Change driven by the patient-consumer: A study of organizational behavior in the context of consumer health informatics

By

Vishnu Mohan, M.D., F.A.C.P.

A Capstone Project

Presented to Department of Medical Informatics & Clinical Epidemiology,

Oregon Health & Science University

School of Medicine

in partial fulfillment of the requirements of the degree of

Master of Biomedical Informatics

May 2009

Oregon Health & Science University

School of Medicine

Master of Biomedical Informatics

Certificate of Approval

This is to certify that the Capstone Project of

Vishnu Mohan, M.D., F.A.C.P.

"Change driven by the patient-consumer: A study of organizational behavior in the context of consumer health informatics"

Has been approved

_____

Holly B. Jimison, Ph.D.

_____

Date

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

To:

Holly Jimison for her advice, and for framing the context of this project,

Stephen R. Jones, who continues to astonish me with his uncanny ability to predict the future,

My wife Regina, the love of my life, for her patience and support,

But above all, to my father, M.V.Ramakrishnan, who taught me language and logic,

Thank you.

****

The opinions expressed in this paper are those of the author, and not those of Oregon Health & Science University (OHSU), Legacy Health System, or any prior employer of the author.

ABSTRACT

Organizations have become adept at initiating and managing change, but tend to enact change in a reactive fashion. Patients are increasingly behaving as consumers, and are beginning to drive the process of organizational change. However, traditional models of initiating and transitioning change appear less relevant in this context.

The personal health record (PHR) perhaps best exemplifies patient empowerment in their medical care. This paper examines the history, advantages, and limitations of personal health records, and delineates patient and provider perceptions. The impact of consumerism on clinical practice, organizational changes driven by patient requests, and the role of patients, providers, the media and marketing are analyzed in this study. Tethered and untethered PHRs are compared and contrasted from the organizational perspective, and safety and security implications of PHR use are discussed.

INTRODUCTION

Change reflects the transition in structure or function that results in the establishment of a new status quo, and can be *developmental*, *translational*, or *transformational* [1]. Developmental change is incremental, with each additional tier of change representing a small, but distinct variation from the previous iteration. Translational change reflects the process that involves restructuring to achieve a new steady state, often as much a psychological as it is a physical process. At the most fundamental level translational change consists of an initial "unfreezing", followed by the change itself, with a subsequent "refreezing" to a new equilibrium [2]. Transformational change is much more radical, and involves a fundamental shift in assumptions that initiate the course of action. This is usually a far-reaching process, often involving the entire organization, and requires the implementation of a distinct shift in strategy as well as culture.

As organizations have become increasingly adept at initiating and managing change, a number of models have been developed to delineate this process. One such representative interpretation argues that the cost of implementing the change should be favorable in comparison to the desirability of the change, the practicality of the implementation, and the dissatisfaction with the current environment [3]. This suggests an inherent inertia to change, which needs to be overcome in order to allow the change to occur, in essence a conflict between resisting and opposing forces [2]. Since change is usually planned and implemented by the organization's leadership, managers are often cast in the opposing role and employees are usually perceived as the resistors.

A deliberate, pre-planned attitude defines the *proactive* approach to change management; this usually begins with a sense of urgency, a vision, the subsequent establishment of goals, leading to the formation of a guiding team to enact change, which then results in a planned process of defining short-term and long-term objectives, followed by the implementation of the change itself, and the creation of a mechanism to consolidate improvements after implementing the change [4].

However, as the pace of business has quickened in today's society, organizations tend to enact change in a *reactive* fashion, where the organization changes in response to an opportunity or threat that has already occurred at the time of the change. This is particularly so in healthcare.

BACKGROUND

Change In The Healthcare Industry

The healthcare industry is an interesting case study of contrasts. A cautious process of scientific enquiry and clinical reasoning with an emphasis on evidence-based medicine has driven proactive changes in clinical management, while consumer or governmental outcry has often heralded the reactive process of organizational infrastructure change.

The complexity of health care poses unique problems. The Institute of Medicine report

"To Err Is Human: Building A Safer Health System" [5] reported on the high prevalence of medical errors inherent in the system, and initiated a discussion on improving health care quality that resulted in organizations making a substantial number of changes to the manner in which they deliver health care. The report raised awareness of health care quality to such a degree that today, the concept of continuous quality improvement has become widely prevalent. The American Board of Internal Medicine, the professional body that certifies and sets standards for physicians who practice internal medicine, has incorporated quality improvement modules as a key component of its recertification process. These modules are designed to allow physicians to identify and implement specific changes in their practices that help improve patient outcomes. Similar processes are being included in the curriculum of many residency training programs to allow physicians in-training to become familiar with the landscape of the world they will practice in [6].

As a consequence of innovations in technology and communication, business has become truly global, transcending political and geographic borders. The advent of the Internet era, in particular, has had extraordinary implications for health care organizations. This transformation of the general operating environment has led to changes in organization strategies, especially so in the methodology of gathering input before initiating change [7]. Organizations can no longer depend only on internal influences, but need to address the growing influence of the external environment that they operate in.

While the phase shifts in the realm of professional regulation and organizational

operating environments are central, another significant area of change has been the relationship between physicians and patients, which has also undergone a spectacular transformation in the last half-century. Specifically, this once-paternalistic relationship has evolved to one of partnership, with physicians offering options and guidance to patients, who make informed decisions to determine their own destiny [8].

Simultaneously, the computerization of society has had a profound influence on patients. There appears to be a distinct correlation between the increasing use of technology, particularly the Internet, and the rise in consumer empowerment [9]. Fortified by the ready availability of information on the Internet, these patients not only actively participate in their care, but have begun to increasingly behave as consumers rather than as traditional patients [10], demanding not only personally defined levels of care, but also the tools traditionally associated with consumerism (such as maintaining personal health records, generating online consumer reviews of organizations, and requesting enhanced access to providers by utilizing emails and online scheduling) to achieve their health care goals. Patients have even begun to select their physicians and treatment options based on their experiences as a consumer, rather than as a sufferer of disease [11].

In response, there have been further refinements in medical education, with an additional emphasis on training physicians to involve patients in their own care [12]. However, many of the changes sought by the consumer-patient are beyond the scope of the individual provider, who then depends on the health care organization to meet the patient's needs.

As traditional models of healthcare erode, organizations need to adapt, but the old-fashioned models of initiating and transitioning change appear less relevant in the face of the patient as consumer, who has irrevocably altered the dynamics of the forces that influence change. Newer methods to manage change need to reflect this change in societal attitudes [13], but have not been well studied, particularly due to the intricacy of organizations and processes in today's complex health care environment.

Personal Health Records

The personal health record (PHR) perhaps best exemplifies patient empowerment in their medical care. Patients can take control of their medical records by using a PHR, and participate actively in their own treatment, especially when knowledge and decision making tools are incorporated into the PHR.

Integrating the PHR to the electronic medical record (EMR) provides an intuitive two-way flow of information, with significant potential benefits for both physicians as well as patients [14]. PHRs can be "***tethered***", when they are associated with a single EMR, or "***untethered***", when they represent autonomous products often marketed by third-party vendors unrelated to the EMR supplier.

History of personal health records

Medical records originated as an effort to document and store data that was generated by the physician-patient encounter. In 1907 Dr. Henry Plummer at the Mayo Clinic

started storing information in folders that were filed under individual patient names [15]. Prior to this, patient information was recorded in an unsystematic fashion, as disorganized annotations or in ledgers that were linked to physicians, not to patients.

This "dossier model" implemented at the Mayo Clinic allowed records to be classified under patient names and stored in a central area, allowing enhanced access by caregivers. This revolutionized the practice of medicine, and defined the classification and storage of medical information and clinical data to this day.

As the complexity and sophistication of medicine increased, an escalating reliance on medical documentation increased the amount of information captured. Legal and economic incentives to document information in a thorough fashion also contributed to the exponential increase in the amount of data captured during the provider-patient encounter. This led to development of efficient medical data classification using standardized documentation formats, such as the SOAP (***S**ubjective-**O**bjective-**A**ssessment-**P**lan*) model, and the problem-oriented medical record (POMR), that distinctly improved efficiencies not only in information storage and retrieval, but also in patient care and clinical research [16]. This ability to clearly label and catalog medical information in a systematic fashion also allowed the transition of paper-based medical records to today's electronic medical records, as computers became increasingly prevalent in the medical workplace.

The practice of medicine also evolved from a paternalistic paradigm to become more patient-centric, but while patients had an increasing role in determining their own

medical care, their access to their own medical records lagged behind. Traditionally, physicians would “print a copy” of labs or other data for patients, who would store them as a duplicate, often incomplete paper record at home – the first generation of patient-maintained health records.

Patient and provider perceptions

The patient’s medical record has traditionally been maintained by the physician, who attempts to incorporate his or her clinical reasoning and decision making process in addition to recording elements of the clinical history, examination, and diagnostic testing. Patients have traditionally not had the freedom to exhaustively review their own records, predominantly because of limitations of access, and organizations did not attempt to significantly alleviate these access issues, since there was no legal or regulatory precedence to do so.

In the UK, the landmark Data Protection Act of 1998 permitted patients access to their computerized health records [17]. Prior to the implementation of the Act, four physicians commented on the perceived consequences of the Act in the British Medical Journal [18]. While they felt that patient access to their medical record would promote trust between patients and providers, they expressed concern that patient access would refocus the record on “the doctor's best interests rather than the patient's”, and prevent providers from recording potentially sensitive information, or comments that would be perceived unfavorably by the patient. The trepidation raised in this article continues to be a valid emotion today.

Patients, on the other hand, are clearly in favor of personal health records. An overwhelming majority of patients, when polled, feel that their health information is incomplete, and want to keep their own health records [19]. Thus, organizations need to balance the demand from patient-consumers with physician concerns, the cost of implementing a PHR, training clinical staff not only on how to use the system but also on how to respond to PHR-related patient requests, as well as advising patients how to choose appropriate PHRs and use them in a manner that is fruitful and fulfilling.

Advantages of the personal health record

While the electronic medical record has improved the storage and retrieval of information, an essential limitation of the current system is that the patient's records are fragmented among the different physicians that they have seen. The ideal state of affairs -- all providers who treat the patient have access to the same EMR -- is, however, rare, and a single provider typically does not have access to the complete database of patient information across an extended period of time, or across different organizational points of care.

Changing the ownership of the medical record from the provider to the patient allows **all data to be maintained at a single source** that can be controlled by the patient. Internet based personal health records can easily be modified by patients or their designate [20], and can often be accessed by providers without the need for standalone software or specialized networks.

PHRs are well suited for **integrating complex medical information** from multiple sources. For example, children with significant learning disabilities, who often have multiple disabilities and have been subjected to multiple interdisciplinary interventions, particularly benefit from a PHR which allows timely and appropriate care [21]. Of course, pediatric patients cannot use PHRs themselves, and it is usually parents who maintain their child's PHR. These parents tend to show high levels of understanding of the PHR, and often spur providers to participate in maintaining the personal health record. Parents most frequently use information related to immunization, growth charts, progress notes and health checks [22].

In addition to allowing patients to manage their medical record, PHRs can act as **gateways for patients**, who can request referrals, and even communicate with their providers through the PHR user interface, enhancing the patient's healthcare experience and convenience. One study of 61 patients suggested a significant (as high as 94%) satisfaction rate with the online referral process [23]. Additionally, clinicians also felt that the communication system was satisfactory, and convenient to use.

A personal health record could assist in **increased patient compliance**. A study conducted in Oxfordshire, UK, found that patients using a computer-generated medical record were more likely to have health checks but noted that patients who received a written personal health record were more likely to change their lifestyle [24]. This result suggests that the PHR is a useful tool to remind patients of events that affect their care.

Personal health records can help to **improve the quality of health care**. In 2001, the Institute of Medicine (IOM) released their landmark report "*Crossing the Quality Chasm: A New Health System for the 21st Century"* that emphasizes care based on continuous healing relationships, customized to the patient's needs and values. In this model the patient is the source of control, in an environment of shared knowledge, and with a free flow of information not just between the doctor and patient, but also between different providers.

Physicians rely on evidence-based decision making, and cooperate with each other to provide a continuously improving level of care that emphasizes systems-based practice, safety, transparency, and safety. Collaboration between the patient and provider is critical, and the PHR plays a crucial role in garnering the cooperation and involvement of the patient. As a consequence, providers can anticipate their patients' needs, and decrease waste [25]. This degree of association between providers and patients might even catalyze the "broader transformation of the health care system" [26].

There is also the hope that PHRs, if integrated with the electronic medical record, will also **contribute to patient safety** [27]. In 1999, the Institute of Medicine' first report*, "To Err is Human: Building a Safer Health System"* suggested that between 44,000 and 98,000 people die every year in US hospitals as the result of medical mistakes [28]. This alarming statistic suggests that critical errors might be the tip of the iceberg, and that the sheer number of medical errors might be colossal. While many types of errors have been identified [29], medication errors, delays in appreciating information, and errors due to a failure of communication might be particularly avoided

by using personal health records.

Increasing use of personal health records

In 2005 the American Medical Informatics Association's College of Medical Informatics defined recommendations for advancing personal health record use. Rather than consider PHRs to be static patient information databases, the recommendations suggested combining data, knowledge and software tools to help patients actively participate in their own care [30]. Anticipating the popularity of personal health records, commercial applications have mushroomed. The majority of these business models are marketed directly at patients. Google offers a PHR tools to the general public [31], and is actively working with third-party corporations; one such example is IBM, which is currently collaborating with Google to stream physician data from mobile devices to patients' personal health records [32]. Competition has spilled over into the PHR marketplace; Microsoft has now created its own personal PHR [33], as has WebMD [34]. Even Medicare has tested the waters, and recently expanded its pilot PHR project in South Carolina (myPHRSC) to include TRICARE data [35]. While some commercial applications are implemented with profit in mind, an important factor is the potential nationwide health care cost savings that might be realized by successfully utilizing PHRs.

Designing a personal health record

Three broad design strategies can be used to create personal health records. *Provider-*

maintained personal health records contain data that is populated and updated by the provider; typically in this model patients can access information but cannot modify it. *Patient-maintained* personal health records allow patients to input data, either using a standalone program on their computer or using an internet-based application, and provider access to this information is usually filtered by the patient. An *interactive* personal health record can be managed by patients in conjunction with their provider, and allows ready access to a core data set of relevant clinical, administrative, and demographic information, held in an aggregated fashion that allows information to be forwarded to any provider or system.

The development of standards that enable flawless electronic data exchange in the healthcare environment, such as Health Level 7) (HL7) [36], allows information to freely flow between electronic medical and personal health records. This is reflected in the ASTM Standard Specification for Continuity of Care Record (ASTM E2369 - 05), created by ASTM International, originally known as the American Society for Testing and Materials (ASTM) [37]. The Continuity of Care Record (CCR) is created in a structured XML format, and specifies the coding required to ensure standardization, interchangeability, and appropriate levels of security and privacy for the CCR.

In sum, the next focus shift in electronic medical documentation will be from the physician-maintained record to the patient-maintained record.

Limitations of personal health records

The transformation of the electronic health care record into a personal health care record has been prophesized, but it has not yet occurred [38]. Most Web-based PHRs enable patients to enter and maintain their own health as personal health records. However, one survey [39] found that many PHRs had limited functionality, with restrictions on the range and content of patient-entered data. Furthermore, when identical data from an actual case was entered into multiple PHRs, several PHR user interfaces displayed distinctly different amounts of information.

THE PROJECT

Aims and Objectives

This capstone project analyzes the patterns of organizational behavioral change that will emerge as a consequence of allowing patient access to a PHR. There has been some research into patient preferences – for example, a Harris Interactive Market Research Study in 2004 surveyed 2,242 adults and suggested that a substantial percentage (42%) keep personal or family health records [40]. In addition, the survey found that 84% of those who did not keep personal health records thought that it would be a good idea.

However, the attitudes and preferences of physicians and organizations have been less well studied. This study examines the views and attitudes of three critical groups of

physicians—faculty, residents, and leadership. Faculty physician, as clinicians and educators, have often been champions of change, especially in the realm of patient care and clinical medicine. Resident physicians have completed their medical degree, but are still training in a branch of medicine (internal medicine, in this study) and demonstrate an easy familiarity with technology that is often more sophisticated than their educators. Physician leaders are crucial in shaping organizational behavior, and often initiate and direct the process of change.

The focus of the project is on high-level changes from an organizational behavior perspective; on the perceptions and the opinions influencing the process of organizational decision making, rather than on the explicit workflow changes that will be seen in individual practices.

In order to keep the scope of the capstone project within a manageable scale, the study attempts to answer two fundamental questions:

1. What specific changes do organizations foresee in order to allow patients to use PHRs?

Organizations will need to change in order to allow clinical care providers to participate in information sharing with a patient who wants to use a PHR. While it is anticipated that some organizations will incorporate the PHR tightly into their EMR (perhaps by choosing products from the same vendor -- a tethered PHR), others will face the scenario where patients

independently select from a multitude of PHRs. Organizations will need to plan these changes that will arise as a consequence of associating with patients who maintain a PHR, and will also need to consider the changes that providers will need to make. This study attempts to delineate the factors that will influence this change.

2. From an organizational perspective, what are the potential benefits and barriers when patients use a PHR?

The study analyzes the expectations of physicians and leadership, with attention to perceived advantages of enabling patient access to PHR, and the barriers that organizations will face as patients request migration of their records.

3. Will organizations need to evaluate individual PHRs?

At present, there are few health data standards that are being used to grade PHRs, and those that are being constructed face a variety of issues and impediments [41]. This study analyzes the priorities of physicians and organizations, and attempts to predict if organizations need to implement specific changes in order to evaluate PHRs that may be used by consumer-patients.

Methods

This capstone project is a qualitative pilot study. The study was conducted at Legacy Emanuel and Good Samaritan Hospitals, in Portland, Oregon. Legacy Health System is a progressive and innovative community health system, with five hospitals and a number of primary care and subspecialty clinics in the Portland, OR and Vancouver, WA metropolitan areas. The system has begun the process of upgrading its current electronic medical record, and plans to incorporate a tethered PHR as part of the new EMR implementation. Legacy Emanuel and Good Samaritan Hospitals sponsor an internal medicine training program.

After conducting an initial observational study of the organization to determine its management structure, we recruited medical residents and faculty physicians by email, to complete a survey. In addition, pre-identified organizational leaders were recruited to participate in one-on-one interviews. Residents and faculty were identified as physicians (MD or DO) and classified as clinician-educators or physicians-in-training. Leaders were required to fall within at least two of four domains: physician, manager, academician, and informatician.

The study was designed as a cross sectional survey, with interviews. All residents were administered the same survey, and a comparably similar survey was administered to all faculty physicians. The same questions, with variations for the degree of organizational

responsibility, were put to leadership during interviews. We used descriptive statistics to summarize the survey data. Interviews were recorded, selectively transcribed, and examined in order to generate a list of themes that were expanded and reviewed. Using a grounded theory approach, these themes were further analyzed and an attempt was made to draw inferences from the data.

RESULTS AND DISCUSSION

The impact of consumerism

A majority of residents (69.2%) and faculty (55%) physicians felt that the patient-driven consumerism had only a "minimal" impact on their practice (Table 1), though a higher percentage of faculty physicians felt that they were significantly impacted by patient consumerism than residents. One attending noted "the internet has brought a new level of negotiation to treatment decisions, with both good and bad consequences", while another was unsure of the extent of its influence, responding "at this time, I believe only a minority of my patients are active consumers, if the number increases the impact will be significant."

Question 1: Faculty		
In your opinion, what degree of impact has patient-driven consumerism had on your practice?		
Answer Options	**Response Frequency**	**Response Count**
Minimal	55.0%	11
Significant	40.0%	8
Other (please specify)	10.0%	2
Question 1: Residents		
In your opinion, what degree of impact has patient-driven consumerism had on your practice?		
Answer Options	**Response Frequency**	**Response Count**
Minimal	69.2%	9
Significant	23.1%	3
Other (please specify)	7.7%	1

Table 1: The impact of consumerism on clinical practice

Patient requests – a new driving force in medicine?

When asked if they had made changes that were specifically driven by patient requests, many faculty physicians felt that change was driven predominantly by the organization in a top-down fashion, rather than by patients. Residents were more likely to feel that they were patient-driven than faculty attendings (Table 2). One resident noted, "we have no control over workflow or front or back office … if I did have control there would be definite changes."

Question 2: Faculty

With respect to technology, what organizational changes have you made in the last two years that have specifically been driven by patient requests? (Check all that apply)

Answer Options	Response Frequency	Response Count
Hardware changes	0.0%	0
Workflow changes	23.1%	3
Front office changes	23.1%	3
Back office changes	7.7%	1
Clinician education	15.4%	2
Other (please specify)	46.2%	6

Question 2: Residents

With respect to technology, what organizational changes have you made in the last two years that have specifically been driven by patient requests? (Check all that apply)

Answer Options	Response Frequency	Response Count
Hardware changes	10.0%	1
Workflow changes	30.0%	3
Front office changes	20.0%	2
Back office changes	20.0%	2
Clinician education	40.0%	4
Other (please specify)	30.0%	3

Table 2: Organizational changes driven by patient requests

Interestingly, even though the message of patient-centricity is highly valued in medical education, patients typically do not currently drive organizational changes in most institutions that provide medical learning. Organizations currently have little direct input from consumers in the planning and implementation of their technology infrastructure. The Information Technology (IT) division of an organization is distanced not only from the public, but also from clinicians. An academic physician felt

that at this time “IT does not have collaboration with patients, but they should”, and went on to say that “physicians and IT people need to work hand in hand when approaching the public. I look forward to a time when there are patients out there with … systems in their home wired for blood pressure, blood glucose, pulse, and clearly IT will have to connect those chronically ill patients in a way that physicians are not equipped to do.” While this concept of directly involvement of the patient in the design of their health care infrastructure is attractive, it is difficult to implement.

Organizations have made tangible attempts to make changes that reflect the desires of patients. In the process of becoming consumer-friendly, health care organizations are closely examining the personal health record, which can contain many functionalities beyond its ability to be a repository for patient’s medical records. The PHR portal can allow the patient to make appointments, initiate secure communications with providers, and even request medication refills from pharmacies.

Faculty felt that major patient-initiated organizational changes, such as email communication with patients, would take up time, create new workflows, and add to their work day. In the context of the extensive amounts of work that physicians currently have to do in addition to direct patient care (such as documentation, care coordination, insurance and billing work), this is not an insignificant concern.

The role of the media and marketing

Organizations assessing an electronic medical record usually look at the broad sweep of

its capabilities during the purchasing stage, but often choose to implement individual components of the EMR in a staged fashion, as opposed to rolling out the entire product at once. From the leadership perspective, there is a well-formed perception that personal health records are an example of a growing trend of consumerization of health care.

The media influences this opinion to a considerable degree, and the marketing divisions of many organizations study trends in public opinion, and attempt to develop strategies that will allow the organization to be perceived favorably by the community it serves. The personal health record is often included in the scope of many EMR implementations not only to improve patient care and convenience, but also as a marketing tool to influence public opinion. The personal health record is perceived as a "patient satisfier", and one reason that organizations tend to offer a tethered PHR option to patients early in the EMR implementation is to gain patient loyalty.

Using the electronic medical record: the role of patients

Physicians in practice still fundamentally view the EMR as a physician-oriented record. In reality, since the EMR and the PHR can share information from the same patient database, there is no absolute need to delineate patient records as "physician-owned" or "patient-owned". Patient information from the same source can be displayed on different user interfaces that can be viewed either by patients or by their providers. Physicians in training seem to grasp the concept of the enhanced patient role in the creation and maintenance of a global medical record more intuitively, perhaps as a

consequence of being able to appreciate the flow of data in a fashion that is less linear, an attribute made possible by their degree of familiarity with the Internet (Table 3).

Question 3: Faculty		
What role do you envisage for your patients in the use of your electronic medical record?		
Answer Options	**Response Frequency**	**Response Count**
Minimal	68.4%	13
Significant	15.8%	3
Other (please specify)	15.8%	3
Question 3: Residents		
What role do you envisage for your patients in the use of your electronic medical record?		
Answer Options	**Response Frequency**	**Response Count**
Minimal	30.0%	3
Significant	70.0%	7
Other (please specify)	0.0%	0

Table 3: The role of patients in EMR use

Attending physicians do have some apprehension about releasing 'raw' data to patients before interpretation, for example laboratory results. One faculty physician responded "I would feel OK about having them (patients) access test results after I have reviewed them."

This is particularly relevant in the context of laboratory testing when the result falls within the normal reference range, but is abnormal in the clinical context of the patient's

presentation. Another common scenario would be a CT or MRI scan report, which could contain information that might alarm a patient, but not their doctor.

Purchasing and implementing the EMR: the role of patients

Currently, patients have little or no input in purchasing or implementing electronic medical records. When opting for a PHR, organizations are more likely to select a tethered PHR product which is embedded in the EMR that they will purchase. There are distinct advantages to this approach: the PHR and EMR are well integrated, and technical support is assured. Patient-consumers will be consulted, but only in an indirect fashion: organizations may consider consumer preferences while evaluating the ability of future information systems to engage the patient.

Once an organization has an EMR and a tethered PHR in place, it will need to consider which other non-tethered PHRs will be allowed to share patient data. It is feasible that patients will be involved in this decision-making process; a senior manager remarked, "I can see us having a focus group and say to them 'with our current functionality, which one (PHR) would you guide us towards, which one do you like better?'"

In time, consumer organizations will probably rate PHRs. Managers will need to factor the information provided by a credible PHR rating scale as they contemplate the purchase of their next EMR product, although in the context of the totality of the decision-making process, the choice of a tethered PHR is not a crucial factor.

Who uses personal health records?

The current trend in US public policy, with a focus on health care spending, has made the public more aware of technology. Patients receive information about personal health records from a plethora of sources on the Internet, and commercial vendors directly advertise PHRs to consumers. Some of these sources are not reliable or current, often lacking validity and accuracy. The same Harris interactive poll that suggested a significant degree of consumer interest in personal health also found that only a minority (13%) of respondents that kept personal heath records in an interactive fashion kept them electronically [40].

There is a dominant view, amongst both physicians and managers, that "patients who are likely to use PHRs are more likely to be comfortable with using computers and the Internet anyway." The Pew Internet & American Life Project tracked the demographics of Internet users in a 2008 survey [42] that polled 2,253 adults who were 18 and older, with a margin of error of ±2% (Table4).

The survey found that adults who were younger, Caucasian, educated, had a higher income, and lived in an urban setting or in suburbia were more likely to use the Internet. If this is the profile of the typical PHR user, then the inference is that the population that is most likely to gain from personal health records – patients with chronic or complex diseases or those in other vulnerable populations, who will show a demonstrable improvement in outcomes by self-monitoring their conditions – are least likely to use them.

Total Adults	74%
Women	75
Men	73
Age	
18-29	87%
30-49	82
50-64	72
65+	41
Race/ethnicity	
White, Non-Hispanic	77%
Black, Non-Hispanic	64
Hispanic**	58
Geography	
Urban	71%
Suburban	74
Rural	63
Household income	
Less than $30,000/yr	57%
$30,000-$49,999	77
$50,000-$74,999	90
$75,000 +	94
Educational attainment	
Less than High School	35%
High School	67
Some College	85
College +	95

Table 4: Demographics of Internet users, November-December 2008.

Source: Pew Internet & American Life Project, November 19-December 20, 2008 Tracking Survey

Discussing personal health records with patients

Both resident (60%) and faculty (63.2%) physicians felt that they would only engage their patients in "minimal" discussion about personal health records (Table 5). One attending commented "I have gone over patients records with them, but haven't specifically talked about electronic records they maintain". Managers reflect this trend; one organizational leader noted "physicians will not necessarily spend a significant amount of time discussing PHRs with their patients."

Question 4: Faculty

How would you describe the level of discussion that you have with your patients about personal health records (PHRs)?

Answer Options	Response Frequency	Response Count
None	31.6%	6
Minimal	63.2%	12
Significant	5.3%	1
Other (please specify)	5.3%	1

Question 4: Residents

How would you describe the level of discussion that you have with your patients about personal health records (PHRs)?

Answer Options	Response Frequency	Response Count
None	20.0%	2
Minimal	60.0%	6
Significant	10.0%	1
Other (please specify)	10.0%	1

Table 5: Discussing PHRs with patients

Many physicians do not have enough time during office visits to incorporate detailed discussions on non-medical topics. Additionally, managers perceive that patients who ask to use PHRs would also not necessarily prefer to have conversations about PHRs with their providers during an office visit for an acute or chronic medical condition.

This implies that organizations do not need to spend time and money in creating and implementing detailed training programs that educate providers on how to communicate with patients about PHRs.

Factors that influence the implementation of a personal health record

Patient demand is the primary factor that both faculty and resident physicians believe is important in implementing a personal health record (Table 6).

One respondent thought that the PHR would "impress upon patients that they are responsible for knowing their health problems, medications, etc." This statement underscores a key benefit of using PHRs; patients who use PHRs feel empowered, and tend to assume responsibility for their health.

Even though technical standards that allow communication between different systems exist, health care organizations still do not possess the capability to seamlessly transfer data between proprietary EMRs. More than one faculty member commented that PHRs would allow patients to have "a universal and complete record", and cut across the traditional barriers that thwart the free transfer of information between different health

care systems.

Question 5: Faculty

What factors would you consider to be important in implementing a personal health record (PHR)?

Answer Options	Response Frequency	Response Count
Patient demand	78.9%	15
Physician demand	36.8%	7
Need to achieve parity with competing organizations	21.1%	4
Legal issues	47.4%	9
Other (please specify)	15.8%	3

Question 5: Residents

What factors would you consider to be important in implementing a personal health record (PHR)?

Answer Options	Response Frequency	Response Count
Patient demand	80.0%	8
Physician demand	50.0%	5
Need to achieve parity with competing organizations	50.0%	5
Legal issues	40.0%	4
Other (please specify)	0.0%	0

Table 6: Factors that residents and faculty physicians considered to be important in implementing PHRs

Leadership also remarked on the need to achieve parity with competing organizations. If one organization in a geographic area allows patients access to a PHR, other local health care organizations are more likely to seriously consider similar choices for their own patients. A physician-manager said “a nod to competition is appropriate, so parity does play into the decision, but I also think that if you are constantly reacting to what other people do instead of forecasting and driving to a place where your organization needs to

be you always lose that game." This was a remarkable illustration of proactive thinking on the part of management; on the need to lead by forethought rather than follow the example of others.

Patient demand drives PHR implementations, but organizations also put in a PHR because "it the right thing to do… I don't think there will be a lot of physician demand for that, although once they get used to distributing their lab results in that context, I think that they will find it helpful."

The converse scenario -- if one major health care organization in a metropolitan area opted out of allowing patients to use personal health records, would other organizations also opt out? "No," said a manager, "I want to consider it (PHR) on its own merits. I can't foresee that happening, but if that were to happen it would likely to be based on a specific incident or a specific technology, we'd have to consider (the events). But we wouldn't turn it off just because a competitor turned it off."

Demonstrating personal health records at the point of care

Physicians were unenthusiastic about extensive patient demonstrations of PHRs in the office (Table 7). This question specifically linked the PHR to the EMR – it was felt that generalizing tethered and non-tethered PHRs together would engage too broad a scope for analysis given the multitude of options available.

One resident expressed the prevailing sentiment: "I feel that it would have to be either

self-explanatory or have a tutorial patients can do on their own. There is not enough time in appointments to demonstrate at PHR."

Question 6: Faculty		
Will you consider demonstrating the personal health record component of your EMR to patients?		
Answer Options	**Response Frequency**	**Response Count**
No demonstration necessary	15.8%	3
Limited demonstration	73.7%	14
Detailed demonstration	5.3%	1
Other (please specify)	5.3%	1

Question 6: Residents		
Will you consider demonstrating the personal health record component of your EMR to patients?		
Answer Options	**Response Frequency**	**Response Count**
No demonstration necessary	10.0%	1
Limited demonstration	50.0%	5
Detailed demonstration	20.0%	2
Other (please specify)	20.0%	2

Table 7: Would resident and faculty physicians consider demonstrating PHRs to patients?

When asked if he would expect providers to educate patients about PHRs, a manager said "I would hope not, for their sake". While most managers felt that some apparatus needed to be available to allow patients to use PHRs effectively, a senior physician-academician was most clearly able to articulate the constituents of the PHR that were most valuable for the clinician, and thus the information that was most important for the patient to keep relevant and current: " clearly the things that would have to be

discussed and thought about would be the medication list, the accuracy of the past medical history, the accuracy of the allergy (list), and the ongoing maintenance of those."

IT departments that fund the implementation of technology products are usually the source of funding for clinician training during EMR implementations. However, any funding for PHR training might have to be disbursed from the budget of the clinics whose patients used the PHR, which would place a strain on their resources. Since it is likely that the PHRs will be explicitly designed to be patient friendly, and have a user interface simple enough to be fairly self explanatory, organizations may expect the patients to self-educate themselves about their PHR's functionality. There are few head-to-head PHR interface comparisons available in the general literature. One study compared Google Health to Microsoft HealthVault [43]. While the study size was small, and respondents reported both systems had flaws, the underlying message was that both PHRs were relatively easy to set up and navigate.

During a new EMR implementation, demonstrating the functionality of a personal health record to physicians is not a high priority. There are other elements that are more directly relevant to physician workflow, such as computerized physician order entry (CPOE), decision support tools, or the ability for physicians to monitor and track quality standards, and these are more pressing issues that need to be demonstrated to providers ahead of the PHR.

Is a tethered or untethered PHR a better solution for organizations?

A tethered PHR is likely to be a component of a vendor's total EMR solution. This factor alone will sway a number of organizations towards supporting a tethered PHR option. The PHR has the potential to significantly streamline current workflow patterns, a factor that some managers hope will influence physicians in a positive fashion. One manager said "I think if you have lab results it may be easier for the physician to communicate with the patient via the PHR rather than the current workflow where (the physician might) send it to the medical assistant who prints it out and puts it in an envelope and sends it to the patient." There will be some functions that untethered PHRs will be better at, and others which are more effectively handled by a tethered PHR.

It is a fairly uncomplicated process to export data from an EMR to a PHR. The flow of information in the reverse direction, which may occur when a patient with a pre-existing PHR establishes with a new physician, is somewhat more problematic.

Information transfer from a tethered PHR to an EMR is a relatively simple process, since the tethered PHR is already substantially linked to the EMR, and both can share the same database. Pulling in data from third-party untethered PHRs to an EMR is a significantly more complicated process, especially if the complexity and volume of the data that needs to be imported is large.

Ultimately, the provider is responsible for validating the data that is received, and the sheer amount of work involved in authentication and import of data from a patient's PHR might be overwhelming for the physician, who might find it easier to start from scratch and obtain a thorough history rather than wade through a substantial amount of PHR information. In addition, the data may be poorly organized or duplicative, and may not necessarily improve care. Industry standards for data imports from PHRs are yet to be defined, and the medicolegal implications of choosing *not* to review the PHR have not yet been fully explored.

Thus, while the patient might be able to continue to add to their personal health record, the physician's electronic medical record, in essence, starts *de novo* with every new patient. This reticence in importing information into the current physician's record may defeat a primary intent of the PHR – if the patient has accumulated a comprehensive record over an extended period of time, the inability to introduce old data into a new EMR is counterintuitive to the concept of consolidation of health information.

One intermediary solution could be to edit information flow between the PHR and EMR by using a transitional interface such as a view station where data from the patient's PHR could be displayed, and the provider could view, edit, and approve the elements of data that would be allowed into the physician's EMR. But this would be complicated to develop and implement, representing not just a freshening of the physician's graphical user interface (GUI) but necessitating a sizeable exercise in programming. A senior physician-manager felt that intermediate translation systems would be "a lot of work and so we'll have to look at it as to how much value it'll add to patient safety, the doctor's

workflow, and to the engagement with the patient. (It's) a critical issue." There might be filters that are developed to facilitate the process, but organizations would, in all likelihood, expect vendors to implement the filter at the PHR rather than the EMR end.

Presently, patients are not involved in maintenance of IT infrastructure. Once a PHR is implemented, the organization will need to create a mechanism to support it. While it not financially feasible to extend support to untethered PHRs, organizations will need to budget and devise a support protocol for their tethered PHR, from telephone customer support to online resource generation.

Security of information released to a PHR

A majority of faculty (73.7%) and resident (60 %) physicians expect their organization to preserve the security of patient records that are released to individual personal health records (Table 8).

Organizations can maintain the security of the tethered PHR, but will find it more difficult to control the actions of independent PHRs. Each organization will need to develop a list of independent PHRs that they find trustworthy, and allow patients to connect only to the PHRs on the list. This sanction will also apply to data that can be ported from the physician's EMR to a PHR. This will require a cautious review of not only the reliability of independent PHRs, but also the legal implications and compliance issues that will arise as a consequence of creating such a register.

Third-party verification is another option for security validation, and organizations such as the Certification Commission for Healthcare Information Technology (CCHIT) are currently developing a set of specific requirements that untethered PHRs will need to demonstrate in order to achieve certification. Once these standards are in place, organizations may find it easiest to insist on using only the PHRs that can meet them.

Question 7: Faculty

Have you considered the steps you will take to preserve the security of patient information that is released to individual personal health records, in the context of HIPAA (the Health Insurance Portability and Accountability Act)? Who would you expect to ensure that information released by you is secure?

Answer Options	Response Frequency	Response Count
You will personally check to ensure security compliance	0.0%	0
Your organization	73.7%	14
A third-party vendor	10.5%	2
You plan to recommend only the PHR module of your	26.3%	5
Other (please specify)	5.3%	1

Question 7: Residents

Have you considered the steps you will take to preserve the security of patient information that is released to individual personal health records, in the context of HIPAA (the Health Insurance Portability and Accountability Act)? Who would you expect to ensure that information released by you is secure?

Answer Options	Response Frequency	Response Count
You will personally check to ensure security compliance	0.0%	0
Your organization	60.0%	6
A third-party vendor	10.0%	1
You plan to recommend only the PHR module of your	20.0%	2
Other (please specify)	10.0%	1

Table 8: Safety and security of information released to a PHR

The perception of quality by physicians and patients

While physicians are committed to improving quality of health care, some do not fully recognize the extent that consumerization has affected patients, or the implications of this growing consumerism in their interactions with patients. In general, however, physicians are becoming increasingly aware that patients tend to judge them not only on how well they practice medicine, but also using standards that are more consumer-oriented than medical – while outcomes data and board certification status are important, so are family centeredness, community orientation, and cultural competence [44].

Managers, in general, have a greater awareness of the degree of societal transformation that has occurred in the last two decades, and if they also have a clinical background, they are able to see both sides: one physician-manager said "I think to some extent physician training needs to change. I think physicians have a huge opportunity to affect patient choice by managing those (patient) expectations. I don't think the average patient understands what a quality provider or quality health care experience is in the same way as the physician understands it, and all things being equal I think there is data out there that says yes, they do judge physicians by the speed at which the nurse answers questions, or the quality of the food in the hospital but if we don't want these to be the driving factors in healthcare then it's incumbent on the healthcare provider to start educating this increasingly knowledgeable patient base as to what they think is important for the profession and the services they provide."

CONCLUSION

The transition from the physician-centered to the patient-centered record

As personal health records become mainstream, patients will begin to have a cumulatively increasing degree of access until finally they will have a total and complete view of their medical record. Some providers find the direct transfer of the entire record to a PHR to be disturbing, especially when the subsequent flow of information is directed by the patient. A physician-manager articulated this best: "doctors will say there are certain people who should not have access to the PHR, and I believe that the doctor should have a right to be involved in that decision…if (the doctor) said 'having that patient access to a PHR is damaging to their health or for my relationship to the patient' then I want to hear that doctor out…and if they want to opt out (of the PHR), they should be allowed to."

However, this assumes a simplified scenario where a patient has a relationship with a single physician. In reality, patients often have ongoing relationships with multiple physicians. Organizations will need to address the scenario where one physician allows the patient access to the EMR, but another does not wish to participate, and the issue of selective provider participation will need to be resolved at a high organizational level.

As comprehensive personal health records become popular, the patient will gradually become the center of the electronic medical universe. Gradually, more features will be

built into the PHR at the expense of the EMR, which is then likely to predominantly become a tool that will capture data to help clinicians become more efficient. It is within the realm of possibility that in the not-so-distant future, the EMR will merely exist as the clinician user interface of the PHR. In this scenario, organizations may have no role in maintaining patient medical records, and may merely have to implement the technology that will provide the appropriate GUI to providers.

As organizations develop, perhaps the next evolutionary step will be the inclusion of the patient-consumer in the planning, implementation, and maintenance of the electronic medical record, with input into the design and execution of consumer-friendly applications such as the personal health record. This would truly be a far-reaching transformational change, and would allow the end user – the patient – to control their health care experience with an extraordinary degree of control.

REFERENCES

1. Ackerman, L (1997) Development, transition or transformation: the question of change in organisations. In: Van Eynde, D., Hoy, J and Van Eynde, D (eds) Organisation Development Classics. San Francisco, Jossey Bass.
2. Lewin K. Field Theory in Social Science. New York: Harper and Row, 1951.
3. Beckhard RF, Harris RT. Organizational Transitions: Managing Complex Change. Reading, MA: Addison-Wesley, 1987.
4. Kotter JP. Leading Change. Boston: Harvard Business School Press, 1996.
5. Kohn et al. The Institute of Medicine. To Err Is Human: Building a safer health system. National Academies Press, 2000. Summary accessed on 3/13/ 2009 at http://www.iom.edu/Object.File/Master/4/117/ToErr-8pager.pdf
6. Oyler J, Vinci L, Arora V, Johnson J. Teaching internal medicine residents quality improvement techniques using the ABIM's practice improvement modules. J Gen Intern Med. 2008 Jul;23(7):927-30.
7. Nadler D, Tushman ML, and Nadler MB. Competing by Design: The Power of Organizational Architecture. New York: Oxford University Press, 1997.
8. Coulter A. Paternalism or partnership? Patients have grown up and there's no going back. BMJ 1999; 319: 719-720
9. Pitt LF, Berthon PR, Watson RT, Zinkhan GM. The Internet and the birth of real consumer power. Business Horizons Volume 45, Issue 4, July-August 2002, Pages 7-14
10. Eysenbach G. Clinical review: Consumer health informatics. BMJ 2000;320:1713-1716.

11. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002;324:573-577
12. Edwards A, Elwyn G. Editorial: Developing professional ability to involve patients in their care: pull or push? Quality in Health Care 2001;10: 129-130
13. Koch, C. (2006). The New Science of Change. CIO Magazine, Sep 15, 2006 (pp 54-56). Accessed on 3/10/2009 at http://www.cio.com/archive/091506/change.html
14. Tang PC, Ash JS, Bates DW, MD, Overhage JM, MD, Sands DZ. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. J Am Med Inform Assoc. 2006;13:121-126.
15. Camp CL, Smoot RL, Kolettis TN, Groenewald CB, Greenlee SM, Farley DR. Patient records at Mayo Clinic: lessons learned from the first 100 patients in Dr Henry S. Plummer's dossier model. Mayo Clin Proc. 2008 Dec;83(12):1396-9.
16. Weed LL. The Problem Orientated Record as a basic tool in medical education, patient care and clinical research. Ann Clin Res 1971; 3: 131-4.
17. United Kingdom/ Data Protection Act 1998. Accessed on 2/27/2009 at http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1
18. Jenkins S, Dickinson CJ, Heasman MA, Ellis BW.Patients' access to personal health information. Br Med J (Clin Res Ed). 1986 Jan 25;292(6515):254-6.
19. Denton IC. Will patients use electronic personal health records? Responses from a real-life experience. JHIM, Vol. 15, No. 3. (2001), pp. 251-259.
20. Sittig D . International Journal of Medical Informatics, Volume 65, Issue 1, Page 1. Personal health records on the internet: a snapshot of the pioneers at the end

of the 20th Century.

21. Vaz I. Personal health record for school children with multiple needs. Child: Care, Health and Development Vol 21 Issue 3, pp 191 – 194.
22. Volkmer RE, Gouldstone MA, Ninnes CP. Parental perception of the use and usefulness of a parent-held child health record. Journal of Paediatrics and Child Health. Vol 29 Issue 2, pp 150 – 153.
23. Wang Lau M, Matsen C, Kim Y. Personal health information management system and its application in referral management. Information Technology in Biomedicine, IEEE Transactions on Vol 8, Issue 3 p 287-297.
24. Liaw T, Lawrence M, Rendell J. The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion. Family Practice Vol. 13, No. 3, 289-293 .
25. Committee on Quality of Health Care in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; 2001.
26. Tang PC, Lansky D. The Missing Link: Bridging The Patient–Provider Health Information Gap. Health Affairs, 24, no. 5 (2005): 1290-1295.
27. Win KT. Web-based personal health record systems evaluation. International Journal of Healthcare Technology and Management. Vol 7, Number 3-4 / 2006 pp 208 - 217.
28. Committee on Quality of Health Care in America, Institute of Medicine. To Err is Human: Building a Safer Health System. Washington, DC: National Academies Press; 1999. Summary accessed on 2/27/2009 at

http://www.iom.edu/Object.File/Master/4/117/ToErr-8pager.pdf

29. Leape L, Brennan AG, Troyen A. Preventing Medical Injury. Qual Rev Bull. 19(5):144–149, 1993.
30. Tang PC, Ash JS, Bates DW, MD, Overhage JM, MD, Sands DZ. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. J Am Med Inform Assoc. 2006;13:121-126.
31. Google Launches Google Personal Health Record Tools. McGee MK. InformationWeek, 5/19/2008. Accessed on 2/28/2009 at http://www.informationweek.com/news/internet/google/showArticle.jhtml?articleID=207801109
32. Google, IBM Team on Health Records Project. Gaudin S. PC World 2/8/2009. Accessed on 2/28/2009 at http://www.pcworld.com/businesscenter/article/159142/google_ibm_team_on_health_records_project.html
33. HealthVault – Microsoft PHR. Accessed on 2/27/2009 at http://www.healthvault.com/Personal/index.html
34. Web MD PHR. Accessed on 2/27/2009 at http://www.webmd.com/phr
35. Medicare News: CMS Expands Personal Health Record Pilot in South Carolina to include data from TRICARE. 9/23/2008. Accessed on 2/27/2009 at http://www.cms.hhs.gov/PerHealthRecords/Downloads/PHRDoDFinal.pdf
36. "What is HL7" from the Health Level 7 webpage. Accessed on 2/27/2009 at http://www.hl7.org
37. ASTM E2369 - 05 Standard Specification for Continuity of Care Record (CCR). Accessed on 2/25/2009 at http://www.astm.org/Standards/E2369.htm

38. Iakovidis I. Towards personal health record: current situation, obstacles and trends in implementation of electronic healthcare record in Europe. International Journal of Medical Informatics, Volume 52, Issue 1, Pages 105-115.
39. Kim MI, Johnson KB. Personal Health Records: Evaluation of Functionality and Utility. Journal of the American Medical Informatics Association 9:171-180 (2002)
40. Harris Interactive Market Research. Two in five adults keep personal or family health records and almost everybody thinks this is a good idea. Accessed on 2/27/2009 at http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2004Vol4_Iss13.pdf
41. Hammond WE. The Making And Adoption Of Health Data Standards. Health Affairs, 24, no. 5 (2005): 1205-1213
42. Pew Internet & American Life Project, November 19-December 20, 2008 Tracking Survey. Accessed on 3/12/2009 at http://www.pewinternet.org/trends.asp
43. Peters K *et al*. Google Health vs. Microsoft HealthVault: Consumers Compare Online Personal Health Record (PHR) Applications. A White Paper Provided by User Centric, Inc. Accessed on 3/11/2009 at http://www.usercentric.com/publications/2009/01/phr/
44. Starfield B, Cassady C, Nanda J, Forrest CB, Berk R. Consumer experiences and provider perceptions of the quality of primary care: implications for managed care. J Fam Pract. 1998 Mar;46(3):216-26.