blood glucose readings and understand their medication regimen. While some glucometers can download readings to computers or specialized software applications, uniform standards for transmission of data from a medical device to the PHR do not exist. Hence, consumers must either hand enter values from their glucose monitors, or copy/manipulate data files in order to get the data into their PHR. Ideally standards would allow for data transmission between home monitoring devices, the PHR and the EHR. Once blood glucose readings were available in the PHR they could be displayed in a graphical format along with instructions for self-adjustment of medication dosages, allowing for improved self-management in care for the consumer. Improved diabetes management would result in fewer emergency room and office visits, and would ultimately reduce diabetes complications and overall health care costs.

Another example where a PHR could serve in consumer disease self-management is for the asthmatic population. A consumer could record home peak flow readings within the PHR and adjust medication use accordingly. Specific trigger events, such as exercise, could be plotted along with its associated peak flow reading. A parent could readily use a PHR for management of their asthmatic child. Patterns of medication use and peak flows recorded within a PHR would provide invaluable information to the provider treating the consumer in changing medication therapy.
7) EASY EXCHANGE OF INFORMATION BETWEEN PATIENT AND PROVIDERS

Ultimately it is the patient’s responsibility to maintain the PHR.\textsuperscript{128} No one health care provider or payer can capture all of the elements within a PHR. Dr. Daniel Sands describes his experience with patients using a tethered PHR in \textit{Perspectives on the Future of Personal Health Records}.\textsuperscript{129} Consumers are able to communicate with office staff via a secure email and can request appointments and prescription refills. Educational tools are available through the PHR and consumers can readily track their own health information. Per Dr. Sands description, “Patients who research health information, view their medical records, and track their own health and wellness make for much better care partners, take better care of themselves, and often have better outcomes.”\textsuperscript{130} The PHR aids in open communication when both the consumer and physician embrace it.

8) BARRIERS TO CONSUMER ACCEPTANCE AND STRATEGIES TO OVERCOME THEM

Perhaps the biggest barrier to consumer acceptance of PHRs is their relatively recent arrival on the health care scene. Like any new tool or technology, awareness of its existence and value are among the first hurdles to overcome. A variety of national organizations are committed to helping promote the use of PHRs in a secure and effective manner for consumers and other stakeholders. The American Health Information Technology Community (AHIC), which provides input and recommendations to the U.S. Department of Health and Human Services (HHS) on consumer impact of PHRs, is one such organization. Another is The Markle Foundation’s “Connecting for Health,”\textsuperscript{131} a Public-Private Collaborative of over 100 organizations working to tackle the challenges of using information technology, specifically including PHRs, to improve health care.

There are numerous vendors involved in the design, implementation, and maintenance of personal health records. Fears about the privacy and security of health information are a persistent concern. This Markle foundation report found that “Almost all respondents (91 percent) are very concerned about their privacy and keeping their health information secure. However, most people believe that technology provides appropriate protections and would not be reluctant to use the PHR features that they value.”\textsuperscript{132}

The National Committee on Vital and Health Statistics reports noted “public support ...depends on the confidence that personal health information is protected.”\textsuperscript{133} It goes on to say that any

\textsuperscript{128} Chin T. EMR 2015: personal health records could give doctors better access to a patient's medical history. \textit{Am Med News}. 2005 (May 9); 48(18):23-24.
\textsuperscript{130} Ibid, pg 14.
system of personal health information retrieval, collection, storage, and dissemination requires the utmost trust of the public.

In a report from The Altarum Institute in January 2007 entitled *Report of the Personal Health Record Service Provider Market Privacy and Security*, regarding a review of existing PHR privacy and security policies, their research discovered a wide variation in the understanding of implementation of 30 publicly available privacy policies. Not every PHR vendor website had a publicly available privacy policy. Because of these findings, the report made several recommendations which include the following:

- Privacy, in the context of PHR, should have a commonly understood meaning to all vendors, health care providers, and consumers,
- Consumers and vendors should agree or establish a forum as to the important components of PHR privacy policy, especially the transparency in secondary data used.

Other practical concerns and barriers follow:

- Low adoption by consumers. A June 2008 news brief published by the Connecting for Health group and the Markle Foundation shows there is high consumer interest in PHRs, but very low adoption. It states that “Almost half of the public - 46.5 percent - say they would be interested in using an online PHR service.” It goes on to add that “Only 2.7 percent of adults have an electronic PHR today... Most (57.3 percent) do not keep any form of personal health records, and 40 percent keep some paper health records.” One Chicago physician who is considered a leader and early adopter of PHR described his use of a PHR much the same as Bob experienced. He related that “I’m listed but haven’t received any patients using it (the PHR). A couple keep their “own” PHR on their computers. No importing yet for my patients. When the couple patients I have with their own PHRs arrive, it assists with reconciling all their meds and ensures we’re always on the same page.”
- Low adoption by providers. As expressed by Bob in the above case study, he is frustrated that none of his doctors or hospitals are willing to accept information from his PHR in electronic form. What incentive does he have for continued use of it? Equally important, what incentives do physicians and other providers have to encourage, use and accept PHRs?
- Ease of use. Use of the system, including data collection, sharing with others, reporting, and disease management tools must be intuitive and quick.
- Interoperability. The American Health Information Association (AHIMA) lists over 80 PHR products on the PHR sections of their website ([http://www.myphr.com/resources/phr_search.asp](http://www.myphr.com/resources/phr_search.asp)). With so many products available, the only way to assure quick and accurate sharing of patient information is by standards for “interoperability” of systems embraced by vendors and users of the PHRs. Without standards...

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136 Ibid, pg 1.
137 Ibid.
138 Personal Communication.
it can be tricky, cumbersome, or infeasible to share data, which will certainly encumber growth and productive consumer use. National standards are currently in development

- Trust issues. Concerns about the motives and uses of providers, insurers, employers and vendors. Much of this ties back to privacy and security concerns. Development of national policies and standards is already underway to address this.

REFERENCES


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Dr. Mary N. Gerard, M.D. is a physician informaticist and Board-Certified internist who has implemented electronic health records and clinical decision support systems in integrated health delivery networks and physician offices. She participated in writing this white paper while working at the Illinois Foundation for Quality Health Care and is currently employed as Physician Terminology Manager at SNOMED Terminology Solutions.

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CHALLENGES SPECIFIC TO RURAL HEALTH CARE

For many rural health providers, the question of PHR adoption comes second in line to more basic healthcare IT adoption issues. Challenges for rural health providers adopting and maintaining healthcare IT are numerous and include the following:

- Financial constraints (typically cited as the top obstacle): Compared to their urban counterparts, many rural practitioners rely on Medicare and Medicaid payments, making them less attractive for commercial lenders. In addition, they are less likely to be part of a system or parent company that would share the costs.
- Lack of high-speed Internet access and service “dead spots”
- Lack of technical IT expertise, either through in-house staff or through the provider’s own education
- Lack of a compelling business case for IT investment: While the cost is incurred by the provider, the benefits are largely realized by the patients and payors.
- Geographic isolation and shortages of rural healthcare providers force rural providers to be self-reliant in all aspects of healthcare delivery. This lack of access to a peer group extends to experience with IT systems. The truth is that urban providers, given their resources, can more strategically plan and implement their IT requirements than their rural counterparts.
- Because of these factors, rural providers tend to fear that their limited resources only afford them one chance to adopt the right IT system that will last beyond technological advances, enable data security and be interoperable with other systems.¹³⁹

To reiterate, the main reasons that rural providers are slow to adopt higher levels of healthcare technology (which includes PHRs) are “very real” financing and human resource obstacles as well as a general ‘paralysis’ due to not knowing where to start and uncertainty about whether the time is right to make an investment.”¹⁴⁰

Challenges aside, the benefits of increased healthcare IT adoption to the individual provider and to the overall network of health care providers are potentially significant. According to the Institute of Medicine (IOM), rural providers are expected to be important partners in federal and state efforts to foster the exchange of patient health information as part of the National Health Information Network. In its 2004 report, “Quality through Collaboration: The Future of Rural Health,” the IOM assigned a pivotal role to health IT as part of a strategy to ensure quality of care in rural areas.¹⁴¹ Therefore, policy makers urge rural health care providers to investigate options or “risk being left behind as the nation moves toward an electronic health care delivery system.”¹⁴² Such policy views healthcare IT not just as a purchase, but as part of larger strategic...

¹⁴⁰ Ibid, 37.
¹⁴² Schoenman, 2.
planning that can help providers achieve organizational objectives. Health IT, including the Electronic Medical Records (EMR) and the longitudinal patient-centered electronic health record (EHR), including personal health records applications have the potential to improve quality of care in rural areas.

HEALTHCARE DELIVERY REDESIGN SURVEY OF LITERATURE

While healthcare is facing a fundamental transition driven by purchasers who can no longer afford the “system” in its current state, providers and their corporate goals are typically out-of-touch with that revolution.

The following citations discuss the disconnect between purchasers of healthcare and providers of healthcare.

Hewitt Associates announced in April that its “survey of approximately 450 major U.S. employers covering more than 8 million employees revealed ...(63%) plan to take more aggressive, multi-year steps to help employees improve their health by ...implementing condition management programs, and using data analysis and other cutting-edge programs to improve health and productivity, while holding participants accountable for their behaviors. Employers ... realize that in order to fundamentally improve outcomes-and effectively lower costs-they need to begin targeting the root of the issue by directly influencing the interactions between providers and patients.”

The April cover story of HealthLeaders magazine, “The State of the CEO,” discusses the depth of the transformation confronting health care leaders.

It suggests that hospital CEOs need to address the question: “Are we in the healthcare business, or the health business?” It quotes Mayo Clinic CEO Denis Cortese, M.D., as saying, “Mayo believes that the healthcare industry is so flawed that it must be an advocate for change. [Many players in today’s healthcare system] ...have made the huge mistake of not...focusing on what is best for patients, and they have actually commoditized patients. The fact is that hospital administrators...will have to come to grips with the fact that an admission to the hospital, except for things like acute appendicitis or trauma, will be a failure of the system.”

The article also quotes Intel President Craig Barrett, “who said this past fall that he doesn’t believe the healthcare industry is ‘capable of transforming itself. They really haven’t...looked at the total system...and that it is going to implode on itself.’”

143 Ibid, 10ff.
144 Committee, 17.
147 Ibid, 24.
148 Ibid, 28.
149 Ibid, 29.
Brian McDonald, in the June 19 HealthLeaders News, articulates this process: “Strategic thinking enables a healthcare organization to identify its customers and to learn what they value. Once this is defined and understood, the strategic-thinking organization strives to create and demonstrate value... to their customers—improving the lives of people with chronic medical conditions and offering high performance networks of providers.”

Given this disconnect, strategic planning in the health care sector that attempts to define objectives for information technology would almost assuredly be flawed. It would likely address needs of the current, failing system while failing to deliver ultimate value to customers – both patients and financers of health care.

Authors’ Opinions

- Healthcare Delivery Redesign
- Challenges Specific to Rural Providers

Providers (doctors, hospitals) and health systems (corporations) are paid to perform procedures, not to keep patients healthy. Prevention is bad for business, as I have been told by numerous hospital CEOs. I have found only a handful of health systems in the upper Midwest that are doing strategic planning around primary level prevention and chronic care management. For now, even these organizations, along with all the rest, are planning to do as many surgeries and diagnostic procedures and generate as many inpatient days as possible from their community populations. A change in the delivery model for the vast majority of health systems is not in their long range strategic thinking.

Rural residents, on average, are older and have a higher burden of chronic illnesses.

--Jim

Many of the hospitals in the rural areas have become critical access hospitals with limited funding capacity, so partnering between these hospitals and providers in the rural areas would be more difficult. These hospitals survival is tenuous at best. At least in our area, most providers are seeing more patients than their metropolitan counterparts, but there is a disproportionate share of non-pay patients that are not even on Medicaid.

--Daniel

Rural hospitals are typically alone in their generally underserved markets, with more of an issue of economic survival, and thus a closer tie to a serious community need to not go without hospital services. On the other hand, urban centers where corporate realities drive a necessarily substantial component of marketing & competition, there is an emphasis on margin for growth and/or profit, having/getting the latest gizmos and being the provider of choice in generally over served markets (or at least having the most market clout), rather than essentially trying to maintain health care access for their local community.

--Steve

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There needs to be an awareness campaign demonstrating that the lack of connectivity in an ever-increasing image- and data-driven environment has a chilling effect on IT and EMR adoption in rural areas. This effect may take many forms, including insufficient and unaffordable local and regional connectivity between hospitals, clinics, and physicians’ offices. Added to the lack of connectivity in rural areas is the issue of scale, as many rural practices have only 1-3 physicians and the ability to offset the cost of connectivity sufficient to meet the requirements for EMR and image and data exchange represents a substantial challenge.

--Alan and Roger

CONCLUSION

While PHR standards are not yet established, it is generally accepted that providers must have a baseline of HIT infrastructure to facilitate their use. Rural healthcare providers differ from their urban counterparts in terms of business model and resource availability, causing them to have unique priorities for adopting HIT in general and slowing their adoption of PHRs. The IT infrastructure required to support PHRs are not yet in place for many of these providers, who are waiting for a clear dominant design before committing the capital and human resources required for adoption and maintenance.

Finally, rural providers who are geographically isolated may find it difficult to partner with other providers or providers systems to share the costs and benefits of HIT adoption.

With these considerations in mind it is likely that PHR adoption will occur at a slower rate in rural healthcare settings compared to urban settings.

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A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings

Alan Kraus is currently Executive Director of the Broadband Development Group at the Regional Development Institute at Northern Illinois University and Project Coordinator for the Illinois Rural HealthNet. Mr. Kraus has been author or co-author of a number of industry papers and articles. Topics discussed were "Effective Implementation of Broadband Technology", "Best Practices and Critical Success Factors for Public Sector Connectivity", "Developing Strategies to Advance Telecommunications Connectivity". Mr. Kraus holds a BS in Communications from Southern Illinois University and a Masters in Liberal Arts from the University of Chicago. He is currently adjunct faculty at Northwestern University School of Continuing Studies and NIU's Civic Leadership Academy.

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When Pat Quinn was sworn in as the 41st Governor of Illinois, Carolyn Hodge transitioned from her position in the Lieutenant Governor's office as Director of Rural Affairs to her current position as the Deputy Chief of Staff in the new administration. In that capacity, she will continue to work with the issues that face rural Illinois along with other issues that are facing the state. Before joining the former Lieutenant Governor, Hodge worked as a Field Director for the American Heart Association. In that capacity, she coordinated community awareness programs and fundraising events for the association's battle against Joe Camel and big tobacco companies' effort at marketing their products to teenagers. Following that, she served as Community Liaison for Secretary of State Jesse White in 15 Illinois counties.
WHY PERSONAL HEALTH RECORDS ARE CRITICAL TO THIRD PARTY PAYERS OF HEALTHCARE

BACKGROUND DEFINITIONS

In order to begin this discussion, we note that there are different types of third party payers of healthcare. First, there are those who pay for care but not as a primary business and from funds that could be allocated for other priorities. These include the following:

1. Public entitlement programs (Medicare, Medicaid, Townships, State CHIPs, etc.)
2. Employers
3. Unions, Societies

They are inherently interested in their constituents. Other third parties are those who do fund healthcare costs as a primary business function, with dedicated funds obtained from the ultimate financers of healthcare (e.g. groups 1-3). They are inherently different from the other groups. Generally they maintain fiscal health and/or profitability regardless of changes in the cost of care (via premium adjustments), but have no direct, or core business self-interest in the effectiveness, availability, and affordability of care. They are, of course:

4. Health Insurance Companies

Why should these entities be interested in individual Personal Health Records? In order to best illustrate the reasons behind the importance of this issue, we must first examine the healthcare costs’ impact on payer/payers.

The following are acronyms utilized in the remainder of this chapter:

ASO – Administrative Service Organization
BP – Blood Pressure
CDC - Center for Disease Control
EBM – Evidence Based Medicine
EMR – Electronic Medical Record (provider use)
ER – Emergency Room
HIT – Health Information Technology
HMO – Healthcare Management Organization
EAP – Employee Assistance Program
IPA – Independent Practice Organization (provider groups)
IS/IT – Information System(s)/Technology
P4P – Pay for Performance (provider quality financial incentives)
PCP – Primary Care Physician
PHO – Physician-Hospital Organization
ROI – Return on Investment
TPA – Third Party Administrator
HEALTHCARE COSTS’ IMPACT ON PAYERS

Irrespective of their business dynamics, all of the third party payer groups above play a “fiscal intermediary” role between consumers and providers. They are affected in different ways, and to different degrees, by what have become relentless cost increases which promise massive, looming long-term liabilities. These progressive liabilities inevitably must either be effectively managed, funded, or abandoned, irrespective of the payer.

Much of the national healthcare discussion in the political arena focuses on how healthcare is, and will, be financed, and who will do the funding. Former U.S. Surgeon General Richard Carmona said at Des Moines University in June, 2007, that “While we decide who pays, the disease burden keeps climbing – driven mainly by preventable, chronic diseases.”¹⁵¹ Ultimately, this is the (seemingly) inescapable issue. Meanwhile, behind the scenes, much work is being appropriately expended on multiple approaches to long-term liability risk management. And, as discussed below, PHRs are a crucial component of lasting solutions. Given our nation’s position in the global economy, and a growing healthcare cost crisis driven by an aging population with expanding longevity, epidemic obesity and chronic illness, it is increasingly recognized that a continuation of current levels of entitlements and effective enabling of unhealthy behaviors is rapidly becoming unaffordable, regardless of the funding means or source. Building on a premise of unaffordability relative to our economy and national interests, and assuming, for obvious reasons that the entities above will not actually abandon healthcare financing in total, we need to further explore the core drivers of the ongoing rapidity of healthcare cost growth.

UNDERLYING PROBLEMS

“We don’t really have a healthcare ‘system’, so much as a collage of illness-response vendors.”¹⁵²

Healthcare providers have largely been passive observers of and participants in group health plan models controlled by government and the financial services industry, where transactional reimbursement models incorporate misalignments between provider reimbursement and community benefit, fostering a participant entitlement mentality by tending to incentivize (or at least not disencourage) often self-destructive health and lifestyle behaviors, lacking any accountability. PCPs today are often significantly unhappy with their situations and the care they can deliver in the current environment, feeling victimized and disempowered. Physician and hospital reimbursement is always cited as an imposing barrier to patient-focused changes in care delivery. Unintentionally, the current third party reimbursement system has spawned an economic system of care...

... in which

¹⁵² Personal Communication
• Consumers have had little financial incentive to take personal responsibility for their health or to prudently and efficiently utilize healthcare.

• Providers, as a group, have become inevitably adept at billing and churning charge procedures in the drive to produce income, without strict correlation to quality, effectiveness, or outcomes. Rewarding doctors and hospitals for their volume of diagnostic and treatment procedures in some regions is resulting in huge spikes of per-capita care with no accountability for or achievement of improved health status. Discussions about how “broken” this reimbursement system is can be found in the media daily. Yet deliberations about alternatives to deal with abuses—such as the migration of physicians to equity positions in surgery and diagnostic infrastructure and corresponding amounts of self-referral—are generating little in the way of practical reimbursement alternatives. Further, reimbursement systems are failing to reward providers for being early adopters of what may prove to be quality-improving technologies, such as virtual colonoscopies, eICU, etc. High Deductible Health Plans with high out-of-pocket maximums, including “consumer-directed” models with Health Savings Accounts offered by employers, are intended to provide incentives for responsible consumer purchasing of care. They have had the effect of increasing bad debt and collection costs for providers (especially when offered as a low-cost alternative elected by employees who can afford no other option), of consumers foregoing needed care, and of increasing consumer debt, generally without overall cost benefit for the sponsoring employers.

• Third party financers of care and their health plan administrators/insurers, except for essentially failed efforts at gate-keeping, have long provided “blank checks” to both consumers and providers on trust, without meaningful accountability. Financers of care are now being forced to re-examine their roles in the system. In the absence of significant, systematic accountability, consumers and providers alike have been shielded from the consequences of failing to address poor lifestyle choices and the lack of systematic application of evidence-based care. To date, payers have shown little interest in PHRs, other than for their ability to provide summaries of claim activities during budget cycles.

• Employers are increasingly signaling readiness to consider abandoning the healthcare benefits arena altogether, and are limiting benefit-eligible employment statuses where possible, moving jobs overseas, and determining or negotiating fixed, defined-contribution levels for health plans. Generally, the cost of health benefits is regarded as having a chilling effect on small business development. Small employers purchase insured employee health plans as a pure market commodity through annual, cost-determined, risk transfer contracts—they are generally not players in the care management game, because cause-effect or ROI is not evident. For many, it is unaffordable in any form. For large employers, employee health plans remain a significant employee recruitment/retention tool in an era in which loss of intellectual capital through Baby Boomer retirements and through growing shortages of skilled labor is emerging as a significant threat. In their self-insured plans, risk/liability management is a given, yet efforts to date have been unsuccessful. In a global economy, current (2008) predictions of annual 10% cost inflation in employer-sponsored plans over the next two years will continue to force jobs overseas or even precipitate the failure of traditional American industries, such as automobile manufacturing, as it is arguable that it
would be virtually impossible for these employers not to offer health care benefits domestically. On December 21, 2007, Forrester Research, Inc. (Forrester.com), published an online survey of 910 U.S. benefits executives affiliated with Employee Benefit News. “How Employers Measure Disease Management” suggests that company size will determine the style and scale of wellness programs, with large employers remaining clear frontrunners. However, unless care management can achieve significant ROI, a government alternative is increasingly attractive in this sector. \[153\]

- Medicaid is warning that its long-term care funding safety-net for Baby Boomers will have to be discontinued because of unaffordability.
- Rand and Dartmouth Atlas studies have dramatized the lack of correlation between much of providers’ acute care activity levels, and ultimate health outcomes.
- Clinical studies and anecdotal incidents provide mounting evidence of the cost and human impact of the systemic degradation of behavioral care in America, a natural consequence of both the stigmatization of mental health issues in the U.S. and managed care imperatives.

The April 2007 cover story of Health Leaders magazine, “The State of the CEO,” discusses the depth of the necessary transformation confronting healthcare leaders. \[154\]

It suggests that hospital CEOs need to address the question: “Are we in the healthcare business, or the health business?” This subtle difference is in fact crucial. The article quotes Mayo Clinic CEO Denis Cortese, M.D.: “Mayo believes that the healthcare industry is so flawed that it must be an advocate for change....[many providers] have made the huge mistake of not...focusing on what is best for patients, and they have actually commoditized patients. The fact is that hospital administrators...will have to come to grips with the fact that an admission to the hospital, except for things like acute appendicitis or trauma, will be a failure of the system”. \[155\] The article also quotes Intel President Craig Barrett, who said this past fall that he doesn’t believe the healthcare industry is even “…capable of transforming itself. They really haven’t...looked at the total system...and that it is going to implode on itself.”\[156\]

The disconnects of underlying motivations, the effective misalignment of incentives among the key constituencies in the marketplace are profound and fundamental, suggesting that any proposed solution to the national healthcare crisis will not be achieved without the expending of significant effort to understand interdependencies and reaching at least minimal consensus regarding how the roles and interests of consumers, providers, and third party payers of healthcare alike can all be effectively aligned. The transparent flow of information among all constituents will not occur so long as each party acts from, and information systems are designed around, a perspective of individual constituent self interests.

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155 Ibid, 28.
156 Ibid, 29.
ON GOING MARKET RESPONSES

Hewitt Associates announced in April 2007 that its “survey of approximately 450 major U.S. employers covering more than 8 million employees revealed...[63%] plan to take more aggressive, multi-year steps to help employees improve their health by...implementing condition management programs, and using data analysis and other cutting-edge programs to improve health and productivity while holding participants accountable for their behaviors. Employers...realize that in order to fundamentally improve outcomes—and effectively lower costs—they need to begin targeting the root of the issue by directly influencing the interactions between providers and patients”. 157

While both public and private third party financers of healthcare share increasingly common goals and strategies, healthcare providers other than exceptions like Dr. Cortese appear largely oblivious to this movement. To wit:

- Employers and ASO vendors are beginning to actively engage in the health and healthcare of their insureds.
- Medicare is increasing participant cost sharing (out-of-pocket exposure).
- The federal government is endorsing and has awarded tax advantaged status to Health Savings Accounts to encourage personal savings for post-employment healthcare, and to premiums for privately purchased long-term care insurance.
- State Medicaid programs have been encouraged to experiment with even “radical” solutions to their fiscal crises. For example, West Virginia requires patient engagement in chronic care management programs; and lack of adherence actually results is loss of coverage.

Brian McDonald, suggests that “strategic thinking enables a healthcare organization to define its customers and to learn what they value. Once this is defined and understood, the strategic thinking organization strives to create value.”158

In addition to defining the value of a healthcare organization’s customers, McDonald suggests that “linkages between providers and health plans have the potential for competitive advantage.”

“Collaboration can cause healthcare providers to better understand the needs of healthcare purchasers.”159 Together, health plans and providers are beginning to demonstrate value to their customers – improving the lives of people with chronic medical conditions and offering high performance networks of providers are cases in point.

Too often, essentially disconnected from the hallways, clinics, and offices inhabited by practicing healthcare providers, healthcare purchasing is clearly evolving from transaction-oriented acute care to patient-centered chronic care and prevention, with accountability for all:

159 Ibid.
• Medicare demonstration projects continue to be funded in order to identify possibly productive changes in reimbursement criteria towards this end.
• National employer coalitions, the CDC and the U.S. Preventive Services Task Force emphasize evidence-based primary, secondary and tertiary level prevention guidelines as routine for healthcare.
• PCP trade groups have endorsed “The Chronic Care Model,” and the “Patient-Centered Medical Home,” with attendant changes in physician practice, and fundamentally realigned reimbursement models.
• Prometheus Payment has developed a payment model based on evidence-informed case rates, a single, risk-adjusted, prospective payment given to providers across inpatient and outpatient settings to care for a patient diagnosed with a specific condition. Payment amounts are based on the resources required to provide care as recommended in well-accepted clinical guidelines.

Also compelling, health and healthcare claims data analytics, “predictive modeling” and chronic care management firms are experiencing enormous growth in the payer marketplace. They have recognized what healthcare financers value, and are working to measure, document, and ultimately facilitate it. Major ASO vendors like Aetna, United Healthcare, Humana, the Blues, and others are urgently acquiring data analytics and care management capacity, often through merger/acquisition, to position themselves for these fast growing market demands.

Several large hospital systems and their physicians (HMOs, PHOs, IPAs, employed groups, etc.) are tuned into these movements and are planning to reposition themselves in the marketplace by recognizing and directly attending to the interests of third party payers and financers of care, sometimes in partnership with the hospital’s largest customer (its own employee health plan). If successful, the hospital systems should be able to deliver lower-cost and higher-quality care, with measurable differences in clinical and population-health outcomes – in other words, demonstrable value for the purchaser/financer. The hospital systems recognize that by doing so, third party payers will eventually (sooner rather than later) have little choice but to designate them in narrow preferred or exclusively covered provider panels.

LASTING PRACTICAL SOLUTIONS

To address the underlying disconnects of motivations, align the incentives, and inexorably drive up individual value of appropriate lifestyle choices, self-care, self-advocacy, and healthcare literacy, improving cost-effective application of effective and efficient care which is accessible and utilized only when fundamentally needed, requires unprecedented realignment of interests, behaviors, and accountabilities among health plan sponsors, participants, physicians, behavioral care practitioners, and hospitals. It further requires the building or buying of infrastructure which supports a new model of health, healthcare, and its financing, coordinated by systematic application of modern information systems, which are reliable, accurate, verifiable, secure, accessible to all, user-friendly, and even inviting. Such technology must facilitate the following:
• Multiple applications of health and healthcare claims data analytics
A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings

- New physician practice and reimbursement models focused on care management and coordination with accountability
- Supplemental patient advocacy and coaching resources
- New inpatient care models focused on identifying systemic failures leading to hospitalizations, along with corrective action plans to reduce recidivism, with reimbursement supporting alignment of health maintenance with hospital fiscal stability
- Integrated behavioral care
- Specialized, tertiary-level preventive care for the highest cost, most complex patients.

West Virginia is on the right track with the use of serious participant accountability incentives. Meanwhile Illinois is among a number of states that have purchased (outsourced) systems incorporating highly sophisticated data analytics and multi-layered care management. The Illinois Medicaid Program is, at least on paper, near the cutting edge in terms of current thinking as to potentially productive third party financer involvement in healthcare (it is not yet, however, selecting value-based, narrow provider panels or providing incentives for patient compliance). Other cutting-edge approaches in Illinois include the following:
- Risk-stratifying plan participants using state-of-the-art modeling tools
- Routine evidence-based universal health screenings
- PCP-based medical “homes” for all participants, with focused screening, prevention, and the following activities:
  1. Comprehensive RN disease management for those at moderate health and cost risks
  3. Real-time claims monitoring with information alerts to PCPs and participants for clinical risks, such as medication interactions
  4. Intensive whole-person management for top 2% of complex, high cost cases, including:
     - multi-disciplinary patient support teams, connecting resources and PCPs
     - holistic assessment of conditions, identification of core issues, co-morbidities, health literacy, self-perceptions, and psycho-social issues.
     - advocacy, health system guidance, education and skill-building
     - self-care and self-management education & coaching
     - individualized comprehensive action plans
     - broad-based, in-depth intervention and follow-up, with objective tracking and outcome measurement
     - the power to arrange and pay for transportation, family involvement, care barrier removal, and even waiving of co-pays and deductibles to assist patients with care plan compliance where documented financial need exists, consequences are more costly without assistance, and temporary financial support is integrated with financial counseling.
  5. Provider practice profiles, including evidence-based medical management and self-care guidelines, specific clinical indicators and clinical improvement goals, clinical-guideline exception reports, supplied to treating physicians.
Implementing such innovations routinely, in order to effectively and sustainably address the underlying problems driving healthcare’s burgeoning costs, necessitates a coordinated and systematic approach. This must include an inherently productive engagement of consumers and providers alike, motivated by and aligned towards common goals. On any significant scale, this requires not only routinely efficacious incentives, but also reliable, accessible and integrated information technology.

Healthcare payers and financers increasingly understand the rationale and potential of such approaches, including the Chronic Care Model of Patient Care and Practice Improvement. It requires different PCP practice staffing, administration, office design, referral patterns, resources, and patient tracking, through changes in organization and access, clinical IS delivery design, decision support, self-management and use of community services. HIT solutions adopted by healthcare providers must be expected to support its implementation.

Hospitals and Health Systems are typically among the largest community employers sponsoring self-insured employee health plans. Their employee health plans can develop and demonstrate a better way, offering a vehicle for provider engagement in redesign and productive reimbursement realignment, while serving as models of measurable value for their community Purchasers/Financers. The Annals of Family Medicine in November/December 2004 published “Task Force Report 6: Report on Financing the New Model of Family Medicine.” It deconstructed and reconstructed, from the ground up, a business model of reimbursement that could financially support PCPs in the new model care.

ROLE OF PHRS AND HEALTH INFORMATION TECHNOLOGY

Any examination of Health Information Technology, including EMRs, PHRs, and ultimately any other proposed solution to the healthcare financing crisis, must address the existing, fundamental misalignments of interests and incentives. Progress must be targeted toward enabling a new, fluent, and coordinated system, as opposed to more patchwork, limited solutions within the current fragmented “non-system” of care. Unfortunately, significant proposals to date generally tend to reflect the paradigm “silos” of their authors. Without an inherently self-aligning approach of interests and incentives, underling cost drivers will not be fundamentally affected.

HIT applications within healthcare can differ significantly depending on the interests of their sponsors:

- Hospitals and doctors alike want fast and efficient communication of diagnostic test results. Defining HIT solutions for this purpose appear at their core to have an economic objective of optimizing reimbursement while minimizing provider time and activity. Reducing unproductive duplication in this manner is suggested to be of value to purchasers. Regrettably, however, a determination of the real value and necessity of individual tests to the diagnostic process in the first place may be absent in this agenda.

Individual providers likewise desire history and physical summaries, with identification of potentially actionable issues, produced with time and effort minimized to the degree allowed by attendant malpractice risks. In the most expensive and/or highest-risk, most complex cases, reimbursement, productivity, and time pressures artificially create a time allotment which is entirely insufficient to unscramble the significant and typically intertwined multiple barriers to an individual’s desires to regain whole-person health and well-being, and thus fail to effectively address the largest concentrations of long-term cost liability.

Doctors rightly fear that patient and other provider input to PHRs will create unacceptable burdens on them to “slog through” reams of data to identify actionable issues without reimbursement for their time under current payer arrangements, while creating additional liability risks for details they might miss. Lauran Neergaard, Associated Press Medical Writer, wrote in a February 5, 2008 article distributed in Yahoo! News, “Can PHRs actually make you healthier?”

“...the quality and scope of PHR programs varies widely, and a good one is supposed to be more than a static repository. Say someone with hypertension starts listing morning blood pressure in a PHR that automatically creates a graph. It shows a pattern of spikes that a one-time check in the doctor’s office never would catch, prompting a call for help. More sophisticated programs allow e-mails for prescription refills; automatic downloads of lab-test results, even blood pressure monitors that plug into the computer to directly record measurements.”  

Clearly, the sophistication of the system is going to be a critical factor in its utility and user acceptance.

Physicians also fear that electronic medical records and PHRs will represent their sponsors’ interests (such as hospitals, insurers, or employers), at the expense of their practice needs, and with insufficient development expenditure on and attention to ultimate consumer (patient) interests.

Ultimately, standards guiding PHR development must balance all interests, with a cautionary approach towards the risk of defining “all” too narrowly. Within this “all,” what are the most significant HIT and related functions which payers/financers are interested in? Essentially, it is the systematic collection and tracking of comprehensive whole-person health status and risk information, as a basis for targeting well-incentivized and appropriate healthcare and support services. Without such a personal information and engagement tracking “device,” individual drivers of chronic illness and illness costs will not be affected.

From a health plan financer’s perspective, every future health liability of consequence is borne by participants and providers who can be stratified using the Pareto Principle, on more than one level. One distribution is those who have significant interest and willingness in engaging in activities designed to mitigate those liabilities, and those who do not. Reducing underwriting risk

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in a population, progressive morbidity of chronic illness, claims for avoidable or duplicative procedures, unproductive medical care consumption driven by unaddressed psycho-social issues, treatment plan non-compliance, reducing economically-driven foregoing of care and economically-driven over-utilization of care, and reducing prescription drug abuses, errors and inefficiencies, cannot and will not happen unless actionable information (i.e., PHR) is truly patient focused, holistic, long term, and comprehensive in scope, and unless that information is systematically acted on by health plan financers (e.g., plan sponsors) who are in the only position to assure both participant and provider accountability by conditioning insurance plan participation on appropriate behaviors.

The alternatives are on the horizon. Without an “overhaul” as described (or some other as yet unforeseen approach which accomplishes the same solutions), healthcare is headed, like lemmings to the sea, to either healthcare for the rich, or nationalized care. While the latter might be expected to reduce cost escalations by economies of scale and addressing some of the problematic misalignments, it would not resolve most of the fundamental problem drivers as described, and thus would have temporizing impact on costs at best, much like the effects of the HMO act. Likewise, as evidenced by other nationalized healthcare systems, it would also likely be rife with new problems and failures. In any case, neither endpoint of the continuation of current system is good for any of the payer groups, nor ultimately providers or patients.

The use of systematically collected personal health and health risk data begins with comprehensive individual risk identification and population stratification, which goes beyond first-generation, simplistic claims analysis to optimize accuracy in assigning patients to appropriate and targeted assistance for health and healthcare intervention. The basic strata of risk levels must differentiate as follows:

- Current low or non-utilizers of healthcare – for primary level prevention or “wellness”, where value is optimized by routine behavioral screening and by focusing on those most likely to become the next members of the chronically ill group.
- Currently chronically ill, regular utilizers of healthcare – which comprise essential, “must-have-all” participants for disease management. Within this group, value is optimized by focusing resources on those most likely to progress to the top tier.
- Ongoing or recurrent high-cost utilizers - those with complex chronic conditions, major special-needs and end-of-life situations, where the net ROI increases dramatically, driven by the intensity and coordination of comprehensive multi-disciplinary intervention and support.

At all three levels of progressively intensive support, effectiveness is optimized by applying a longer time-window than current case and disease management models (years, as opposed to weeks or months), and routinely attending to psycho-social aspects of whole-person or even “whole-life” care, as equal in import as traditional medical aspects.

To do this, “predictive modeling” must and is moving rapidly away from underwriting-type use by payers to identify future health care cost liability of members, and toward identification of current whole-person health status so as to allow focus of the significant investment that will be required to deal with the Pareto Principle related to that status. This shift toward enriched individual health profiling can offer provider decision support and facilitate interventions,
including Employee Assistant Program (EAP) issues, participant education and health status improvement. Ultimately, input should include anything that may significantly affect health, healthcare needs, behavior and utilization, such as a broad-based assessment from multiple sources of health data, incorporating the following:

- All known medical and mental health conditions, with individual diagnoses verified
- Identification of healthcare barriers and maladaptive behaviors
- Non-invasive biometrics (e.g., weight or % body fat, BP, etc.)
- Lab values, diagnostic procedure results, and inpatient summary information.
- Physician, ER, and inpatient utilization patterns
- Absence of appropriate care, and patient care adherence
- Prescription use, noting compliance, duplicate or contraindicated medications
- Workers’ compensation and disability claims, and absenteeism
- Self perception, self-efficacy, self-worth, readiness for change and health literacy
- Lifestyle, family, financial and other psycho-social factors (e.g., dietary, exercise, sleep habits; high risk behaviors; chronic stressors)

Once participants are validly stratified to level of health risk, systematic uses of such data allow the following:

- Individual risk profiling/indexing over time, to measure the impact (“value”) of interventions and healthcare which has been delivered.
- Healthcare claims oversight to compare actual care to evidence-based protocols, identify opportunities/gaps/abuse, send alerts to providers and/or patients, and ultimately:
  - Profile providers based on patterns revealed through this activity for determining and limiting plan coverage to high-quality, high value providers.
  - Assure patient adherence to evidence-based healthcare, by limiting or deleting coverage for those who are capable, but choose to be non-compliant patients.
- Value-based plan design assistance, with a specific focus on medical and prescription drug plan restructuring to improve coverage for select chronic care maintenance meds and other high value prescriptions and medical services, while reducing coverage for others with less or no value to health maintenance or health status improvement. (Up to 40% of participants in employer-sponsored health plans today admit to not following prescription protocols because of cost.)
- Data driven, integrated health coaching and chronic care management, including behavioral care, holistic care for the most challenging, complex and costly patients, and routine palliative and end-of-life care for terminally ill patients, with coordination of care across all providers and venues.

The similarities of these fast-developing, highly sophisticated processes to the intent and components of a PHR are evident. These business-driven models are used in environments where accountability of all involved is identifiable and evidence based.

Corporate wellness and care management efforts to date have failed to produce ROI essentially because the individuals who could most benefit from them mostly fail to or are unable to
participate. Similarly, physicians in P4P programs identify patient adherence as the biggest barrier to their success.

Likewise, a PHR offered only and purely as a personal voluntary tool will appeal primarily to the segment of the population that already takes responsibility for its own health, and cannot be expected to make a significant difference with the larger plan participant population, within which lie dramatically more expensive segments of the population who are unwilling or unable to participate.

Plan sponsor adoption of membership criteria that require participation in relevant risk management activities can be difficult, due to deeply held social and political mores that value individual lifestyle and behavior choices as an inalienable right of Americans, and because employer plan sponsors have oft been mistrusted by their employees, failing to ever demonstrate the spirit of ERISA for managing limited benefit plan resources in their individual and collective best interests.

VISION

Without facilitation of consumerism, information access, financial enticements, and participant and provider engagement, through a systematically accessible data collection and information tracking and disseminating method, the underlying cost drivers of healthcare’s ongoing relentless growth cannot be addressed in a sustainable manner. Personal Health Records are a logical, applicable, and facile mechanism for all of the above endpoints. While they will not solve every problem in healthcare’s bag of dilemmas, they can be coordinated with other efforts, including Electronic Medical Records, claims data, data warehouses, clinical guidelines and care gap engines, pharmacy records, and biometrics, to support a truly integrated systematic approach to actually caring for health, rather than reacting to its loss.

By focusing whole-person preventive care and “whole life support” resources on those in most total need and at most total risk for further healthcare services (tied to sufficient motivating incentives—enough to drive near-maximal participation), we can stem the flow of the healthy-but-at-risk population to the unhealthy, and from there on to the costly group of unhealthy with complications, chronic suffering, progression, and disability.

Using PHRs and other engagement, intervention and support tools, we can avert an otherwise inescapable burgeoning of healthcare costs and chronic disease, which are heading to a point where the current healthcare payer relationships are no longer feasible on a macroeconomic scale.

Integrated health systems might support full implementation of such models with physician employment, their own health plan’s reimbursement, and fully aligned HIT tools, giving themselves a competitive advantage in the payer/financer marketplace. But in considering reimbursement options, it is important to note that physician practices have often failed to embrace team approaches to care as well as care models that embrace the whole person by extending beyond purely traditional medical intervention.
Data analysis of health claims can now be used to stratify populations into specific risk groupings. The 5% to 12% of participants responsible for up to 60% of total costs fall into a small number of categories that require intensive, longer term, whole person care delivered by specialty teams of professionals representing several disciplines, processes likely beyond the scope of primary medical practice.

- Patients with 4 or more highly complex, co-morbid, chronic medical, behavioral and psycho-social issues comprise the first and largest of these categories. Hospitals across Illinois and Indiana have employed the Integrated Health Advocacy Program™ (IHAP®) for this sub-group. Extensive patient histories, whole-person barrier and stressor screening, along with intensive integrated multi-disciplinary interventions are key components in this program’s success. Unfortunately these comprise a process that has been abbreviated in PCP practice by current reimbursement systems to a few minutes of checklist review and questioning. PHR privacy concerns that suggest medical and behavioral health issues be segregated in secure silos are in conflict with the delivery of effective care for this most critical patient group. It is the very separation of so-called “mind” and “body” issues that have, in significant part, precipitated the failures of care for this most burdened and high-risk group. Ongoing laboratory and clinical science, such as psychoneuroimmunology, clearly document that our emotions are chemically intertwined in our physical biological processes and vice-versa.

- Patients dealing with terminal conditions, and special-need patients with long-term and challenging care issues and family care-giving responsibilities, comprise tertiary level care groups. These situations benefit from specialized palliative care assistance and care-giver support. Both services should address financial and/or legal issues, behavioral health, and family dynamics and give consideration for a spiritual journey.

- Another high-cost group is low-birth-weight, premature, and multiple-birth infants, addressed first by a primary (vs. tertiary) prevention approach, spelled out in new CDC guidelines for pre-conception care, in intelligent health plan coverage, and in significant participant education and decision support regarding infertility and assisted conception.

Physicians who learn how to productively engage specialty care resources beyond their own practice group, if adequately reimbursed for an active role in the care continuum will be most effective in obtaining desired outcomes in these high-cost cases. PHRs must contemplate these care models in supporting providers, patients and payers who will benefit from them. Bridges to Excellence® (BTE) and other entities, create incentive programs for physician practices to encourage safer, more effective and efficient care. They have enlisted thousands of physicians across the country. However, unless P4P sponsors acknowledge the need for separate and resource intensive care for and investment in the outlier populations above, P4P systems are destined to continue to fail.
CONCLUSION

Barriers that must be addressed and short term self-interests aside, we arrive at a proposed definition of PHR in this environment of needed, urgent, and fundamental changes in healthcare delivery:

The ideal Personal Health Record (PHR) should provide a secure but accessible web-based site for the following and that provides or integrates with an automatic provider care-alert for condition changes, guideline variances, failed treatment adherence or follow up, and critical test results.

- Relevant, comprehensive, validated, and longitudinal patient health and healthcare data; e.g., demographics, health risks, conditions, biometrics, care encounters, and diagnostic test results.
- Patient-populated information not captured through other means; e.g., over-the-counter medications, sense of health self-efficacy, psycho-social barriers to patient adherence, health goals that is gathered with the use of standardized, evidence-based, smart inquiry technology to assure validity, cohesiveness, and relevance to whole person care, and that is efficiently and effectively integrated with clinical data.

The PHR should provide real-time, point-of-care, clinical decision support that is facile, functional, and flexible (so as to effect reliable, efficient, and economically sustainable provider identification of important, actionable issues). Decision support needs to reflect the latest established clinical research and guideline evidence as it applies to individual patients, with interconnected facilitation of communication and coordinated care among clinicians and ancillary service providers treating the same patient and, where applicable and appropriate, payers and patients themselves, so as to support full system transparency, whole person care, patient self care and responsibility, and individual and collective accountability.

In the end, without such transformation to realign incentives for prevention, evidence-based medicine, accountable lifestyles, whole-person care, and the HIT to support it (such as personal health records), continuing underlying drivers of cost increases will inevitably force other changes in current healthcare financing relationships, none of which are likely to benefit either the ultimate or intermediary third party payers of healthcare as sustainably as the redesigns described here.

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TECHNICAL CHAPTERS

PRIVACY, SECURITY AND AUTHORIZATION-MANAGING YOUR IDENTITY USING THE INTERNET

This whitepaper is about you, validating and authenticating who you are, and creating a digital identity so you can access, control, and direct how and when your private and confidential health information is used in an Internet environment. The emerging trends in healthcare automation focus on empowering the consumer and safeguarding his or her protected health information. The following paper recognizes this challenge and offers a possible path for building a consumer-centered trusted solution for electronically interacting with physicians and interfacing with an automated healthcare enterprise.

We are living in a dynamic and changing world driven in part by technology and the Internet, which is rapidly revolutionizing the way we communicate and share information. In the healthcare industry, technology is the catalyst driving the automation process. It will have a profound impact on how we create, capture, control, manage, interpret, monitor, document, and securely share health information electronically in caring for patients. Technology will also improve the business process of sharing information in a timely and cost effective manner, in an effort to improve quality of care and reduce duplicate services. Yet, for this evolution to occur, individuals must become active participants by creating unique digital identities with a trusted level of assurance to authenticate (prove) who they are electronically, if they are going to be part of an automated community healthcare system.

The use of a digital identity with an authentication process will empower a consumer/patient with the ability to electronically sign consents and authorizations and will provide them with controls and capabilities to provide electronic directives that are digitally signed (non-repudiation) with audit trails. A trusted ID would set the stage for secure communications between patients using a Personal Health Record (PHR) and physicians using an Electronic Medical Record (EMR) to include future e-visits, e-prescribing of controlled substances, and secure messaging.

In order to build a common integrated framework for securely sharing health information, standards and use cases are being developed and approved at the national level, giving life to the protocols for sharing secure clinical information (e.g., lab results, medications, clinical notes, discharge summaries, etc.) with authorized recipients. The information exchange process is being implemented under the jurisdiction of federal law, the Health Insurance Portability and Accountability Act (HIPAA), and state privacy and security laws that collectively focus on medical privacy, security, portability of health data, and consent management. Trusted access service functions must embrace some form of an authentication process to verify that individuals are who they say they are. Armed with a verified and trusted ID, individuals can gain the ability to view their Protected Health Information (PHI) and, in some cases, download their PHI to their secure PHR, thereby becoming active participants in managing their healthcare activities.

For an integrated health enterprise network to function and provide assurance in the confidential information exchange process between patients, providers, and related trusted
parties, there must be common agreement on several fundamental terms. As noted in the HIPAA legislation (a federal law), there is discussion about privacy and security. Consider the following:

The term PRIVACY in healthcare refers to the process of ensuring an individual’s right to control the acquisition, use, and disclosure of his or her identifiable data and disclosing PHI only to those who have been granted permissions to view and use such data. This includes any and all individually identifiable health information, defined as PHI under HIPAA, which is maintained, stored, and/or shared by those employed by a “covered entity.” An entity could be a hospital, a trusted business associate (agreement required), a claims payor, a walk-in clinic, a licensed medical professional or a claims clearinghouse. Each must address and track how a patient’s PHI is handled, stored, and shared, regardless of medium.

SECURITY in healthcare assumes a different theme under HIPAA and specifically addresses the physical, administrative, and technical/electronic features and functions; including how PHI is maintained, accessed, shared, transmitted, and protected from unwarranted use-disclosure and stored in an electronic healthcare environment that embraces computers, databases, websites, the Internet, intranets, and network protocols. Security addresses the requirements of maintaining the confidentiality and integrity of PHI data in an electronic environment, be it at an office or enterprise level to include availability, audit trails, privilege management, encryption, physical protections, and access control. Additional requirements include staff training, disaster recovery, role-based access controls, and authentication. This security focus embodies all components of an electronic healthcare setting to include hardware, software, the communication protocol, devices that capture or receive PHI and business partner/associate agreements that may assist in the implementation and support process of serving a “covered entity,” and related medical professionals.

Confidentiality is the obligation of authorized individuals receiving patient data or protected health information to respect the privacy interests of those to whom the data relates. It is a secure process of documenting or authenticating an individual(s), then granting controlled access to PHI (patient privacy preferences) and ensuring the designated information is only accessible to and viewed by those who have been granted consent, authorization, and access privileges. Protected health information is not made available or disclosed to unauthorized persons.

The Authentication discussion has been a sleeper (off-radar) in the healthcare automation process specifically as it relates to HIPAA privacy and security. Authentication is a corroboration process that validates a person is who they claim to be. This process is called “credentialing.” Validating includes proving one’s legal name, date of birth, birthplace, gender, address, social security number, and, most likely, a phone number. Other personal information included in the verification process might be a historic address, a financial reference, a professional license number, a national organization’s name, a membership number, or a utility bill.
Authentication is not the same as identification which is used to prove the individual passed the validation process.

Authorization is the process by which one party grants permission to another individual to have a specified level of access to his or her protected health information. In effect, an electronic authorization is an electronic transaction using a digital identity signifying that a person has been authorized to access or process the protected data and cannot credibly deny that s/he has done so.162

Healthcare automation has the potential to empower consumers with respect to their PHI and increase both accountability and responsibility at all levels in the delivery system. When PHI is shared over a secure health information network it must incorporate an authentication process with audit trails in order to build trust and confidence in the process. Governments, businesses, caregivers, and licensed medical providers are starting to engage stakeholders, noting the urgency and need for increasing efficiency and quality of care while maintaining privacy rights and access controls to PHI. Until recently, medical privacy and security discussions have rarely included authentication, yet it is the center piece in electronically verifying a patient’s authenticity using a digital medium. Privacy, security, and authentication functions go hand in hand and must be integrated in order to build trust for physicians, patients, and related parties within the healthcare information exchange process.

It is only with identity management functions, secure tokens (like a personal key to a safe deposit box), and a trusted authentication process that individuals can prove who they are electronically and then over the Internet securely share health information. Once appropriately authenticated, individuals will have the ability to provide authorizations and digitally sign documents to provide specific non-repudiated directives (document authenticity is strong and not easily disputed being that it is digitally signed, date/time stamped and encrypted). They will also be able to exercise their security and privacy rights to protect their confidential PHI with e-consent and authorizations in an automated healthcare environment.

In addressing the issue of automation, healthcare has been compared to the banking industry, because it, too, is consumer- and corporate-focused, is concerned about privacy, and is regulated. Surely, the banking sector has demonstrated the value of exchanging data and money electronically. Yet there is a stark difference between security and authentication of a financial customer versus a patient. The relationship between a bank and its customer is a one-to-one relationship enabling banks to securely deploy authentication tools and a control process for conducting secure electronic financial transactions. On the other hand, a patient’s relationship with his or her medical community of doctors, clinics, labs, pharmacies, insurers, etc. is a one-to-many relationship which further complicates the solution.

Privacy and confidentiality are paramount to a patient but there is no single solution for accessing, viewing, securely sharing, and directing PHI to selected trusted parties. This effort incorporates another dimension of complexity because, in many cases, the patient is responsible for executing and providing consents, authorizations, and access rights to providers and

caregivers, designating who can view, use, and share his or her protected health information. Hence, the need for multifactor authentication takes on the critical function of empowering the patient to interact within multiple healthcare delivery environments to view his or her PHI and to provide consent direction and directives on use of that PHI.

As e-commerce, online banking, and ATMs have become commonplace, so have identity theft and privacy violations, hence the reason for recent banking rules to increase the use of multifactor authentication with their customers. Identity theft, now prominent on the FBI's radar as one of the fastest growing crimes, has moved consumer privacy concerns to the national stage. At the same time, it has created havoc for families, consumers, and businesses; cost millions; and affected credit ratings and, in some cases, medical records. On a per-incident basis, businesses affected by data losses spend an average of 231 hours addressing policy, network, and theft issues, while individuals spend an average of 97 frustrating hours, with an average loss of $1,342.00 attempting to correct their files and credit scores and to clear their good names.

Recognizing the rapid growth in e-commerce and identity theft activities, the banking industry acknowledges that its reliance on a user name and password (one-factor authentication) for conducting electronic transactions is a weak form of security. The Federal Reserve Board, Federal Deposit Insurance Corporation, Federal Trade Commission, and other oversight boards have announced new federal rules for a more reliable form of identity management and security known as multifactor authentication or layered security. Financial institutions are now required to have the new security rules implemented by November 2008.

With increased medical identity theft and acceptance of health saving accounts, coupled with a heightened interest in medical banking activities, healthcare leaders might consider following in the footsteps of the banking industry, by educating patients and physicians. There is a growing need to learn how to manage and protect one's identity with multifactor authentication functions and other forms of security. This would be a positive signal for enhancing and building consumer/patient confidence and trust and would promote the framework for securely sharing PHI.

An individual's trusted identity is paramount to the success of an integrated, community-focused healthcare system. In multiple national surveys, the strongest trusted relationships are between patient and physician, with hospital administrators placing a close second. Similar to a banker and a client, clinical providers and patients must have strong assurance that only qualified persons, who are trusted and authenticated individuals, will have access to all or part of a patient's PHI. Both parties must demand a high level of assurance in the electronic sharing process and seek a level of confidence that PHI will only be used and viewed by those authorized to participate in the delivery of care process or access based on the privacy preferences of the

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patient. Secondarily, the entities who have been allowed access should be able to verify and provide proof of the accessed records through transparent audit trails.

During the past year, physicians have started to adopt Electronic Medical Records (EMRs) at an increasing rate, according to Medical Records Institute, thanks in part to the national Certification Commission for Healthcare Information Technology (CCHIT) certification process, and increased emphasis by medical societies, hospitals, and payers. As adoption continues, currently at about 27%\textsuperscript{165}, the tipping point for widespread adoption by physicians could become a reality if there is an interoperability function that allows for securely sharing PHI between disparate systems, which is being incorporated into the CCHIT program, and which harbors an identity and consent management function and an authorization process. Hospital inpatient clinical systems, also defined as EMRs, are now in the initial stages of being CCHIT-certified, and as enhanced applications come to market, they will start interfacing with physician-owned EMR systems so PHI can be securely exchanged electronically based on privileges and authorizations. These events are critical stepping stones for the widespread adoption of PHRs. Most hospitals, including medical staff, already have a security-control process in place for controlled access to facilities and medical records. Most caregivers have a National Provider Identifier (NPI) as a unique form of physician identity used in serving the Medicare/Medicaid population. The natural next step is for the patients to have some form of digital or “trusted” identity, so that they can authenticate themselves and become part of the health information exchange process and gain access to their health information.

According to a Markle Foundation study, most patients would likely adopt PHRs recommended by their physicians because their physicians are a trusted source for personal health and medical information. There is high probability that a provider would more likely recommend a PHR that falls under the HIPAA umbrella, giving the patient some form of a trust comfort. The current PHR market touches an array of stakeholders, yet there is no broad-base adoption underway, with a possible exception in the area of chronic disease management. The primary reason for the lackluster adoption rate is a lack of trust in the electronic process of sharing PHI, and patients would prefer to have their stand-alone PHR pre-populated with their available PHI. Some health insurance companies do offer a “tethered” PHR, which is basically pre-populated with claims data owned by the insurance company and is accessible by the insured but, for the most part, is not electronically portable. If patients could authenticate themselves with their caregivers and insurers, that would open the door for initial steps in securely sharing PHI and possibly populating a standards-based PHR with claims data. With the insurer, personal health/claims information is not electronically transferable, but there might be interest by an insurer in sharing some of the claims data if the insured parties could demonstrate that they have a secure standards-based PHR and can truly authenticate themselves to the insurer. The same might apply to other specialized entities authorized to store claims data.

In order for the PHR’s adoption rate to accelerate, several key functions must be acknowledged. First, PHR vendors must embrace and demonstrate the use of nationally recognized standards practice guidelines and policies for authentication, accessing, and auditing and for securely

sharing and receiving PHI via standard formats, such as ASTM’s Continuity of Care Record (CCR)\textsuperscript{4166} standard and the forthcoming HL7 Clinical Care Documentation (CCD) format. When an individual elects to “opt-in” or consent to participate in a community, employer or private health network and make available his or her emergency contact information and directives, such data should be made available, with high assurance, in a standardized CCR format (readability) within an electronic transport container such as a PDF-Healthcare\textsuperscript{5167} vehicle specifically designed for the digital healthcare/medical record.

PDF, standing for Portable Document Format, transforms a text document, while keeping the layout, font size, and text from its original structure, and converts it to a portable format and lets the recipient view the pages just as they are in their original form. The PDF Healthcare Best Practices Guide sets forth features and functions to capture, exchange, preserve, and protect health information. The PDF container also allows images and files to be attached and securely encrypted with a password or digital certificate. Data could then be viewed by emergency caregivers who are authenticated and authorized to view restricted PHI datasets. At some future date, PHRs should have a formal review or certification process by a qualified third party. Initially, it would be helpful if CCHIT would formulate initial guidelines as first steps towards a formal review process which would benefit all in the healthcare community. Currently, CCHIT is developing testing criteria for Health Information Exchanges, and later there are possible plans to develop testing criteria for PHRs.

Regarding PHRs, it should not be assumed that all PHRs are equal and/or covered under HIPAA. It should not be assumed that PHR privacy protections follow healthcare files or data sets. In the absence of a Security Statement and Terms of Service Agreement for a PHR that acknowledges compliance with HIPAA Privacy and Security rules and items such as PHI ownership, protecting such data consent and authorization functions, one should assume the PHR vendor or the entity implementing/representing the PHR could elect to disclose or use any of the health information it harbors at any time. Only if a PHR vendor or an entity using and representing PHR service clearly states in writing that it will conform and treat PHI according to HIPAA privacy and security does one have some assurance of legal protection.

PHRs that are implemented by a covered entity (medical practice, hospital, payer, clearing house) are in part covered under HIPAA and this should be reflected in the organization’s privacy and security statements and service agreement. Such statements should also reflect a commitment to portability of PHI. A PHR user should question how revenue is generated, such as in selling advertising or bundled personal medical data. Are revenues generated from an individual/corporate subscription agreement where a direct purchase is made or from advertising or selling of data? One must also question PHI ownership and control and if there is a designated custodian. PHRs offered at low or no cost are usually supported by advertising or funded by a third party source; ownership and control should be questioned. PHRs that require an annual fee from the consumer and are free of advertising most likely are owned and


controlled by the consumer, who can then, under discretion, elect to opt in and participate in a targeted health program, research project, or drug trial.

The PHR and EMR adoption rate might be stimulated if the Department of Health and Human Services (DHHS) would adopt the National Committee of Vital Health Statistics (NCVHS) recommendation that PHRs be considered a covered entity under HIPAA guidelines. This would send a positive signal to major insurance carriers and self-insured organizations that PHRs must follow and be accountable to a formal process similar to certified EMRs. If PHRs are included as covered entities, then they would be required to meet or exceed all HIPAA security and privacy rules and thus provide some legal protection for consumers.

Consumers/patients must be educated on privacy issues and how they can protect their and their family’s PHI. The consumer must learn the value of identity-proofing and authenticating their identity in order to gain access, view, and then receive available PHI. They also need easy-to-read information and user-friendly graphics and tools to manage their PHI and health activities, as well as be able to electronically acknowledge consents, authorizations, and directives. Once empowered, consumers might need coaching to understand the value, meaning, and how to use the health data provided. Most have been sheltered from their medical data and the real costs of healthcare services provided, and thus lack experience in managing their health activities. This is a recognized shortcoming in the third party payment system, and now most acknowledge that one path to increased efficiencies and quality of life is through automation and greater consumer responsibility in managing their ongoing healthcare activities. Hence the need for identity-proofing and secure sharing of PHI coupled with educational health information, incentives and benchmarks for quality measurements.

Not to be overlooked, physicians and licensed caregivers also need educational material on privacy, security, identity management, and authentication/authorization issues related to protecting and sharing personal health information. This is a critical path, since physicians and staff play a central role in educating and empowering patients with their personal health data, and can encourage them to be more responsible in managing their health activities. In the future, patients may make electronic office visits and do secure file-sharing and self reporting, especially chronic patients who currently manage their diseases. The medical staff will also be the medical coaches. Once again, identity-proofing and secure file sharing will be required.

For secure file sharing to become a reality, PHRs must be recognized as part of a trusted community health network or enterprise of disparate systems where providers and patients alike have authenticated and trusted identities. Then it is not out of the question that patients may see the value and elect to have a standards-based Voluntary Universal Healthcare Identifier integrated with their secure PHR. The community and the consumer benefit of using a voluntary identifier could reduce duplication of medical files/records and recognize privacy preferences in any medical enterprise and could increase the accuracy of linking to other confidential medical files/information when available online. The user would have the additional benefit of being able to start building his or her own electronic longitudinal medical profile which could positively affect medical errors and improve patient privacy awareness.
Identity management, security, and privacy go hand-in-hand and are key elements in the electronic sharing of PHI. With a digital identification, a patient does not have to reveal his or her personal and identifiable information such as age, SSN, place of birth, etc. However, until individuals can validate and authenticate who they are, entities such as hospitals, insurers, pharmacies, labs, licensed care providers, and home health agencies will not electronically share PHI or grant access to or pre-populate a PHR that is not under their trusted control. The liability of PHI being compromised is too great.

To jump-start the acceptance process for PHRs and to assist consumers in accessing their personal health data, individuals must go through some form of an authentication process in order to electronically and digitally validate who they say they are. Once this is accomplished, physicians and possibly hospitals will likely recommend PHRs which can securely exchange PHI with their certified EMRs based on this authentication. This process will also encourage patients to participate and take steps to engage in managing their healthcare activities and share critical information with their providers on an as-needed basis.

The identity management process involves various means and methods to verify one’s identity. Once an identity is verified, there are a variety of tools that can be used to create access controls and audit trails for sharing PHI using various forms of a multi-factor authentication process. 

Trusted access service tools might include a Public Key Infrastructure (PKI—a secure communications process between parties who are authenticated and have trusted digital identities and a private key to open a secure document), digital certificates for access control, (your private key), encryption, and digital signing (your digital signature/identity) for non-repudiation. Other forms may include server-based certificates, smart cards, proximity cards, grid cards, out of band calls, and Universal Serial Bus (USB) tokens in combination with enhanced passwords and knowledge-based questions or a combination of a password or pre-selected image along with a biometric such as facial, fingerprint, and/or speech recognition.

Not to be excluded are behavioral, typing/signing patterns, risk-based, and geographical (location) factors that could be part of the layered security process. The identity management and multi-factor authentication process incorporates a combination of tools and unique functions integrated around a combination of something you know, something you have, something you are, and in some cases, someone you know.

A community medical network or enterprise, though functional in a ‘closed’ intranet environment, has its greatest financial, quality of care and self-empowering impact at all levels in the delivery of care process when it is integrated into a federated, open source, standards-based secure network which tends to be cost effective. The network must have all the appropriate certifications and layered levels of digital and multi-factor security with audit trails. To achieve a federated enterprise status, the industry’s goal should be to strive to gain a high level of trust and assurance among consumers/patients/employees, using standards-based approaches that can be adopted by all participating parties, inviting them to view their PHI. That is when consumers will have stronger confidence in the process and less fear about their health information falling into the wrong hands or being lost in cyberspace.
In the author’s opinion, the foregoing builds upon the Best Practice Guidelines\(^\text{168}\) set forth by the National Business Group on Health, representing millions of employees, which published their guidelines December 2007. They specifically emphasized the importance of empowering the consumer/employees and their families by putting them in control of their secure PHI. The national guidelines, if followed and integrated with an overall health network, will build trust. The key ingredient, once again, is that the individual must be in control and the employer specifically prohibited from accessing the Personal Health Record.

To stimulate consumer empowerment and PHR adoption and to educate on identify proofing and personal health management, employers and communities should consider teaming up on an educational campaign stressing healthcare privacy and security and responsible health data management. Simultaneously, they should offer the consumers/employees/patients a path to view and possibly access their PHI, and, to do that, they must elect to opt in and take a responsible role in validating their identity via a standard recognized process. Other educational themes to be shared include portability of protected health information, identity management, authorizations, consent management, and access and control privileges, to name a few. The focus must be on empowering consumers with their PHI and promoting healthcare privacy, and control, ownership, and management of their protected health data. Such a campaign must be a public/private effort with shared costs. The economic benefits and quality of care improvements nationally could be profound and the quality of life and privacy for each individual can be enriched to the extent they elect to participate and be responsible for managing their healthcare activities.

In summary, it is all about you, your identity, and connecting you and others with your protected health information and providers of care. Recognizing the fragmented landscape in medical care, patient mobility, healthcare automation, and the effort to harmonize the industry with standards and use cases, it is a natural next step to empower the consumer with their PHI. The path is set for a consumer-centric, patient focused, secure-network-based-process that invites participation, letting consumers claim their digital identity and then empowering them with their confidential information. Consumers have been insulated by third-party payers as to the value and costs of care. Now they can be catalysts for change in jumpstarting the healthcare automation process.

The cornerstone for a consumer/patient transformation process is beginning to take hold. Guidelines and rules that address HIPAA Privacy and Security, identity management, authentication, transparent audit trails, and trusted access services are being formulated and fine-tuned for live testing. Enterprise networks with integrated standard-based EMRs and PHRs that can securely share PHI electronically are starting to emerge. As the structural pieces in healthcare automation take shape, the weakest link in the formation process is the one who could gain the greatest value in quality of life and health – you, the consumer. The entire automation framework hinges on a very fundamental kernel in the process: validating who you claim to be electronically….. your digital identity!

James F. Kragh, President/CEO, *Good Health Network*, has over 17 years experience in the national standards-setting process for automated patient health records and related security and privacy issues. He has served on standards committees that impact HIPA and the sharing of Protected Health Information. *Good Health Network* focuses its energies and corporate resources on healthcare issues relating to Consumer Privacy, Security, Identity Proofing, Health Data Capture, and Integrity, along with other Trusted Solutions relating to Health Information sharing.

Visit the GHN website for additional information at: [http://security.ghnetwork.com](http://security.ghnetwork.com)
TECHNICAL ISSUES – INTEROPERABILITY OF ELECTRONIC HEALTH RECORDS AND PERSONAL HEALTH RECORDS

As patients receive medical care, their clinical history may be tracked and recorded by multiple electronic systems developed by independent vendors. Medical providers might use electronic health record (EHR) software tailored to the needs of trained medical personnel, whereas patients may interact with personal health records (PHR). The purpose of this essay is to identify the key interoperability issues associated with the information exchange between these two types of systems and offer an approach for enhancing interoperability.

System of Record is the term used to describe a computer-based storage system which is considered to be the authoritative data source for a particular type of information. The System of Record is considered to have the “official” version of the information.

Information pertaining to a patient's clinical history is typically distributed among multiple electronic systems, such as EHRs and PHRs, each of which is the System of Record for at least a portion of the medical history. The patient's neighborhood pharmacy may contain the most accurate record of the patient's prescription medication history. Insurance companies will have the most accurate claims-based data. The Primary Care Provider's EHR might have the best clinical summary, while the patient's PHR might be the best source of self-monitored medical data, such as blood glucose or health journals (e.g. migraines, mood, etc).

Information exchanges between independent Systems of Record with overlapping data content naturally face significant challenges. Though the most significant challenges in our time relate to socio-political, legal, and ethical considerations, whenever any portion of a patient's health record is exchanged among EHR and PHR systems, the functional quality of the exchange is dependent upon the extent to which the technical implementation addresses interoperability between the Systems of Record.

Building true functional interoperability—not just sharing data—requires addressing several different components: the provenance of the data (consideration of how the data was collected to get to its current state – what events drove the collection of the data and the human workflows that define what the data is); and the data schema (the definition of how the data can be represented in a structured format for uniform parsing).

Representation of the data as a controlled vocabulary within the data schema, to achieve semantic interoperability; when possible: the software tools that enable data exchange (e.g., Web services), security considerations; and data federation or integration architecture (e.g., central data repository synchronization or distributed queries or hybrids).

Each may be discrepant among Systems of Record and technical solutions must allow the flexibility to interact while maintaining a coherent management of the data. Simply put, it is not reasonable to rely on interoperability solutions that are wholly focused on addressing systemic identity mismatches and fail to account for variance in the controls and quality of the data that is entered into the system. In fact, developing interoperability requires addressing both software tools and data.
An example that illustrates the challenges of reconciling data from among multiple Systems of Record can be found in the financial world, with regards to security measures in the payment card industry (PCI). PCI regulatory compliance will typically require that various security tracking and logging systems be time-synchronized to make it possible to trace the step-by-step activities of individuals who may attempt to gain unlawful access to individuals' credit card data. This requirement establishes the need for the coordination of systems as disparate as those used for controlling physical premise access (electronic key card), video surveillance recordings, and database logs. PCI compliance in this context imposes the requirement that disparate Systems of Record rely on standardized protocols and services such as the Network Time Protocol (NTP) facilitating time-based record reconciliation.

While there are similarities in the technical challenges faced by healthcare and other industries where independent Systems of Record interoperate, there are also unique considerations. In many contexts in healthcare, information exchange is reviewed by human intervention and it is still acceptable in some circumstances for data to be stored in a non-machine-processable format (free-text vs. structured data). Also, the quality of the data and errors are more substantial challenges and concerns.

Interoperability issues that hinder the fidelity of the automated exchange of information among healthcare systems, such as EHRs and PHRs, include the following.

**Data Definition Related**
- Mismatches between vocabularies and differences between native data element definitions (naming, size, granularity, validation, etc.)
- Differences in code sets, including code set versions
- Scope of data – identifying which data is actually relevant for the exchange – avoiding information overload, particularly to providers
- Data federation / integration (systemic architecture)

**Workflow and Change Related**
- Software interoperation (syntactic)
- Health “event” identification
- Data messaging – in automated environments, incompatibility of electronic messages
- Deltas of change for data updates – difficulty in separating what is new from what has previously been exchanged
- Currency – ensuring that newer data is not overridden by older data
- Mapping between newer and older versions of codes – it is rare for all systems of record to be on the same version

**Security, Identity and Quality Related**
- Translation of policy into technology
- Security and privacy – ensuring that only data approved for the pairing of partners is exposed and exchanged- access is provided on a documented consent basis
- Identity resolution – ensuring that the data exchanged is for the right person
• Quality of data (validity and reliability of data)
• Error correction and recovery – lots of reentry of data in many cases, potential to overwrite steps and be able to recover to what was there before data in error was applied

There are degrees to which interoperability issues can be addressed. The less the interoperability issues are addressed, the more data is “lost”. Technologists will often refer to the degree to which information exchange leads to loss of information as the “lossiness” of the exchange. It is desirable to minimize lossiness either by redesigning Systems of Record to comply with openly available specifications (such as industry standards) and/or by establishing conventions in the form of implementation guidelines.

When considering how to minimize lossiness, specific transactions should be considered, in which context the guidelines apply. Data reconciliation is a useful scenario to consider in the information exchange between Systems of Record, such as EHRs and PHRs, is how data is merged.

DATA RECONCILIATION

When EHRs and PHRs exchange data, a common objective is to update one or both of these systems with patient health information that is potentially missing from one system, but available in the other. In the case of a patient downloading medical history data to his/her PHR, this would be a similar activity to downloading a bank statement for the purpose of reconciling the most recent bank account activities such as deposits and withdrawals.

Systems of Record have the benefit of being updated in the context of well defined transactions: the patient is prescribed a new medication, or has been diagnosed with a new condition, or has been recently hospitalized. The context of each transaction generally removes ambiguities (except in cases where the data is in fact “historical” such as a history of a chronic disease or prior operations (though these can be converted to a transaction context).
Figure 7 illustrates the changes affected into a System of Record as a result of two separate transactions (incoming “arrows”): change in prescription dosage and the addition of hospitalization information. In the case of the addition of hospitalization information, a new record is added to the data store. Records are represented as circles with data elements; e.g., discharge date, assisting doctor, being displayed as colored rectangular. The update transaction is shown as a change (in color from green to orange) of data in a pre-existing element; e.g., prescription dosage was increased.

In contrast, the process of reconciling data among multiple Systems of Records, such as between EHRs and PHRs, can be akin to a forensic discovery effort, where transactional history is lost and recoverable audit trails are not kept. In such situations, reconciliation needs to be inferred from the changes that were affected in the System of Record. See Figure 8.

![Figure 8 System of Record before Changes and After Changes](image)

If an external system interacts with the System of Record before and after the two transactions were executed (change to prescription dosage and addition of hospitalization data), it will need to contrast the before and after data and infer the changes that will need to be incorporated into its own storage area.

Historically, when computerized systems automated data reconciliation (aka merge), they typically engaged in a complex, multi-step process, with variable reliability depending upon the degree of data and protocol standardization, which includes the following:

- Establishing the **scope and range of the exchange**; e.g., all currently active medications, hospitalizations since the beginning of the year, complete medical history summary, etc.
- For each of the component data elements of a patient’s record (medication, problem, alert, etc.), decide whether this is a **new or existing** element, from the point of view of the target system. This requires a two-step activity of **identifying** and **matching**.
- For pre-existing records, additional steps are required to infer whether data has been updated since the most recent data exchange and if so, what the nature of the update was.
A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings

- Once the scope of the changes has been identified and the receiving system is ready to incorporate the updated data, the final process is to map from the source to the target data model.

Since Systems of Record are independently designed, the criteria used for defining the scope of the exchange, identifying and matching and comparing for changes, are typically different for each implementation. This implies that each of the steps listed above will contribute to a degree of lossiness in the exchange of patient medical information.

The introduction of interoperability open standards, such as the ASTM CCR (Continuity of Care Record) and now its successor, the [CCD] (Continuity of Care document), which maps the CCR into the HL7 CDA (Clinical Document Architecture), enables systems to map their internal models to a limited set of data exchange models, instead of having to map to multiple potentially proprietary data representations. These data interoperability standards do not necessarily help with the other sources of lossiness identified above, in particular with the identification of data updates (“deltas”) that occurred since the most recent synchronization point. An implementation guide may help provide guidelines that include support for standardizing on the exchange of transactional activity and simplify the forensic effort.

A next generation of standards and certification organizations is attempting to harmonize these standards into a common set that can be used by PHRs and EHRs alike. An example is CCHIT (Certification Commission for Healthcare Information Technology, found at http://www.cchit.org/), which started by certifying EHRs and is now expanding into HIEs (Health Information Exchanges). It is unclear to what extent CCHIT will venture into the PHR world, but it will undoubtedly have an influence. So far CCHIT certification activities have had a direct impact on EHRs, forcing consolidation and standardization.

ADDITIONAL INITIATIVES TO ADDRESS THE ABOVE

In addition to the collaboration between Northern Illinois Physicians For Connectivity and the Chicago Patient Safety Forum that resulted in A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings, there are three parallel efforts with some overlap in southern Illinois, both in medical trading areas and mission. These groups include The Illinois Critical Access Hospital Network (ICAHN) beginning with Washington County and Salem Township Hospitals, Southern Illinois Healthcare, and the BJC Medical Group in St. Louis.

Our intention is to share information, work product, and problem resolution with these initiatives as much as possible. The three initiatives in Southern Illinois address a number of the challenges outlined above through the use of an intermediary “Community System of Record” for each patient, effectively creating a shared source of truth. Based on a set of business rules, each record is updated in near real-time based on on-going input from providers, hospitals, inpatient and outpatient nursing, patients and proxies/guardians, pharmacies, and payers, amongst other business associates. Each update/encounter/event from any member is pushed by the system of record to the community through database triggers, HL7 messages, CCR and [CCD] records, and
the like, and is then either distributed (pushed) to other systems of record as appropriate, or pulled as needed when records are queried. Initially, development is focused on the building of the EHR, and patient input, reviewed and approved by providers. Once these efforts are more mature, than the data accumulated and continuously maintained can serve as a solid foundation for building PHRs that will get past the time-consuming, de-motivating, and inherently risky input of clinical data from patients.

This community system of record attempts to relieve each individual provider/chart system of record of many of the burdens of health information exchange among electronic systems, such as EHRs and PHRs, by performing services such as the following:

Data Definition Related
- Maintaining a “source of truth” and portable community health record including a [CCD], a virtual extension of the eMPl (electronic Master Patient Index) and its demographic data, defined additional clinical documentation such as most recent vital signs, consult reports, and the like, as well as historical data useful to management of chronic conditions, health management, predictive risk management.
- Reflection of community-agreed data sharing and data-quality business rules; for example, who is permitted to update the source of truth and under what circumstances, how discrepancies are resolved, etc.
- Mapping of disparate data definitions, code sets, and vocabularies.
- Appropriate review and approval of data before entry into the source of truth system, including Provider sign off of lab results, consult reports, and the like for completeness, accuracy; and Provider sign off of patient entered data such as family, medical and social histories
- Patient review of source of truth data across providers and other data sources, analogous to reviewing their credit report for inaccuracy and completeness

Workflow and Change Related
- Scope of data – identifying which data is actually relevant for the exchange and avoiding information overload, particularly to providers
- Maintaining audit trails of updates, including institutional/provider/patient sources, dates and times permitting, including reconstruction of a sequence of events in a patients care across all sources to reconstruct where care might have gone wrong and/or to learn from experience; drilling down into a particular component of care or demographic or clinical data such as a medication, chronic condition or episode of care; and maintenance of flow sheets shared between providers and patients related to health and disease management to help monitor progress, assess current situations, and develop goals and plans.
- Maintaining transaction and event status – orders without results, preliminary vs. final versions of documents, signed off and not signed off labs, raw vs. provider vetted patient input, etc.;
- Closed-loop clinical messaging to permit the patient, providers and institutions to identify inconsistencies, lack of completeness, and potential patient safety issues such as
contraindicated medications, conflicting care and nutritional plans, and the like. Each one is tracked until mutual resolution;

- Responding to commonly accepted health “events” with updates to applicable systems of record;
- Enforcing data quality;
- Managing deltas of change for data updates through state control, keeping track of what data each system of record has;
- Currency – ensuring that newer data is not overridden by older data;
- Data messaging – repackaging of data to meet formats of systems of record; e.g., CCR vs. CCD vs. HL7, etc.

**Security, Identity, and Quality Related**

- Security and privacy – ensuring that only data approved for the pairing of partners is exposed and exchanged;
- Error correction and recovery – audit trailing of all changes, never overwriting, ability to restore data if it is lost;
- Code version maintenance – reconciling older and newer versions of code sets; Application of interim changes;
- Identity resolution – ensuring that the data exchanged is for the right person.

Driving this approach is a “circle of care” approach of shared responsibility by the patient, the patient’s agents, and all providers who touch the patient. In many cases, a primary care provider or “health/medical care home” takes on responsibility for each individual’s care. In addition to the PHR and EHR key elements may include the Community “System of Record” and CCD/CCR-like repository; patient portal and/or PHR-accessible services and communications linking the patient to his or her providers for on-going interaction, such as questions, monitoring, and coaching; and record bank external to the community, often national in scope, that the patient can maintain over a lifetime.

**PROPOSAL FOR A TECHNICAL IMPLEMENTATION GUIDE FOR CONNECTIVITY BETWEEN PHRS AND EHRS**

A number of technical issues stem from technical challenges that exist even outside the scope of healthcare applications and services. Attempting to address the entirety of technical issues that present themselves is a daunting task and one that, if taken in its broadest sense, is outside the scope of this publication. The proposed Technical Implementation Guide looks to the resolution of technical concerns from National Collaborative Efforts, including:

**The Healthcare Information Technology Standards Panel (HITSP)**

HITSP is a cooperative partnership between the public and private sectors focused on enabling healthcare interoperability. The panel was formed for the purpose of harmonizing and integrating
standards that will meet clinical and business needs for sharing information among organizations and systems.

**Certification Commission for Healthcare Information Technology (CCHIT)**

This group was referenced in the prior section, in regard to its role in certifying EHRs and eventually Health Information Exchanges (HIEs). In 2009, CCHIT plans to begin certifying HIEs, which will, by definition, need to address systems of record data exchange, as well as concepts such as “lossiness”. In addition, CCHIT formed a PHR Work Group in 2008 which developed Personal Health Record Certification Criteria submitted for public comment, test scripts and an alpha certification criteria test plan. The PHR certification program was supposed to have begun in 2009. However, it has been delayed to accommodate review of the program’s compliance with privacy requirements promulgated by the American Recovery and Reinvestment Act of 2009 (ARRA).

**IHE (Integrating the Healthcare Enterprise, found at [www.ihe.net](http://www.ihe.net))** is a global initiative that creates the framework for passing vital health information seamlessly – from application to application, system to system, and setting to setting – across multiple healthcare enterprises. IHE brings together healthcare information technology stakeholders to implement standards for communicating patient information efficiently throughout and among healthcare enterprises by developing a framework for interoperability. This interoperability is demonstrated at the HIMSS (Healthcare Information and Management Systems Society) showcases. These showcases, taking the form of model electronic healthcare communities, demonstrate vendors exchanging data amongst hospitals, ambulatory care amongst and other healthcare institutions.

American Health Information Community (AHIC), sponsored by HHS, which pushed for PHR standards in 2007.

**American Health Information Community (AHIC),** sponsored by HHS, which pushed for PHR standards in 2007 and is contributing to the CCHIT Work Group efforts with public comments. HL7 which has contributed the Personal Health Record System Functional Model (PHR-S FM) to serve as a draft reference standard for PHR system functionality that is frequently cited in the CCHIT Personal Health Record Certification Criteria draft.

**The Markle Foundation Personal Health Working Group** which has developed a broad PHR framework including available evidence regarding expected benefits of PHR/stakeholder (with a special emphasis on patients/consumers) requirements and concerns, and commercial experience to date. This group developed a shared vision and advocacy position. This framework is also frequently cited in the CCHIT Personal Health Record Certification Criteria draft.

**Health Record Banking Alliance** ([www.healthbanking.org](http://www.healthbanking.org)). HRBA is a non-profit corporation formed to assist stakeholders in the promotion of community repositories of electronic health records. Health Record Banks improve the safety and efficiency of patient care, public health, and medical research through the availability of secure and complete electronic lifetime health records.

The creation and specification of implementation guides is a common practice in support of technical implementations that require the integration of multiple software data systems, even
when a data/document exchange model is present. In the context of CCR-based integrations, a few implementation guides are particularly noteworthy: the ASTM CCR Implementation Guide [IMPL], the Retail Clinic CCR Profile of the MinuteClinic [MC] and the CCR/G API developed by Google [CCR/G]. An important additional example would be HL7 CDA Templates [TEMPL].

SCOPE

A Community Health Record encompasses the technical infrastructure and processes that create an environment that allows providers and patients to collaborate on the creation and maintenance of an individual's health record. The proposed Technical Implementation Guide for the White Paper for an Illinois Personal Health Record would be limited to technical specifications and constraints designed to eliminate—or at least minimize—the extent of lossiness present in the exchange of patient clinical data between and among systems such as PHRs and EHRs. A Technical Implementation Guide is likely to be part of a larger set of policy artifacts that define clinical and administrative business processes and workflows.


It should be noted that the development of a Technical Implementation Guide should be undertaken as an iterative, multi-versioned process, which at each revision captures sufficient information to support CHRI's target use cases, to within acceptable levels of tolerance for variations of implementation.

OBJECTIVES

The primary objectives of the Technical Implementation Guide are to document technical constraints that will achieve measurable/demonstrable interoperability standards and

- Allow for a choices related to applications and services appropriate to all stakeholders in a person's healthcare; and
- Support and enforce the clinical and administrative requirements of a Community Health Record;
- While preserving the most accurate representation possible of the patient clinical data in multi-system exchanges.

These objectives may be seemingly at odds with one another, with the first broadening the inventory of available solutions, while the second narrows the choice spectrum to those solutions that are aligned with business and regulatory mandates. The Technical Implementation Guide will document the sets of technical specifications and configurations that will guide implementations that best meet a Community Health Record's business needs in the most optimal fashion at any given point in time, so as to maximize the quality of the information being exchanged between systems. In point of fact, a Community Health Record's business needs should be documented as part of the Technical Implementation Guide as desirable outcomes...
that are both demonstrable and measurable, validating the benefits of increased interoperability between the participating EHR and PHR systems.

**CONTENT**

The Technical reference model will contain references to use cases and requirements; overviews, including technical exchange protocols such as SOAP and HTTPS, messaging Standards such as [CCD]/CCR and HL7, terminology and Coding Sets such as SNOMED CT and ICD-9, and integrated specifications and Standards Organizations such as HITSP and CCHIT; shared solution sets: Resolutions or partial resolutions in practice where applicable to interoperability between systems of record, lossiness etc., including consensus standards as applicable, Illinois Community Systems of Record, other National and outstanding challenges and proposed resolutions; and references to other technical implementation guides and templates; e.g., CCR/G.

**BUSINESS USE CASES, WORKFLOWS AND REQUIREMENTS**

Strictly speaking, the Technical Implementation Guide would not contain business use cases, workflows, and requirements, but rather it should contain references to specific business-centric artifacts that guide all aspects of implementation, including technical considerations.

While an exhaustive list of use cases does not exist at this point in time and is likely to evolve, the sampling below illustrates the breadth of clinical and administrative scenarios that would be supported by applications and services: referrals, transfer of care, ER visit, immediate care visit; hospitalization and discharge – inpatient care; hospital outpatient care; ambulatory care; guardian add / delete / change, demographics and identity management; nursing care, telemedicine and remote monitoring; ambulance service; med reconciliation; chronic disease and wellness management; critical care patients; and public health.

Interactions between patients and providers in the context of these encounters can lead to circumstances where patients and caregivers direct their software applications (PHRs and EHRs) to exchange data, exported from one system (System of Record) and imported to the other.

**USE CASE SAMPLES FOR TECHNICAL IMPLEMENTATION GUIDE**

An interesting partitioning of the use cases would be to consider exchanges that are intended for initial data population vs. updates to pre-existing systems.

**Initial Data Population**

It is not uncommon for the initial data population of PHR systems to be based on data stored in institutional systems, such as hospital or ER discharge, ambulatory data, claims-based data from an insurer's system, pharmacy information system, etc.

When a PHR is being populated for the first time, there is no ambiguity as to how a particular entry (medication, condition, allergy, etc) is to be interpreted when coming from a source that
has proven adherence to published standards; all data is new and it is expected that the target PHR will need to allocate new elements for each new entry being imported.

In this context, primary sources of data lossiness – as described earlier – are differences between the PHR and the source system’s data models, mismatches in the selection of supported vocabularies, and differing data management practices (plus software interoperability and security).

Let us consider some examples of the technical challenges that may be faced when populating a PHR for the first time:

- The PHR may lack the ability to store certain types of data. In this case, source data will be lost when exchanged with the PHR. It is interesting to note that there is no definitive definition of what all PHR data models should contain. Multiple efforts in this space have been undertaken including efforts by the Markle Foundation as well as HL7.
- The PHR may not support coding systems from the source system (e.g. the PHR might not support CPT procedure codes). In this case, a conversion from unsupported to supported vocabularies, adding a column to indicate the coding system of the source, or even textual representation may be required.
- There may be different ways of representing and interpreting data within the same standard. Consider for instance, the flexibility of representation of family history data in the CCR standard, allowing for multiple ways to map conditions to specific relatives. If the PHR interprets the standard representation in a manner that differs from that of the source system, there is the potential for incorrectly storing the original data, either storing it redundantly or not at all.

IMPORTING TO PRE-POPULATED PHR

Importing data to a pre-populated PHR is riddled with the same issues as in the initial PHR population, as well as with additional challenges that were identified earlier pertaining to data merge.

Consider the following:

- A method for determining when portions of the patient’s medical record are equivalent when different words are used to describe the same concept. How will the PHR identify that portions of the patient’s medical record are identical? In general, there is no commonly agreed-upon identity mechanism between independently developed systems. A PHR may list a patient-entered medication as 'antibiotic', while the EHR system may list the medication as 'amoxicillin'. Consider that even if the names matched, should the PHR consider a medication record the same if there are gaps in the date ranges identified in the two systems?
- A set of rules for overwriting data imported from external sources. Once a record is considered a “match,” should all imported data override the data contained in the PHR? Clearly not. For instance, if the PHR contains an entry for plan of care and the patient had listed, in his/her own words, medical instructions then importing data from an EHR should not cause the patient's notes to be overwritten with the doctor's notes. However, will merging of data sub-elements create an inconsistent result, with mixed information from the patient and provider?
Alternatively, if each source and data element is kept and provenance maintained for each, it can become a navigation challenge to gain an understanding of the data.

- A set of rules must be created to avoid re-merging data in the PHR. How does the PHR avoid re-merging data? Consider the scenario where the PHR allows the patient to interact with the merge process, allowing certain merges to occur and preventing others. It would be irritating to the patient to have to review the same data each time synchronization with the source system (EHR) was initiated. This would be akin to balancing your entire checkbook every time you downloaded your bank statements.
- A set of rules for making deletions to a patient’s PHR. Is it reasonable to expect that the PHR should recognize that the source system deleted a particular record? Consider the case where an entry was incorrectly associated with the patient's record. Once the mistake is identified, the EHR can be corrected and the erroneous record “deleted.” If the PHR imported that record at an earlier exchange, should it now recognize the deletion?

**EXPORTING FROM PHR TO EHR**

Typically, EHR data will not be overwritten as a result of interaction with a PHR. The EHR system will need to systematically extract from the PHR “patient-reported” data that will typically require the review of the assisting staff prior to incorporation into the EHR system. It is possible that the EHR system can implement a system of identifying “new” information originating from the patient and then provide a mechanism for clearly identifying it as patient-sourced. In this case, importing from a PHR is less of a fully automated merge and more like the identification of changes for the purposes of enabling the controlled editing of the EHR data by the medical staff.

An alternative model is to consider the import as a “document snapshot” as opposed to using the data with the intent of directly importing.

**CLOSING THE LOOP EXPORTING FROM PHR TO EHR TO PHR AND ON-GOING UPDATES**

EHRs and HIE (Health Information Exchange) community systems of record can play major roles in “refreshing” PHRs after ambulatory patient provider interaction or inpatient care. Segregation of patient, provider, and payer data may be helpful, especially in the short-term, to work around “lossiness” issues in general, with EHR, HIE, and payer data maintaining its own internal integrity.

**CONCLUSION**

The automated exchange of patient clinical data is subject to a number of technical challenges. A tried and tested approach towards overcoming interoperability challenges is the creation of a set of agreements (technical implementation guide) aimed at minimizing circumstances where data is either lost or misinterpreted, supported, or approved by all participants. Implementing active enforcement and gaining trust from all participants is a prerequisite for the technical implementation guide to be effective. Community systems of record / sources of truth are amongst a number of alternatives yet to be proven in exchanging data between EHRs and PHRs.
The authors of the Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings, recommend the formation of a National Collaborative with representatives from the standards organizations referenced in this chapter, whose sole purpose would be to create a Technical Implementation Guide which will identify data exchange standards, controlled vocabularies, and processes for supporting data initialization and merge.


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HEALTH INFORMATION TECHNOLOGY ACCESSIBILITY FOR PERSONS WITH DISABILITIES

ABSTRACT

People with disabilities may encounter obstacles when using health information technology (e.g., PHR software that can only be operated with a mouse). These challenges may not be readily apparent to those unfamiliar with assistive technologies used by people with disabilities. This chapter will discuss the impact of such technology barriers on health disparities. Issues addressed will include types of technologies, disability categories, and stakeholder populations affected by public policies related to accessibility. Recommendations are provided to help close the gap in universal access to health information technology.

INTRODUCTION AND BACKGROUND

In 2004, President George W. Bush signed Executive Order 13335 and spearheaded a nationwide endeavor to make electronic health records (EHRs) available to all Americans by the year 2014. Much recent attention has been focused on EHR interoperability. Although federal leadership has privately acknowledged that accessibility to people with disabilities is being taken seriously, it has been absent from the core values communicated by most principals involved in this collaboration. Amazingly, even though EHRs are covered by a major federal accessibility regulation (Section 508), no easily discoverable hits on the subject are returned through an Internet search of relevant key words (as of June 2008).

This apparent oversight is significant for multiple reasons: First, even if they own a personal health record (PHR), many individuals with disabilities may not be able to use the health information due to technical problems with the PHR metadata or coding, an interoperability barrier to assistive technologies used by people with disabilities. Second, people with disabilities are major consumers (or potential consumers) of health information. Third, this health disparity conflicts with the democratic intent of the Presidential directive, which is to truly make the electronic health information available to all the users of the healthcare system.

The disability community is very interested in this health information technology initiative because it sees an opportunity to positively impact the development of a new infrastructure to ensure equal access to health information by all Americans. For those involved with consumer health access, this is just as exciting as when President Eisenhower passed a law for the creation of an improved national highway system a half century ago. However, people with disabilities are worried that they are going to be left behind as we move forward along the health information superhighway. From the disability perspective, the consumer interest is already behind the ball in


170 Private email communication with Eileen Elias, HHS Office on Disability, May 8, 2008.
some respects. For example, without regard to 508-accessibility, cooperative agreements have been awarded to multiple organizations to expand trial implementations of the National Health Information Network. Therefore, an aggressive approach is needed at this point to catch up.

It is important to understand that we are not talking about helping a small number of people. An estimated 1 in 5 people in the United States has a disability (roughly 54 million people).\footnote{Interagency Committee on Disability Research: Current Research: Latest Disability Statistics: http://www.icdr.us/statistics.html (Accessed 10 July 2009)} This makes people with disabilities the largest minority in the country. It includes people who have disabilities that vary from mild to severe, and it includes people with temporary as well as chronic disabilities. In fact, it has been said that everyone will acquire a disability at some point in their lifetime -- unless they die first! The size of this demographic is surprising to many people because of a limiting conception of people with disabilities as those with visual manifestations of their disability (e.g., you can see white canes, service dogs, sign language, and wheelchairs). In fact, many people with disabilities have an invisible impairment that you cannot detect by simply looking at them (e.g., they are hard of hearing).

Another fundamental point to clarify is that the term “accessible” means something very different in the disability community than it does in the public health community, and this has been the cause of misunderstandings in communication. In the disability community, it refers to design standards and guidelines that reduce or eliminate impediments to people with disabilities. For example, the rate of a blinking object on a website can be adjusted so that it does not induce a seizure in people with photosensitive epilepsy. In the public health community, however, accessibility simply means availability. For example, if you hand someone a health record, it is then assumed that he or she has access to that health record. However, just because people possess a PHR does not mean they can actually read it, as is often the case with inaccessible PDF documents of health information.

People with disabilities encounter this type of misunderstanding repeatedly in other environments as well. For example, in the past, public transportation officials may have informed people with disabilities that buses were “accessible” to them because of new routes that stopped near their homes. However, that availability, which they called accessibility, did not necessarily mean that the vehicle was wheelchair-accessible.

**PUBLIC POLICY**

There are many public policies that impact accessible health information technology. One of the most relevant laws is Section 508 of the Rehabilitation Act. This is a Federal law that requires Federal agencies and departments to comply with accessibility standards for electronic and information technology promulgated by the U.S. Access Board.\footnote{"Title V.\" The Rehabilitation Act Amendments of 1973, as amended. Washington DC: U. S. Access Board; 1998. Available at: http://www.access-board.gov/enforcement/Rehab-Act-text/title5.htm (Accessed 10 July 2009)} \footnote{U.S. Access Board: Section 508 Homepage: Electronic and Information Technology: http://www.access-board.gov/508.htm (Accessed 10 July 2009)} Section 508 has...
received a great deal of attention, in part, because Federal agencies can get sued if they don’t abide by the regulations, and the rules affect a 37 billion dollar federal information technology market. The 508 standards have an effect that reaches far beyond the Federal government through, as it has been adopted, in whole or in part, by state and local governments, as well as universities and private companies. It has generated a great deal of international interest as well, as other countries are addressing accessibility challenges using the U.S. as a model.

Section 508 specifically requires that when Federal departments or agencies develop, procure, maintain, or use electronic and information technology, they shall ensure that the technology is accessible to people with disabilities, unless an undue burden would be imposed on the department or agency. Many products meet some but not all applicable 508 provisions. Fortunately, exceptions, such as lack of commercial availability, listed in Subpart A of the 508 Standard, allow Federal agencies to be fully compliant with the 508 statute, while procuring non-conforming products.

The standards provide technical criteria particular to various types of technologies and performance-based requirements, which focus on the functional capabilities of covered technologies. The 508 standard allows a product to either have accessibility built-in or to be made compatible with assistive technology. The 508 Standard also requires compliance with provisions for information, documentation, and support.

There is no 508 certification of products, nor are there plans by the Federal government to create such a system of evaluation. There are also no official testing methods published for use in assessing products for 508-conformance. However, a great deal of free training material has been developed over the past decade by GSA (Government Services Administration) and the Access Board to assist those affected by Section 508, including manufacturers as well as government customers. This technical assistance includes guides, tutorials and a database with information on product accessibility. In addition, many federal agencies with an interest in accessible health information technology, such as SSA, VA and HHS, have developed information to assist their product development and procurement staff.

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SCOPING

It is important to have a big-picture perspective on the impact of accessibility on various technologies, disabilities, and stakeholders. The Section 508 Standard includes approximately 70 design requirements, and a few examples of the barriers they address will be discussed below.

Electronic forms can be a problem to people who are blind, especially when trying to fill out PHRs using assistive technologies, because they may not know which field they are in or their cursor may be stuck in a field. Another issue might be that they may not know that checkboxes have been presented, how many boxes there are, and the status of the boxes (checked or not).

Websites not only serve as a portal to access health record information but they can also be used for other health information applications, such as when searching for medical specialists on insurance company databases before scheduling an appointment. On the issue of scheduling appointments, accessible telephone response systems can support consumers who wish to directly contact the offices of their health providers. Specifically, people with hearing or speech impairments may converse over the telephone with TTYs and therefore need telephone voice mail and auto attendants to be TTY-compatible.

Types of technology cannot be viewed in isolation though because accessible health information technology extends beyond the health record itself. For example, videos may be provided to train people on how to use their health records, and the videos will probably require captioning so that people with hearing loss can understand the narration. Software is used to create electronic health records as well as manage them, and PHRs are delivered to users through web applications. Even if PHRs were usable by people with disabilities, individuals would still be frustrated if they discovered that they could not develop their own PHRs because of software glitches or could not access parts of a website.

Other health information products include features of different technologies and are considered “convergent”. An example is a handheld device used by consumers to enter personal health data to be synchronized with their computer. In addition, there are complex hardware/software information systems used by professionals to administer EHR data.

Accessible health information technology opens doors to people with a variety of disabilities: hearing, vision, speech, mobility, dexterity, and cognitive. Access to electronic content has primarily been viewed as a blindness issue. People who are blind may use assistive technology, such as screen readers, to access electronic information. This speaks the written words out loud for them to hear. They might also use a refreshable Braille display, which allows them to feel the letters through raised pins that move in correspondence with text. If a website is not coded with accessibility in mind, then the assistive technology may not convey information essential for comprehension. For example, if the assistive technology encounters an EKG reading, it might simply say “graphic”, but if the graphic were described through a text equivalent (e.g., EKG of

182 Ham B. When getting to the doctor is half the battle. The Prepared Patient. 2008 May:1(7)
183 Blechman EA. Technical standards, individuals with disabilities, and personal health records. [Presentation at the 2007 American Public Health Association Conference]. [Boulder, CO]:TheSmartPHR; 2007. Available at:
office visit on 6-7-08) then the user might know at least the title of it and type of data within it. By the way, since others might benefit from the seeing the title, this is an example of how accessibility can improve usability for all users.

Electronic information that is designed in conformance with accessibility standards will naturally benefit other users as well. For example, people with dexterity disabilities will be able to navigate through the information effectively by using speech recognition software. Also people with learning disabilities may be able to follow information more efficiently when they can hear it at the same time they read it.

People with dexterity disabilities also benefit from accessible health information technologies. For example, portable devices used to enter blood glucose levels, could be designed with controls that are easier to use by consumers with dexterity disabilities (e.g., the buttons are raised, separated, and non-slip like those found on some ATMs). A touch screen, such as wireless computer tablets used by healthcare providers in treatment rooms, might be difficult for clinicians who have difficulty holding their hand steady and pointing a finger to touch soft buttons. They would pose an accessibility challenge to people who are blind, because the display feels flat and is therefore not usable to them. For purposes of accessibility, touch screens are allowed, but an additional means of input must provided.

Sometimes accessible design seems daunting because it would appear to fundamentally alter the product, but that design challenge does not negate the barrier faced by people with disabilities. Unless we shine a spotlight on these obstacles, manufacturers will not know to consider these issues when planning future product development lifecycles. In some cases, data input could be controlled through voice input and information output can be provided through signals sent to compatible devices with assistive technologies attached to them (but voice input must not be required as the only means of access, less another barrier be created).

Many stakeholder groups benefit from accessible health information technology. Often the users are referred to as consumers, clients or patients. However, people with disabilities are actually integrated everywhere and should not be viewed as a segregated population. For example, there are physicians and nurses with disabilities. Their disabilities may be recently acquired or lifelong and that makes a difference in whether their challenge is getting a job or keeping their job. In fact, a blind doctor was recently inducted into the National Hall of Fame for Persons with Disabilities (2002), to acknowledge her achievement -- getting through medical school and a residency while facing disability discrimination. Other stakeholders with disabilities include, but are not limited to: hospital administrative staff, manufacturers, insurance company personnel, government analysts, researchers, students and educators. Note that when it comes to reducing disparities in use of health information technology, some people start out with a vision of wanting to help consumers make better informed healthcare decisions and soon realize that accessible health information technology also opens doors in academia and employment.

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185 National Hall of Fame for Persons with Disabilities, Inc., P.O. Box 151053, Columbus, Ohio 43215; (614) 878-3390
RECOMMENDATIONS

A robust strategic plan is needed to elevate the accessibility of health information technology to a level of prominence and help ensure that people with disabilities are not left behind in the health information age. Here are some starting points to consider the following:

- Accessibility should be considered a core requirement mentioned alongside privacy, confidentiality, and security. This should be documented in top-down policies and reflected in website communication and public presentations. IT accessibility should be a high-level value broadly impacting the federal health information technology ecosystem, including the work products of: ONC, FHA, AHIC, CCHIT, and HITSP. In addition, the American Public Health Association is encouraged to follow through with its intention to incorporate accessibility into its PHR/EHR position statement.

- Stakeholder organizations should appoint people who are accountable for ensuring health information technology accessibility. Such people should receive training to become qualified as accessibility coordinators. This follows the “508 coordinator” model used in the Federal sphere.

- Advisory committees should include accessibility specialists, preferably those with health information technology background, to advocate for implementation of an accessibility strategic plan.

- Public outreach should affirmatively solicit input from the disability community. Disability organizations may not be aware of this window of opportunity to influence health information technology universal design. Barriers to their participation in the public comment process should be identified and remedied.

- Standards development organizations should incorporate or reference existing applicable accessibility requirements that cover health information technology.

- Certification of health records and other health information technology should include accessibility (defined as conformance to the Section 508 Standards) as success criteria.

- Best practices could be developed to encourage incorporation of accessibility into procurement solicitations. This needs to be enforced to effectively drive accessible design. (Government wide, only 3 percent of Federal solicitations for electronic and IT products properly included Section 508 accessibility standards, according to a 2007 GSA assessment of solicitation notices on the Federal Business Opportunities Web site.)

- Ongoing technical assistance and training on health information technology accessibility needs to be available at all levels.

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• Identify areas for research in accessible health information technology.

David Baquis works as an IT Accessibility Specialist with the U.S. Access Board. He delivers presentations on accessible electronic and information technology; writes technical assistance materials and responds to public inquiries on Sections 508 of the Rehabilitation Act and 255 of the Telecommunications Act. His background blends experience in healthcare, consumer education, disability issues, technology, and public policy.

David Baquis, U.S. Access Board, baquis@access-board.gov, 202-272-0013

Special thanks to Bruce Bailey of the Access Board for his editorial review and helpful remarks.
# APPENDIX I - ACRONYMS

<table>
<thead>
<tr>
<th>TERMS</th>
<th>DEFINITIONS</th>
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<tr>
<td>CCHIT</td>
<td>Certification Commission for Healthcare Information Technology</td>
</tr>
<tr>
<td>CCR</td>
<td>Continuity of Care Record</td>
</tr>
<tr>
<td>CCD</td>
<td>Continuity of Care Document</td>
</tr>
<tr>
<td>CDA</td>
<td>Clinical Document Architecture</td>
</tr>
<tr>
<td>DOQ-IT</td>
<td>Doctor’s Office Quality – Information Technology</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Record</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record</td>
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<tr>
<td>HHS</td>
<td>Department of Health and Human Services</td>
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<td>HIE</td>
<td>Health Information Exchange</td>
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<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
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<td>HISPC</td>
<td>Health Information Security and Privacy Collaborative</td>
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<td>HIT</td>
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<td>HITSP</td>
<td>Health Information Technology Standards Panel</td>
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<td>HL7</td>
<td>Health Level 7</td>
</tr>
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<td>IT</td>
<td>Information Technology</td>
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<td>NAHIT</td>
<td>National Alliance for Health Information Technology</td>
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<td>NHIN</td>
<td>National Health Information Network</td>
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<td>ONC</td>
<td>Office of the National Coordinator</td>
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<td>ONCHIT</td>
<td>Office of the National Coordinator for Health Information Technology</td>
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<td>PHR</td>
<td>Personal Health Record</td>
</tr>
<tr>
<td>QIO</td>
<td>Quality Improvement Organization</td>
</tr>
<tr>
<td>RHIO</td>
<td>Regional Health Information Organization</td>
</tr>
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<td>SDO</td>
<td>Standards Development Organization</td>
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# APPENDIX II - TERMINOLOGY

<table>
<thead>
<tr>
<th>TERMS</th>
<th>DEFINITIONS</th>
<th>SOURCE</th>
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</thead>
<tbody>
<tr>
<td>Access</td>
<td>Your ability to get needed medical care and services. The process of obtaining data from, or placing into a computer system or storage device. It refers to such actions by any individual or entity who has the appropriate authorization for such actions.</td>
<td>Patient Privacy Rights</td>
</tr>
<tr>
<td>Authentication</td>
<td>Verifying the identity of a user, process, or device, often as a prerequisite to allowing access to resources in an information system.</td>
<td>Office of the National Coordinator for Health IT</td>
</tr>
<tr>
<td>CCD</td>
<td>Continuity of Care Document is an electronic document exchange standard for sharing patient summary information among providers and within personal health records. It summarizes the most commonly needed pertinent information about current and past health status in a form that can be shared by all computer applications, from web browsers to electronic medical records. In a formal, technical sense, the Continuity of Care Document (CCD) is a set of constraints on CDA that define how to use the CDA to communicate clinical summaries.</td>
<td>Healthcare Information and Management Systems Society Electronic Health Record Vendors Association (EHRVA)-2007 <a href="http://www.himssehrva.org/ASP/CCD_QSG_20071112.asp">http://www.himssehrva.org/ASP/CCD_QSG_20071112.asp</a></td>
</tr>
<tr>
<td>CCR</td>
<td>Continuity of Care Record is a health record standard specification developed jointly by ASTM International, the Massachusetts Medical Society, the HIMSS, the American Academy of Family Physicians, the American Academy of Pediatrics, and other health informatics vendors. The CCR standard is a patient health summary standard. It is a way to create flexible documents that contain the most relevant and timely core health information about a patient, and to send these electronically from one caregiver to another. It contains various sections such as patient demographics, insurance information, diagnosis and problem list, medications, allergies and care plan. These represent a “snapshot” of a patient’s health data that can be useful or possibly lifesaving, if available at the time of clinical encounter. The ASTM CCR standard is designed to permit easy creation by a physician using an electronic health record (EHR) system at the end of an encounter. Because it is expressed in the standard data interchange language known as XML, a CCR can potentially be created, read and interpreted by any EHR and EMR software applications.</td>
<td><a href="http://en.wikipedia.org/wiki/Continuity_of_Care_Record">http://en.wikipedia.org/wiki/Continuity_of_Care_Record</a> see: ASTM E2369-05, <em>Standard specification for continuity of care record (CCR)</em>. West Conshohocken, PA: ASTM; 2005. <a href="http://www.astm.org/Standards/E2369.htm">http://www.astm.org/Standards/E2369.htm</a></td>
</tr>
<tr>
<td>CDA</td>
<td>The Clinical Document Architecture which was until recently known as the Patient record Architecture (PRA), provides an exchange model for clinical documents (such as discharge summaries and progress notes) and brings the healthcare industry closer to the realization of an electronic medical record.</td>
<td><a href="http://www.hl7.org">http://www.hl7.org</a></td>
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<tr>
<td>CDA</td>
<td>The HL7 Clinical Document Architecture is a document markup standard that specifies the structure and semantics of a clinical document (such as a discharge summary, progress note, procedure report) for the purpose of exchange. A CDA document is a defined and complete information object that can include text, images, sounds, and other multimedia content. It can be transferred within a message, and can exist independently, outside the transferring message.</td>
<td>Dolin RH, Alschuler L, Boyer S, Beebe C, Behlin FM, Biron PV, Shabo Shvo A. HL7 clinical document architecture, release 2. J AM Med Inform Assoc. 2006 Jan-Feb;13(1):30-39 <a href="http://www.jamia.org/cgi/reprint/13/1/30">http://www.jamia.org/cgi/reprint/13/1/30</a></td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Preserving authorized restrictions on information access and disclosure, including means for protecting personal privacy and proprietary information.</td>
<td>Office of the National Coordinator for Health IT</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record is an electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization.</td>
<td>NAHIT <a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf</a></td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record is an application environment composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications. This environment supports the patient’s electronic medical record across inpatient and outpatient environments, and is used by healthcare practitioners to document, monitor and manage health care delivery within a care delivery organization (CDO). The data in the EMR is the legal record of what happened to the patient during their encounter at the CDO and is owned by the CDO.</td>
<td>HIMSS Analytics</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
<td>Source</td>
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</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Record is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff, across more than one health care organization.</td>
<td>NAHIT <a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf</a></td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Record is a subset of each care delivery organization’s EMR, presently assumed to be summaries like ASTM’s Continuity of Care Record (CCR) or HL7’s Continuity of Care Document (CCD), is owned by the patient and has patient input and access that pans episodes of care across multiple CDOs within a community, region, or state (or in some countries, the entire country). The EHR in the US will ride on the proposed National Health Information Network (NHIN).</td>
<td>HIMSS Analytics</td>
</tr>
<tr>
<td>HIO</td>
<td>Health Information Organization is an organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards.</td>
<td>NAHIT <a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf</a></td>
</tr>
<tr>
<td>Interoperability</td>
<td>The ability of two or more systems or components to exchange information and to use the information that has been exchanged</td>
<td>IEE Standard Computer Dictionary</td>
</tr>
<tr>
<td>NHIN</td>
<td>National Health Information Network is a ‘network of networks’ that will securely connect consumers, provider and others who have, or use, health-related data and services while protecting the confidentiality of health information. The NHIN will not include a national data store or centralized systems at the national level. Instead, the NHIN will use shared architecture (services, standards and requirements), processes an procedures to interconnect health information exchanges and the users they support.</td>
<td>Office of the National Coordinator for Health IT</td>
</tr>
<tr>
<td>PHR</td>
<td>Personal Health Record is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.</td>
<td>NAHIT <a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf</a></td>
</tr>
<tr>
<td><strong>PHR</strong></td>
<td>Personal Health Record is a private, secure application through which an individual may access, manage and share his health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and care providers. The PHR might or might not include information from the electronic health record (HER) which is maintained by the health care provider and is not synonymous with the EGR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers.</td>
<td>National Library of Medicine</td>
</tr>
<tr>
<td><strong>Patient Registry</strong></td>
<td>A Patient Registry is a patient database maintained by a hospital, doctor’s practice or health plan that allows providers to identify their patients according to disease, demographic characteristics and other factors. Patient registries can help providers better coordinate care for their patients, monitor treatment and progress and improve overall quality of care.</td>
<td>Robert Woods Johnson Foundation [<a href="http://www.rwjf.org/qualityeq">http://www.rwjf.org/qualityeq</a> uality/products.jsp?id=30712](<a href="http://www.rwjf.org/qualityeq">http://www.rwjf.org/qualityeq</a> uality/products.jsp?id=30712)</td>
</tr>
<tr>
<td><strong>Privacy, the right of</strong></td>
<td>The right of privacy is: “the claim of individuals, groups, or institutions to determine for themselves, when, how, and to what extent information about them is communicated.”</td>
<td>65 Fed. Reg. At 82,465</td>
</tr>
<tr>
<td><strong>RHIO</strong></td>
<td>Regional Health Information Organization is a health information organization that brings together health care stakeholders in a defined geographic area and governs health information exchange among them for a purpose of improving health care in that community</td>
<td>NAHIT [<a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051</a> 508.pdf](<a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051</a> 508.pdf)</td>
</tr>
<tr>
<td><strong>Security</strong></td>
<td>The protection of information and information systems from unauthorized access, use, disclosure, disruption, modification, or destruction in order to provide confidentiality, integrity, and availability</td>
<td>US Department of Health and Human Services</td>
</tr>
<tr>
<td><strong>Smart Card</strong></td>
<td>A smart card is approximately the size of a standard credit card, and conforms to the requirements of ISO/IEC 7816 (identification cards-integrated circuits(s) cards with contacts),, and ISO/IEC 7810 (identification cards-Physical characteristics. A computer chip is embedded in the smart card and presents a set of electrical contacts for interface to a separate smart card reader. Because of this integrated set of contacts, it is referred to as a “contact chip” A smart card has only limited onboard memory, typically 32 to 128 kilobytes of information</td>
<td>AllIM &amp;ASTM Portable Document Format for Healthcare (PDF/H) Best Practices Guide 2007</td>
</tr>
<tr>
<td><strong>USB</strong></td>
<td>Universal Serial Bus Cryptographic Token variously referred to as a secure token, a dongle, or a USB fob, the USB cryptographic token resembles a USB thumb or flash drive. That resemblance is only skin deep as a USB cryptographic token includes an internal computer chip with functional capabilities equivalent to a smart card.</td>
<td>AIIM &amp; ASTM Portable Document Format for Healthcare (PDF/H) Best Practices Guide 2007</td>
</tr>
<tr>
<td><strong>Flash Drive/ Memory Card</strong></td>
<td>A flash drive can take on multiple formats such as a USB thumb drive, a memory stick, or a memory card. The flash drive is primarily a data storage device. Storage capacities vary from 128 megabytes to 8 gigabytes today with higher capacities likely on the way. While some devices tout data encryption capabilities, this is accomplished using software on a computer external to the device, with its associated security and performance limitations.</td>
<td>AIIM &amp; ASTM Portable Document Format for Healthcare (PDF/H) Best Practices Guide 2007</td>
</tr>
<tr>
<td><strong>Web Services</strong></td>
<td>Programs running on computers connected to the Internet that can interoperate with programs on other computers, using XML as a standard way of formatting data to be communicated.</td>
<td>Barron’s dictionary of Computer and Internet Terms 9th Edition</td>
</tr>
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</table>
## APPENDIX III – PHRS ON THE MARKET (AS OF DECEMBER 2008)

<table>
<thead>
<tr>
<th>PRODUCT NAME</th>
<th>FORMAT</th>
<th>COST</th>
<th>URL</th>
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</thead>
<tbody>
<tr>
<td>A Smart PHR</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.thesmartphr.com">http://www.thesmartphr.com</a></td>
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<tr>
<td>AboutMyHealth</td>
<td>Internet Service</td>
<td>Free Tools</td>
<td><a href="http://www.aboutmyhealth.org">http://www.aboutmyhealth.org</a></td>
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<tr>
<td>AccessMyRecords</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.accessmyrecords.com/">http://www.accessmyrecords.com/</a></td>
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<tr>
<td>ActivePHR</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="https://www.activehealthphr.net/dtc/">https://www.activehealthphr.net/dtc/</a></td>
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<tr>
<td>AMESMyFile</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.amesmyfile.com%20">http://www.amesmyfile.com%20</a></td>
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<tr>
<td>Bartlett</td>
<td>Software Program</td>
<td>Product for Purchase</td>
<td><a href="http://www.pehrtech.com/">http://www.pehrtech.com/</a></td>
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<tr>
<td>CapMedPHR</td>
<td>Software Program</td>
<td>Product for Purchase</td>
<td><a href="http://www.capmedphr.com/">http://www.capmedphr.com/</a></td>
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<tr>
<td>Caregiver Alliance Web Services™</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.caregiveralliance.com">http://www.caregiveralliance.com</a></td>
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<tr>
<td>CheckUp</td>
<td>Software Program</td>
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<td>Compiling Your Family Health History</td>
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<td>Product for Purchase</td>
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<td>dLife</td>
<td>Internet Service</td>
<td>Free Tools</td>
<td><a href="http://www.dlife.com">http://www.dlife.com</a></td>
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<td>Dr. I-Net</td>
<td>Internet Service</td>
<td>Free Tools</td>
<td><a href="http://www.drinet.com">http://www.drinet.com</a></td>
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<td>DrGlobe.com</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.drglobe.com">http://www.drglobe.com</a></td>
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<td>EMRY STICK</td>
<td>Internet Service</td>
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<td>ER Card</td>
<td>Software Program</td>
<td>Product for Purchase</td>
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<td>ER-IDcard</td>
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<td>Follow Me</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
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<td>Full Circle Registry</td>
<td>Internet Service</td>
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<td>GlobalPatientRecord</td>
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<td>Good Health Network</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.ghnetwork.com/">http://www.ghnetwork.com/</a></td>
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<td>Google Health Records</td>
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<td>Free Tools</td>
<td><a href="http://www.google.com/health">http://www.google.com/health</a></td>
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<td>Handymedical.com</td>
<td>Internet Service</td>
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<td>Health File</td>
<td>Software Program</td>
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<td><a href="http://www.wakefieldsoft.com/healthfile">http://www.wakefieldsoft.com/healthfile</a></td>
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<td>Health Minder</td>
<td>Software Program</td>
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<td>Health Profiler</td>
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<td>Health Records Online</td>
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<td>HealthButler</td>
<td>Internet Service</td>
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<td><a href="http://www.healthbutler.com/">http://www.healthbutler.com/</a></td>
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<td>HealthCapture PHR</td>
<td>Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.healthcapture.com">http://www.healthcapture.com</a></td>
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<tr>
<td>HealthTracks™</td>
<td>Paper-based/Internet Service</td>
<td>Product for Purchase</td>
<td><a href="http://www.healthetracks.com/">http://www.healthetracks.com/</a></td>
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<tr>
<td>HealthFolio</td>
<td>Software Program</td>
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<td><a href="http://www.healthfolio.net">http://www.healthfolio.net</a></td>
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<td>Software Program</td>
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<td>HealthNote</td>
<td>Paper-based</td>
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<td>HealthString</td>
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<tr>
<td>I.C.E. Alert™</td>
<td>Software Program</td>
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