

Personal Health Records – Term Paper

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*“Technology is not kind. It does not wait. It does not say please. It slams into existing systems...and often destroys them. While creating a new system”*

Joseph Schumpeter- excerpt from The Change Function, Pip Coburn.

## Introduction

In health care, there are specialized tools and standards emerging to help individuals and providers to manage the stream of information as it pertains to personal health. One tool is a personal health records (PHR). A 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 healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider (*American Health Information Management Association (AHIMA), 2003*).

The PHR could take on various formats. In its most primitive form, it could be a paper based system, stored in folders or binders in a physical drawer. Electronic scans stored in a virtual file system on a computer, server or portable storage device could also make up a PHR. Portable devices such as smart cards, personal digital assistants, mobile phones and memory devices that plug into a personal computer also could contain PHRs. A PHR can also be a

hosted tool offered by a provider or solutions vendor that extends access to a consumer's record through a web based informational portal. The consumer could access their health records, but not actively control them. (Moore, 2010)

The crucial areas for PHR research are better delineation of their functions and of their impact on care. Primary PHR functions fall into four general categories, based on use of information from the patient's perspective:

- Information Collection—PHR functions that help patients to enter their own health information and to retrieve their information from external sources.
- Information Sharing—PHR functions that allow patients to engage in one-way sharing of their health information with others.
- Information Exchange—PHR functions that allow patients to engage in two-way data exchange with others.
- Information Self-Management—PHR functions that allow patients to better manage their own health/healthcare. Examples of PHR functions in this category include those functions that allow patients to record, track, and edit information about their own health/healthcare, as well as obtain relevant patient oriented disease information and decision support (CITL, 2009).

The majority of solutions emerging and gaining popularity in this market space are internet-based. For obvious reasons, internet-based personal health records give added

convenience for accessibility where they are able to be accessed by any computer or device that has internet capabilities.

One of the fundamental requirements of a PHR is that it be portable, allowing for it to be exchanged with other systems easily. In order to be portable and interoperable with different systems and providers, the PHR must contain certain common data elements.

Suggested elements are:

- Personal demographic information
- General medical information
- Conditions
- Hospitalizations
- Surgeries
- Medications
- Vaccinations
- Laboratory test results
- Clinical tests
- Pregnancy History
- Family Medical History

Consensus is forming on these elements to achieve the needed portability that PHR's require. Since September 2002, the Markle Foundation established Connecting for Health to accelerate the adoption of electronic health records. Their goals were in two parts. First, to engage the public in the endeavor to utilize electronically connected health information systems. The second goal was to engage with the public and start forming acceptance of a PHR (Markle, 2002). In 2003, AHIMA launched myPHR to educate the consumer directly on managing their personal health records (AHIMA, 2003). In 2005, AHIMA launched a public education presentation kit titled "Your Personal Health Information: How to Access, Manage and Protect It" (AHIMA, 2005). So for more than 8 years, the focus has been on educating the

general public. It has only been as recent as 2008 when vendors started offering viable solutions.

An understanding of personal health records requires at least a basic understanding in many areas. For the purpose of this paper, we will be focused primarily on internet-based personal health records or iPHR. We will provide a basic analysis of the market, provide a view of the current and potential barriers to acceptance, and a look at the future of PHRs to provide a complete picture of the PHR.

### U.S. Market Analysis

Over the last 10-15 years due to economic growth and conditions in the United States, many large U.S. based companies are deriving a greater proportion of their revenue globally. As the U.S. markets have slowed, it has become increasingly necessary to identify and infiltrate new emerging markets around the world. The healthcare market is a part of this shift in strategy with many traditional and consumer facing IT and consumer facing internet driven organizations now focused on expanding their opportunities in what is viewed as a highly profitable market. While most early attempts at leveraging their prior experience in this market were simply extensions of their prior technology platforms brought into healthcare, several of these organizations clearly made significant penetration in the rapidly growing markets of Electronic Health Records (EHR). In more recent times, these same vendors along with a score of newly formed businesses have either extended or solely focused on the PHR market so that it is simply becoming more than a feature offered as an extension of these leading EHR players.

Currently, healthcare reform and its associated financial windfalls are driving a significant increase in the movement in the PHR market. However, to date there is not a consensus on a strategy that presents itself as a market differentiator or one shown to be a profitable solution (although admittedly there are several case studies that do show significant ROI improvements for some institutions that we will illustrate later.)

Given this lack of clear revenue models for this business there is still widespread experimentation as a variety of companies are offering widely dissimilar solutions under the general banner of PHR. Our market analysis will focus on the U.S. market and where applicable allude to the broader global market for PHRs.

#### **iPHR market overview**

There are between 100 – 200 PHR vendors in the market today (myPHR, 2010; Moore, 2009, 2010). It is difficult to gauge the exact number of vendors due to the changing nature of the space as well the different types of businesses offering PHRs. John Moore of Chilmark Research posits at most 40 vendors can be characterized as iPHR solutions. Of these 40 vendors, Moore goes on to say that 40% are thriving, 35% are treading water and the remaining 25% are walking zombies (Moore, 2010). The remaining vendors are dominated by providers and health plans offering tethered solutions. Early attempts at marketing directly to consumers have been replaced by a new strategy of marketing to businesses. The shift occurred due to challenges of creating a viable business model, as well as difficulty with data collection methods. One of the early vendors of consumer based PHRs, Revolution Health

(founded by Steve Case, of AOL fame), decided earlier this year to retire its PHR offering on its website (Monegain, 2010).

Marjorie Martin, General Manager for Everyday Health, the parent of Revolution Health is quoted as saying, “PHRs are not catching on with consumers as quickly as anticipated by some companies, she said, in part because of habit and part because they are no always easy to use”(Monegain, 2010). With the shift away from consumers and towards businesses, PHR companies are using different offerings to sell to their customers who then serve as the conduit to consumers.

### Types of iPHRs

iPHRs in the market today are comprised of three different types. John Moore defines them as Standalone, Tethered and Non Tethered. Each of these types has pros and cons associated with them. Moore’s description of each:

Standalone model:

*Example - Company: Passport MD*

- Independent – no affiliation – paper, USB
- relies on consumer input
- highly portable
- hard to keep current
- consumer input solutions have a much higher potential for entry errors

Tethered model:

*Example - Company: Kaiser*

- Tied to an EMR -hosted by providers, insurers, employers

- Up to date (although somewhat restricted) information
- Low portability
- Restrictions on views

Non Tethered:

*Example - Company: Microsoft, Google Health, Dossia*

- Web based – iPHR
- Consumer control
- Highly portable
- Security/Trust barriers

Associated with each of the types of PHRs are the market segments themselves. The market is fragmented along typical lines within the healthcare space. These areas are consumer, provider, health plans, employer and others (government). The areas that have gained the highest concentration of users are health plans, employers and providers. Determining the largest vendors within the market is quite difficult considering the only real measurement is number of customers/patients using the system. Of those, it is somewhat dependent on what information is released to the public. The top vendors in terms of non tethered iPHRs are Google, Microsoft and WebMd. The top vendor in the tethered category is Kaiser. Kaiser claims 3.0 million users of its approximately 8 million potential users (iHealthBeat, 2009). One other vendor is Dossia, who is marketing itself as a Personal Health System. Dossia sees an ecosystem of sorts with the PHR as a component of a larger network of data aggregation tools (Moore, 2009).

The U.S. Government has begun to play in the evolutionary development of PHRs. The establishment of interoperability standards for data transmission and security will certainly help

define the market. The ARRA passage should help usher in adoption on EHRs which should in turn advance the business case for PHRs (RWJF, 2010). U.S. government policy makers with meaningful uses as the backdrop are advocating that physicians offer their patients a PHR by 2013 (Moore, 2009). This could lead to a boon in provider basis iPHR offerings. Most recently the privacy violation notice regulations found in the HITECH Act of 2009, should improve consumers trust of the systems adherence to privacy standards.

### PHR Technologies

Reflecting the relatively nascent phase of the PHR market the technological platforms that these offerings stand upon, as we have briefly mentioned, are still widely diverse:

- Some PHRs are simple local software applications for personal computer or even applications that are served from a removable thumb drive.
- Others are web-based services (accessed through the Internet) that store information in a central repository.)
- Many others have taken on a hybrid format allowing the consumer/patient the ability to store the information on a personal computer and transfer the information to a web-based account.

As stated earlier, the focus of this paper is on the primarily web-based iPHR models, which would include both hybrid and exclusively web-based forms.

An iPHR consists of three primary components: data, infrastructure, and applications. Data at its most basic definition is the information that is exchanged, analyzed, and stored by different information technologies. Traditional forms of healthcare data include claims information, laboratory and imaging results, treatment and pharmaceutical histories, and other

indicators of patient's medical history. Infrastructure is generally the hardware and software platforms, websites, and even mobile devices used to collect, process, and exchange data. Lastly, applications are traditionally the combination of this data and infrastructure, through which data transactions for such basic functions as appointment scheduling and pharmacy renewals, content delivery systems for educational and wellness informational materials, and more complex support systems such as daily health tracking and monitoring can be made.

Of course, one of the key elements in creating an effective iPHR is ensuring significant interoperability with other HIT platforms. A fairly expansive, yet easy to follow, model of this is provided by recent illustration of the Microsoft HealthVault EHR platform. In terms of configuration architecture it exists as a fairly common hub and spoke network model. The importance of the consumer services / PHR connection to different stakeholders (hospitals, physicians, pharmacies, etc.) is clearly driving the value model.

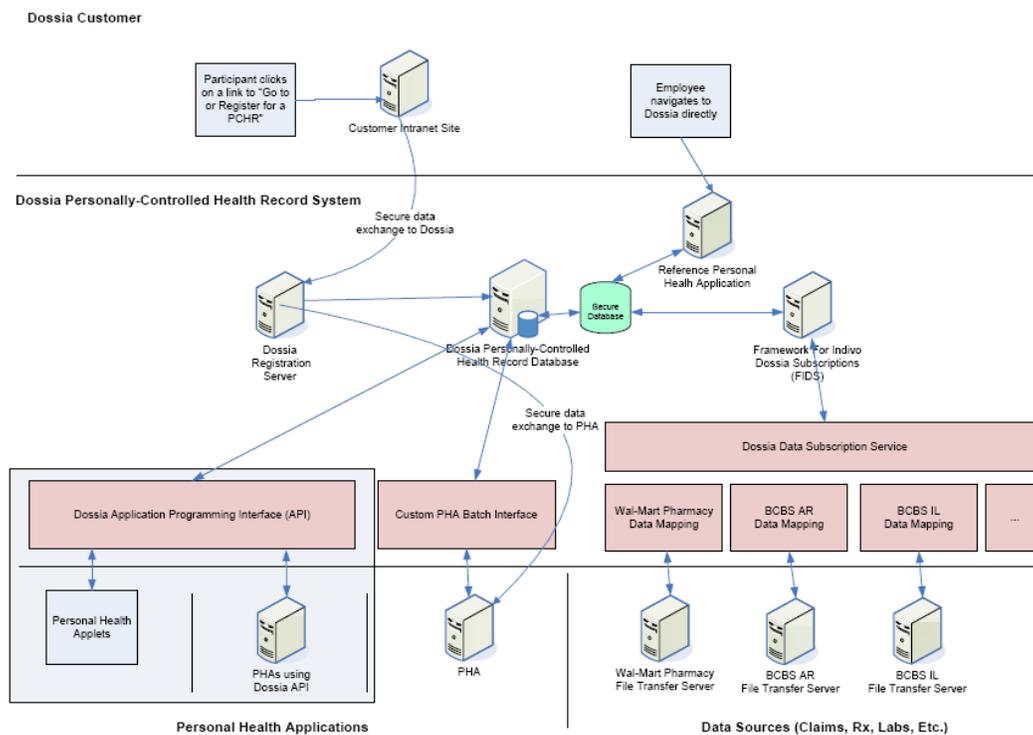


Category	Description	Standard/specification
Functionality	What does a PHR do?	HL7 PHR-S Functional Model
Content	What information does a PHR contain?	HL7 CCD/CDA, IHE XPHR, DICOM IODs, ASTM CCR
Vocabulary and coding	How the information is coded?	SNOMED-CT, LOINC, ICD 9/10, CPT 4/5
Information exchange	How information is exchanged between systems?	HL7 V2&V3, IHE XDS, NCPD (X12N), DICOM
On-line forms	How information is captured and exchanged via forms?	XForms, IHE RFD Profile, OASIS Open Document Format
Personal health devices	How information is captured from devices?	IEEE PHR, Continua Health Alliance Guideline 1.0
Portable media	How is information exchanged using portable media?	USB key, CD-ROM, smart card, IHE XDM, IHE XDR
Web Services	What is needed for a web services based PHR system?	SOAP, WSDL, WS-I Basic Profile

Source: J. H. Kaufman (IBM), Healthcare 2015 and Personal Health Records -A standards Framework, 2009.

In addition to these standards and specifications there must also be a fair assessment of the underlying technology platforms that drive these systems. Conventional web client technologies simply are not robust enough to handle the variety of security and transactional levels required in a web-based, iPHR environment. Several models have been proposed on an open-source level to allow for robust security while also allowing for a variety of access and input points.

One of the leading models, as illustrated here, is provided by Dossia, a non-profit, sponsored by leading corporations such as Wal-Mart, Intel & AT&T, which is focused on providing a share, open PHR platform.



(Source: Dossia Technical Overview, 2009)

As the illustration notes, there are multiple points of entry into the system for patient centric-information, yet most central to the system is the layered security protocols between the Dossia Registration Server, the Dossia Personally-Controlled Health Record Database, and the core Secure Database. This model of multiple layers of security fits their own definition of a "hypersecure" environment for PHRs. Although not clearly expressed in the above illustration, the personal access points to this system, using OpenID standards, literally goes through eight levels of confirmation, further highlighting the critical role of security and by extension privacy to the system.

Finally, as with any other healthcare technology acquisition, understanding the initial and potential costs of iPHRs is of vital importance here. Further, as we have mentioned earlier,

in almost every case study to date there has been limited success in truly finding either a successful profit model for consumer-facing business focused on providing iPHRs or a solid return-on-investment strategy for companies offering PHRs to employees or members (with the significant exception of Kaiser which will be discussed in detail later in this paper.) In response to this lack of positive cost models one can look at the excellent study, *“A Cost Model for Personal Health Records (PHRs)”* issued by a research team with the Center for Information Technology Leadership (CITL) at Harvard Medical School that details the various cost structures for PHR implementation based on system architecture (Shah, *et al.*, 2008).

In this first of a kind study, the researchers at CITL designed a PHR cost model that focused on the primary components of iPHRs: data, infrastructure, and applications. In addition, they developed models to estimate both initial and annual maintenance costs for PHR infrastructure and applications. As the following chart details there are a wide range of inputs necessary to measure the actual costs of PHRs.

PHR single installation total costs acquisition and annual costs by architecture.

PHR Component	Provider -Tethered (\$)		Payer-Tethered (\$)		Third-Party (\$)	
	Acquisition	Annual	Acquisition	Annual	Acquisition	Annual
Clinical Data Repositories	\$0	\$0	\$0	\$0	\$400,000	\$100,000
Client User Authentication	\$95,000	\$14,000	\$95,000	\$14,000	\$95,000	\$14,000
Core Data User Interface	\$450,000	\$90,000	\$450,000	\$90,000	\$450,000	\$90,000
Data Center	\$1,700,000	\$930,000	\$1,700,000	\$930,000	\$1,700,000	\$930,000
Doctor Matching	\$0	\$0	\$0	\$0	\$0	\$57,000
Interfaces	\$40,000	\$8,000	\$20,000	\$4,000	\$6,600,000,000	\$1,300,000,000
Medication Matching	\$0	\$0	\$0	\$0	\$0	\$17,000
Network Connectivity	\$0	\$1,000	\$0	\$1,000	\$0	\$1,000
Patient Matching	\$0	\$0	\$0	\$0	\$67,000	\$125,000
PHR Data Repository	\$0	\$25,000	\$0	\$25,000	\$0	\$25,000
Results Answer Matching	\$0	\$0	\$0	\$0	\$17,000	\$15,000
Results Name Matching	\$0	\$0	\$0	\$0	\$0	\$460,000
User Support	\$0	\$2,700,000	\$0	\$2,700,000	\$0	\$2,700,000
Secure Messaging	\$50,000	\$10,000	\$50,000	\$10,000	\$50,000	\$10,000
<b>Total Cost</b>	<b>\$2,300,000</b>	<b>\$3,800,000</b>	<b>\$2,300,000</b>	<b>\$3,800,000</b>	<b>\$6,600,000,000</b>	<b>\$1,300,000,000</b>
Single Application Cost	\$450,000	\$90,000	\$450,000	\$90,000	\$450,000	\$90,000
Total Cost w/Application*	\$2,800,000	\$3,900,000	\$2,800,000	\$3,900,000	\$6,600,000,000	\$1,300,000,000
Cost per user**	\$3	\$4	\$3	\$4	<b>\$6,600</b>	<b>\$1,300</b>

\*Numbers may be off due to rounding

\*\* assuming one million users

(Source: Shah, et al., 2008)

What is most interesting (or troubling) in the model that the study provides is that for provider-tethered and payer-tethered PHRs, there is minimal interface costs (& one would suppose development), mostly due to the fact that they are simply accessing their own data in an electronic format. Whereas third-party PHRs it is suggested would require many more customized interfaces because these applications only have external access to clinical or administrative data. Honestly while the interface costs number for third-party providers appear to be overinflated, suggesting limits to this study's perspective, there other cost factors seem to indicate a fairly reasonable cost structure for all platform types given significant scale. It is this

effect of scale, reached only in a few instances that has supported a real return-on-investment case for iPHR models.

### Acceptance of and barriers to adoption

#### *Patient (Consumer) Perspective*

Really to look at the consumer market for iPHR's, one must look at the transformational role of the internet in a consumer's participation in their own healthcare. The forces that are pushing the convergence of the Internet and healthcare are myriad. However, the key drivers of change all appear to ensure that the Internet increasingly will be integrated in our healthcare. Foremost amongst these drivers is what is popularly being described as e-patients, the online consumers of healthcare (Chapter 1 - Hunters and Gatherers of Medical Information, 2007).

E-patients, according to a 2008 survey by Harris Interactive represent "66% of all adults in the US, and 81% of adults online" and show a rate of growth of almost 12 percent per year from 1998 to 2008 (Comer, 2009). These health care consumers are more actively involved in making decisions about the health care they receive, with 47% of e-patients having discussed the information they obtained online with their doctors and 49% having gone online to look for information after a doctor's appointment (Comer, 2009). As evidenced in these examples and in other research findings, e-patients expect high levels of choice, control, customer service, interaction with their health care providers, and access to information (Chapter 1 - Hunters and Gatherers of Medical Information, 2007). As the rapid growth of e-patients denotes, consumers of healthcare use the Internet to help meet those expectations. It is this rapid growth in the

consumer health information space and the prospect of yet another consumer informational platform that has driven much of the early excitement about iPHRs.

However, even with this significant consumer excitement the penetration of iPHRs has remained relatively low, certainly at less than ten percent (>10%), and the number of active users is probably much lower (Deloitte, 2009; Forrester Research, 2009; Westin, 2008). Meanwhile, roughly 4 in 5 U.S. adults believe that online PHRs would provide major benefits in managing their health and health care services (Lemieux, 2008). In addition nearly half the public are interested in using a free online PHR system.

To further muddy the waters these same studies show relatively low adoption rates among patients who have been offered free access to a PHR. While the high desire expressed by consumers for this technology would say otherwise; the lack of clearly beneficial consumer facing products; the fact that most consumer facing health portals require time intensive information input and maintenance; and the still limited physician, employer, and insurance support for iPHR platforms have all further stalled consumers' enrollment.

The benefits of iPHRs however are fairly clear. According to a recent study sponsored by WebMD, consumers who were actively engaged with their PHRs when compared to users who do not visit their PHR, showed a number of positive health trends, including:

- Greater readiness to change unhealthy behaviors
  - 7.5% increase of those in the preparation/action/maintenance stages of change vs. 5.3% increase for control group
- Better preventive screening compliance

- Control group had a compliance rate 8.1% higher than the control group
- Fewer missed days due to illness/absenteeism
- Decreased number of missed work days by 10%, while control group increased by 33%
- Larger decreases
  - Depression: 2.9% vs. 0.9%
  - Stress: 3.3% vs. 0.5% (WebMD Health Services Group, 2009).

This brings us full circle back to the importance of “Informed Patients” as these statistics show the obvious benefits of a PHR and dovetail well with the prevalent understanding that engaged, informed patients have a large hand in improving their personal health status. As a variety of studies have shown, enhancing a consumer’s connection to their own health dramatically expands the information seeking for preventive health opportunities (Fox, 2009). “Activating” these healthcare consumers with the skills, knowledge, beliefs and motivations to become an effective health care participant, creates multiple opportunities to expand an individual’s healthcare options. For instance, web-based healthcare tools have the potential to provide education on diseases, allow for the development of decision support mechanisms that facilitate preventive screening decisions by (and of) patients, and even simply provide reminders for patients to ensure timely screening. These web-based Personal Health Records (PHR) platforms that give patients detailed access to their medical information, allow for customization based on patient needs and preferences, and provided a conduit to educational and empowerment opportunities can all play a significant role in increasing a patient’s want to actively seek ways to improve the quality of care that they receive and consequently significantly improve their healthcare outcomes.

### *Physician Perspective*

There are undoubtedly many influencing factors that promote the adoption of or lack therein to technological changes.

In an article study from Health Affairs the barriers to adoption of a computerized physician order entry (CPOE) were considered. Through such a system, accuracy is improved by limiting the number of inputs from a patient visit. The physician electronically records the patient's data, prescribes treatment and orders labs. Such systems could potentially update a patient's personal health record or use it as input for treating provider to make decisions from. In the study, three barriers were mentioned with regard to the adoption of CPOE and certainly apply to computer information systems in general.

Physician and organization resistance is the first and most challenging barrier to overcome as suggested by the article. Many influencing factors can contribute to this. For example, average age of the medical staff. Older physicians will be less likely to change their ways of practicing medicine. For obvious reasons, they have done something long enough that it becomes difficult to retrain and do it differently. Another factor might be lack of motivation to change. The study suggests that "Leadership is as important as the quality of the technology." It goes further to say, "During uncertainties and setbacks, hospital leadership needed to maintain and aggressively communicate a common vision to the hospital staff. This vision must describe not only how CPOE would improve patient safety, quality, and efficiency, but also how it would strengthen the hospital's core mission and consolidate its leadership position within the local market" (Poon, 2004).

The second barrier to implementing new technologies is the cost to implement. New technologies often come with a high price tag. Without necessary funds, implementation is out of reach.

Product and vendor immaturity is the last barrier. Nobody wants to be the pioneer as it can be a painful endeavor working alongside with the vendor to work out kinks and bugs of their system. Being put in such a situation can put patient's safety at risk and cost the organization more money along the way.

### *Employers Perspective*

From an employer perspective there are real incentives to adopting iPHR tools, which help manage the health and improve the productivity of employees. One such tool could be the iPHR. Most employers actively promote overall health and wellness to their employees as a response to cost pressures they face in several areas but predominately around the incentive to reduce the cost of insurance premiums.

Employers today are still trying to figure out what to do with PHRs. What will it solve and what will emerge as a business case? Employers struggle with employee issues as well as employer side issues. Each side of this equation must be carefully thought out. Employee issues revolve around the concepts of trust and portability. Employers are not seen as trustworthy as physicians (Moore, 2009). Employees wonder what data an employer will collect and for what purpose. Equally challenging is the fact that the health record would be owned by the company and therefore not portable by the employee.

From the employer perspective, initiating an implementation of a PHR incurs cost that today cannot be easily measured in 'hard dollar' values with existing ROI. Soft measurement would have to be first identified and then measured, as well as ongoing annual budgetary figures to determine cost basis for implementation. To date, most employer health and wellness is centered on communication and facilitation not necessarily action.

Today there is also a lack of an established goal for the iPHR and the assurance of confidentiality (Moore, 2009). Most businesses have not been able to determine what critical piece a PHR can solve of their healthcare puzzle.

However, the most concerning aspect of the employer based PHR offering is the lack of maturity within the iPHR market. Vendor selection would be crucial. Early adoption is not without risk (Moore, 2009).

### *Health Plans Perspective*

Health plan insurance providers stand as one positive force that are pushing adoption of personal health records. As early as 2006 in an article from information week, author Marianne Kolbasuk McGee said "Health insurers, which have troves of patient medical data from the billions of claim transactions they process annually, are hoping that they can help speed adoption of consumer personal health records". It was cited in the same article that Blue Cross Blue Shield Association and America's Health Insurance Plans provide a combined 200 million Americans with coverage. When the article was written, the health insurers had set a goal to provide consumers with a new, standard-based PHR by 2008. It is evident from this that insurers' were one of the early proponents to foster widespread adoption. The goals were

focused around defining common data elements that all insurance plans would provide in a PHR so that it would then be portable when a consumer chose to move to another plan. It would be accessible electronically for a member to update and provide their own subsequent information, such as family history of illness (McGee, 2006).

Insurers play an important role in managing the health of its members. Motivated by reducing costs, many health plans will proactively monitor and engage with its members to improve their health. They will employ physicians and nurses on staff to manage the care of their members with special needs. Such efforts are usually focused on members living with Diabetes, Heart Disease, Lower Back Pain and mental illness just to name a few. Their efforts while managing the plans out of pocket expense also serves a better purpose of making sure those in these managed care programs are being given the long term medical care they need.

The insurer contributes to the larger electronic health record, but cannot complete the whole puzzle alone. Because their perspective is founded only in claims related data it represents only a smaller puzzle piece of the whole landscape. "Insurers providing their members with digital personal health records aren't a substitute for the use of interoperable e-medical record tools by doctors, says an AHIP spokeswoman." We hope our work is a building block for when we have a fully interoperable national health information network," she says. (McGee, 2006. It will require the coordinated efforts of the greater medical community to link all the pieces of the PHR to make it useful and portable for consumers.

There are certainly barriers as well to greater adoption rates among health insurers. Like in other areas, many are shared. The cost of implementation is high and can act as a

deterrent. For this reason the trend as of late has been to look to free solutions such as Google Healthcare. In a interactive interview with John Moore of Chilmark Research he shared that Blue Cross in Massachusetts had recently moved from WebMD to Google for this very reason. Blue Cross Blue Shield is a national plan and implemented in the states individually as a franchise type model. It would be expected to see other plans follow this same direction.

### Future

Throughout this paper we have tried to present a picture of the present day landscape of iPHRs and to articulate just how far we think they have to go in order to be utilized by a predominance of citizens in the United States. We believe that the keys to this industry's maturation will be to address consumer trust and adoption issues as well as tackling the broad problem of data aggregation and its subcomponent interest areas. There are several key themes that could be used to galvanize and ultimately standardize the industry, yet each to date has not been accomplished. They are as follows in no particular order.

1. Rise of the PHS – potential next stage in the development of the PHR where it can be 'fed' various sources of data and therefore be free to be associated with the patient.
2. Privacy – consumer demands as well as strategies for consumer acceptance. Opt-in, Opt-out strategies.
3. Data aggregation – Extremely difficult to collect. Extremely difficult to codify. Extremely difficult to make actionable.

4. Business case – What is the monetary incentive?
5. Increase in provider adoption – Providers need to focus on PHR as a complement to EHR.
6. PHR development and depth- today's PHRs are too generic without real substantive depth. Not enough development dollars.
7. Truly actionable data – Data today is primarily bucketized. Ex. Lab, billing, prescriptions. There needs to be ways to tie it together.
8. Standards and governance – The role of states versus the federal government. The use of acceptable means of data exchange and security.
9. Consumer acceptance – What events need to happen for consumers to want to use this product.

John Moore of Chilmark mentions the rise of Google, and Microsoft, and the creation of the personal health system or PHS. (Moore, 2010). Moore sees a future, where these PHS's will create a way to gather medical data from multiple sources using their considerable marketing and human resources. (Moore, 2010). The future we see is more of the same. There will be more consolidation of vendors, changes within the industry, and continued fragmentation along the lines of offerings. Until one offering proves to be better equipped to handle the complex needs of a 'true' PHR there will be competing business philosophies.

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[http://acor.org/epatientwiki/index.php/Hunters\\_and\\_Gatherers\\_of\\_Medical\\_Information](http://acor.org/epatientwiki/index.php/Hunters_and_Gatherers_of_Medical_Information)

An editorial controlled Wiki, this website offers a significant overview of the prior research in the field of consumer healthcare information. Written by a diverse group of medical professionals and individuals with strong prior health care information usage history, the site offers a diverse range of healthcare support information. Also included is an excellent summary of the history of consumer healthcare information "gatherers" and the rise of "e-patients".

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Comer, B. (2008, August 8). "Cyberchondriac" numbers stagnant: Harris Interactive. *Medical Marketing & Media*. Retrieved July 2, 2009, from <http://www.mmm-online.com/Cyberchondriac-numbers-stagnant-Harris-Interactive/article/113594/>

Very brief article that provides the highlights of the 2008 Harris Interactive poll of ?Cyberchondriacs? (defined as users of Internet-based healthcare information.)

Research highlights include that 66% of all adults in the US, and 81% of adults online are users of online healthcare information. Other interesting figures include a steep rise in the number of "cyberchondriacs" from 54 million in 1998 to 150 million in 2008.

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