

A PATIENT-ORIENTED APPROACH TO COMPREHENSIVE HEALTH INFORMATION QUALITY IMPROVEMENT

(Practice-oriented paper)

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Abstract: This paper presents a new approach to comprehensive health care information quality improvement based on the IQ principle of all information stakeholder participation in quality improvement. We propose Personal Health Information Manager (PHIM), an entity that enables the participation of patients in the management of their health information thereby creating an environment for the implementation of a comprehensive health IQ improvement. Specifically, the PHIM addresses the limited medical and technical knowledge of patients, major factors limiting their active participation in health information lifecycle. Converse to pervious research on personally controlled health records, PHIM provides a way to systematically collect and integrate information about entire patients' health history. It delivers a relatively more accurate, timely, consistent and accessible information product to patients, physicians, researchers and other authorized stakeholders. In concluding, we describe some models of PHIM operation as well as possible concerns.

Key Words: Personally Controlled Health Records (PCHR), Personal Health Information Manager (PHIM), Data Quality (DQ), Information Quality (IQ), Health care information, Health care cost.

INTRODUCTION

Effective management of health information has been identified as a key component of controlling health care cost and improving the health care delivery system in the US [1]. In this regard, several strategies to increase the penetration of Health Information Technology (HIT) [2], improve health information exchange and develop medical record standards have been developed and implemented (Becich, 2006). However these precedent efforts involved a very limited patient participation in that they play little or no active role in the process of improving their health information quality. Given patients' unique position in the health care system, their involvement is important to the success of a comprehensive process to improve the quality of health information.

Information Quality (IQ) research offers several techniques and tools for assessing the quality of health information. Pipino et al [3] comparative approach can be used to compare the subjective and objective IQ measures obtained from each category of heath information stakeholder. This technique provides a scientific method of diagnosing and prioritizing key areas for improvement. Lee et al [4] AIMQ methodology provides a framework within which aggregate data quality measurements for gap analysis, benchmark analysis etc. In addition, evaluating the current metrics of health information in the context of Strong et al [5] dimensions of IQ helps to better isolate the IQ issue category and compare measurements across stakeholder categories. In general, IQ research has identified the participation of all major stakeholders as important to the success of a comprehensive IQ assessment or improvement [6] [3] [7].

A major obstacle of adapting comprehensive IQ improvement frameworks for health information is that historically patients have never been really involved in the management of their own medical information besides keeping their immunization cards [8]. Traditionally, health information has been managed mainly in hospitals and health care providers' office. Although the Health Information Portability Accountability Act (HIPAA) mandates that patients can access their medical information, only a few are aware or have shown interest [9]. Furthermore, the limited patients' expertise in medical lingo is often raised as the main factor for this low level of involvement [10]. Finally, unlike other stakeholders like care delivery organizations (CDOs), health management organizations (HMOs), health insurances or third parties, patient do not have legal obligations towards managing their health information.

The major advances in personalized medicine have highlighted the enormous opportunities presented by more complete and readily available patient's health information. In order to more efficiently manage health information, maximize the benefits of HIT to achieve better care delivery and higher health information quality, patients' contributions are essential for harmonizing the needs and expectations of the different health information stakeholders who, most of the time, do not have direct communication with one another.

Although several researches has identified the benefits of more active patient involvement in health information management, in particular through personally controlled health records (PCHR) [11] [12] [13] [14], a method that enables them to easily and continuously collect their information from different sources, check it for errors and integrate it to create a unified personal health history is not available. The currently available health information is the result of the operations of other health-related industries that have invested time and money in creating, storing and managing these records for their business use following federal regulations. Consequently, patients must rely on other stakeholders as sources for their PCHR.

In line with major IQ improvement frameworks, our approach to addressing health IQ revolves around the active participation of all the major stakeholders of health care information in general and patients in particular. By active participation, we refer to playing a consistent and systematic role in the lifecycle of health information management like collecting, analyzing and storing the information. Our solution framework allows entities with specialized health information management skills called Personal Health Information Manager (PHIM) to help patients in physically and conceptually integrating their health information from various sources while monitoring the quality attributes of its individual source. This framework is analogous to the hire of financial experts to manage complex business transactions. The PHIM would ensure that patients' rights are not only fully protected but also facilitate the interpretation of the information and its communication to and from any authorized stakeholder. The details about the PHIM operating processes are discussed in following sections of the paper.

LITERATURE REVIEW/BACKGROUND

In the United States, millions of dollars have recently been invested in increasing the penetration of HIT as part of the efforts to improve efficiencies in the health care industry [2]. The potentials of HIT solutions in improving the quality of health care, safety, efficiency, disease management, preventive care and other related health issues have been widely discussed [15] [16]. Elson and Connelly showed how Electronic Medical Records contributed to improvements in timing and quality of clinical decision-making [17]. However, research into reconfiguring the health information system in order to maximize the benefits of HIT revealed significant opportunities for improvement [18]. Finally, Judd and Raymond described how HIT infrastructures can be leveraged such that the information could be used as medical research databases [19].

The increased level of specialization of physicians and increasing patient's mobility over the past decades has increased the fragmentation of patients' health care information [20]. Integration mechanisms for health information have also been subject of interest to researchers. Weed introduced the problem-oriented medical record, which logically structures medical records and improves communication about patients among clinicians [21]. Acheson later proposed the linkage of medical records in order to arrive at a personal medical record [22] in order to overcome the fragmentation of the patient's medical information profile.

The concept of Personally Controlled Health Record (PCHR) [11] has been identified as enabling more effective, more flexible, and cheaper healthcare. Riva et al presented the Personal Internetworked Notary and Guardian (PING) a scalable architecture an implementation of the Guardian Angel concept. PING has iteratively been improved upon [23] with the current version termed Indivo X [14]. Weitzman et al studied patients interaction with the PCHR and its effect on policy and design requirement [24]. Bourgeois et al assessed the value of PCHR in health promotion program [25].

The ubiquity of technology over the past decade has increased the visibility of this idea and increased the penetration of Personal Health Records (PHR); seventy million people in the US have access to PHR [26]. These consumer-centric health information systems usually provided to patients through their employers, health insurance companies or independent vendors are promoting a more active patient participation in their health information lifecycle. However, a significant number of consumers with access to PHR are still unable to address certain significant IQ issues such as consistency and completeness; among the 91 PHRs systems identified by the Medical Library Association, 54% were standalone application i.e. completely and voluntarily created by the patient-consumers, 26% were integrated with Electronic Health Records (EHRs) and 11% only had both characteristics [26].

HEALTH INFORMATION LIFECYCLE – STAKEHOLDERS AND IQ PERSPECTIVES

The scope of health information usage has expanded significantly over the past decades. Factors such as the involvement of more actors, patients' mobility and the introduction of new technologies in medicine have expanded the use of this information significantly [20]. Current uses include communication between care providers to provide continuity of care, management and business intelligence for HMOs and HIOs like risk analysis or payments. It is also used by governmental organizations for public health surveillance and decision support, planning budget and funding research projects; by research organizations for discovering new medical solutions, isolating diseases factors, recruiting potential subjects to clinical trials etc.

A comprehensive IQ assessment evaluates subjective and objective data quality measurements from all stakeholders [4] [3]. This evaluation reveals among other things the perceptions of each stakeholder category [27]. The understanding of these different perceptions is important for communicating IQ needs among them and for “manufacturing” a high quality information product (IP) [6]. This is particularly important in health care where several autonomous stakeholders are involved in the IP lifecycle. The perspectives of health information of major stakeholders are briefly summarized in Table 1. These views are informed by the data requirements of their primary responsibilities. For example age, allergies and current medications may be adequate for flu vaccine administration, but incomplete for epidemiology research.

Medical Information Stakeholder	Primary view of Health Information
CDO	Management of patients and services; Quality records for liability and Regulatory records mandated by law.
HMO and HIO	Business transaction records.
Patient	Health history/condition
Research Organizations	Research datasets
Government Organizations	Public Health Surveillance and decision support information

Table 1: Stakeholders' perceptions of health information. Traditionally, patients are not involved despite the benefits (completeness, accuracy, etc...) of their internal view of the information.

Pipino et al [3] information stakeholder classification into collector, custodian and consumer also known as 3Cs, provides a framework for categorizing and comparing stakeholder perceptions and roles in health information lifecycle. These well defined roles helps in continuously monitor and improve the quality of the IP "manufactured" at different stages of the information lifecycle. We briefly describe these categories of actors with respect to health information and indicate the levels of participation of the major stakeholders namely, CDOs, HMOs, HIOs, patients, research and government organizations.

Collector

In general, information collectors create data or collect raw measurements for the system. Collectors of health care information are entities that directly collect health information relevant to a patient's profile. Because of the technical and medical expertise required in performing this task and the necessity of this information to their primary functions, this role is often and solely performed by CDOs. Only biographical information like name, age, height, weight can be satisfactorily collected by patients.

Custodian

Custodians store and maintain the information. They are generally responsible for designing, developing and supporting information systems infrastructures. With the increasing adoption of HIT, most health information custodians today are technically savvy. They integrate data from different health care providers into central databases, retrieve information and create complex reports. However, IT departments are not the usually the best funded in the health care setting and most of the existing solutions try to work around functional solutions with pre-existing disparate systems and processes rather than creating optimal ones. Computer literate patients with access to PHR solutions can also in a limited way perform this role. Other than patients, other stakeholders have legal, ethical or financial obligations regarding the information. For example, in North America, the Medical Information Bureau Inc. (MIB) a for-profit medical exchange organization stores the information as a shared repository for its members (insurance companies) for a period of 7 years [28].

Consumer

Consumers use the information to perform multiple activities. In particular, health information consumers are entities that use the information to perform their primary or main function e.g. patient care (CDOs), processing payments (HMOs), data mining (research) and public health surveillance (government). Given patients' limited knowledge in interpreting health information in its entirety, they are inefficient

consumers.

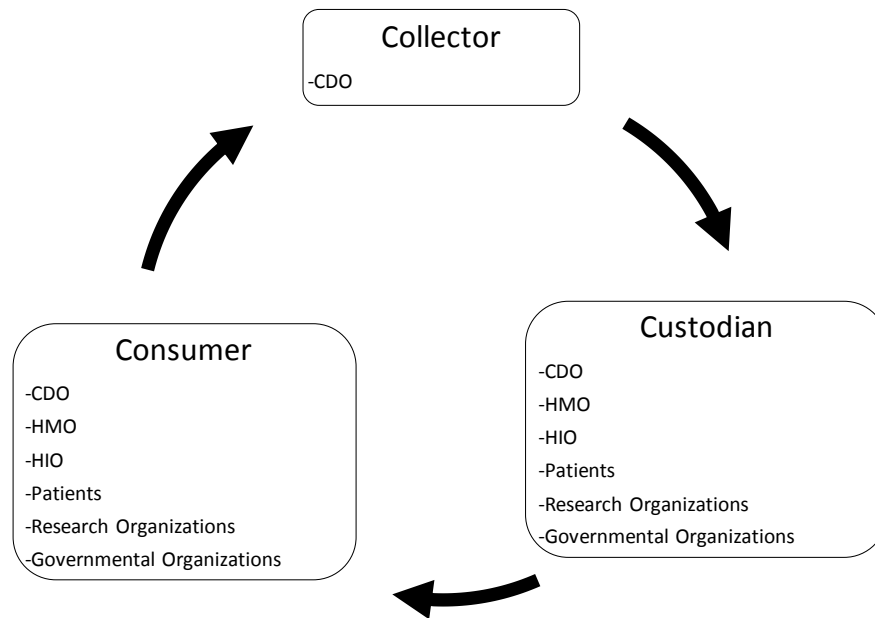


Figure 1: Health information stakeholders' roles in the information lifecycle. The classification of a stakeholder into the 3 categories is not exclusive i.e. stakeholders may belong to more than one class.

PATIENT'S PARTICIPATION IN HEALTH CARE INFORMATION MANAGEMENT

Historically patients have never been really involved in the management of their own medical information besides keeping their immunization card [8]; only about 5% request for copies of their medical records [9]. This inactive role played by patients can be partly attributed to their lack of expertise of medical information and absence of legal obligation [10]. On the other hand, patients are in a unique position to relatively easily access all their health information from other stakeholders and can play significant roles in the achieving higher IQ standards. Research on patients' empowerment has revealed the potentials of patients playing a central role in the management of their health care information [21]. Furthermore, research has indicated that the unified view of health information available to patients can help in avoiding unnecessary or possibly dangerous decisions based on incomplete or incorrect information [29].

The increasing availability and popularity of Personal Health Records (PHR) and other consumer-centric health information systems in recent years are promoting the participation of patients in the management of their medical information [30]. For example 76% of respondents to a survey indicated interest in online access to medical records and test results [18]. Because each organization usually uniquely identify individual patient using different identifier(s), creating a conceptual view of individual patient's health information using information from multiple organizations sources often require record linkage or entity resolution. An advantage of the unified view available to patients' is the elimination or mitigation of the errors associated with this processes. Talburt described these 2 views of identity are as internal (patient) and external (other stakeholder) view of identity framework and identified completeness and accuracy as two IQ challenges associated with the external view [31].

We describe below an approach called the Personal Health Information Manager (PHIM) that enables increased patient's participation in the management of their health information thereby creating an environment for a comprehensive health IQ improvement.

Personal Health Information Manager (PHIM) System

As previously stated, the lack of expert knowledge of health information and the absence of legal obligation for them to archive them are major factors inhibiting the active participation of patients in health information management. The PHIM system increases the participation by addressing the former. This system consists of the PHIM as an expert body specialized in health information to help patients in physically and conceptually integrating their health information. Its functions include obtaining patients information from all available sources, checking for errors and consistency, standardizing, regular reports to patients and providing authorized access to other stakeholders. This approach is analogous to the use of financial experts like accountants for handling complex financial transactions like major investments and taxes. It would also ensure that patients' privacy rights are fully protected in compliance with major regulations like HIPPA. In contrast to other stakeholders, a PHIM's primary role is health information management. Hence, it is in a position to devote relatively more significant proportion of its resources towards more efficient information management including improving IQ e.g. HIT investments, specialized health information analytics.

PHIM System Operational Model

Similar to subscribing to online tax service such as TurboTax®, patients will subscribe to a PHIM entity of their choice. Once this first major step has been completed, the PHIM initiates the process of collecting all available patients' historical health information. This collection process would include direct requests from stakeholders like CDOs, HMOs and HIOs with which patients have had interaction. A simple questionnaire filled out by patients may be used to provide information on specific organizations to contact for such information. Also, any information such as medicine prescriptions would also be included in this compilation. Subsequent patient's health information will be obtained either through scheduled and/or ad-hoc requests. Given the PHIM's specialized medical knowledge skills, it is able to check the quality attributes of incoming information and detect any IQ issue.

PHIM's access to relatively more complete information on the patient's health history also enables it to perform this IQ evaluation in proper contexts. Talburt described the PHIM's view of patient medical information as internal; in that the patient identity is analyzed in a closed universe. Unlike when only external view of patient identity is available and entity resolution or record linkage is required to manage identities, the internal view offers more complete and accurate information.

Due to the heterogeneity of the sources and format of the information acquired by the PHIM, standardization of data is a natural part of its information management process. Also, given the increasing HIT penetration in the U.S. healthcare system, it is conceivable that the majority of the information will be communicated electronically there by allowing the automatic assessment of the IQ state thereby streamlining the detection and communication of IQ issues to concerned parties. This systematic request, standardization, IQ analysis and storing of patients' health information creates a single point access to unified patient health history with potentially higher quality information relative to all its sources. This high quality information available to the PHIM allows it to help patients understand their complete health history through regular and easily understandable comprehensive health reports. The PHIM's technical expertise also allows them to make the information platform independent available to patients, other authorized stakeholders and third party applications like Indivo X [14] and Trial X an organization helping patients search for clinical trial [32] independent of platform. In this regard, patients are able to access their entire health history from a single access point using a variety of options like web portals and

telephone. Patients' easy accessibility to their health information helps to reduce considerably the amount of time needed to transfer the information among stakeholders. This takes its importance in case of having the information readily available for emergency care when no or little input is possible from the patient. . This single-point access entity also alleviates the demand on other stakeholders for providing the information to patients who are entitled by law to obtain a copy of their medical record within 30 days maximum of request. At the same time, the PHIM will offer a wide array of personalized services like clinical visit reminders and ad-hoc information requests to patients while offering customized services like recruitment of study subjects (research) to other authorized stakeholders.

Other custodians of health information can also benefit from the expertise of PHIM in information management in that they can considerably reduce their HIT investments by subscribing to PHIM services while focusing on their core competencies. This consolidation of expertise has great potentials for cost saving on both organizational level and in the entire industry; particularly for small organizations (small insurance groups or private practices) with limited human and technological resources. Given the very sensitive nature of health information and regulations designed to safeguard it [33] [34], PHIM entities will be required to at the minimum adhere to the government regulations, HIT committees recommendations and industry standards. Market forces may be used to ensure that patients can easily transfer from one PHIM to the other. For example the motivation to attract patients from non-PHIM competitors may prompt PHIMs to develop interfaces and/or standards that make it easy for new patients to subscribe and transfer their data. Also, government regulations may be used to ensure that patients' information is protected in the event they unsubscribe from PHIM service.

Proposed Scientific Evaluation and Monitoring of PHIM effectiveness

Although the described PHIM is new and not yet implemented, scientific evaluation methods of similar PHR systems like HealthSpace [35] in addition health survey tools like the SF36 questionnaires [36] provide excellent framework for evaluating and monitoring the effectiveness of this system. We propose a combination of objective analysis and in-depth interviews to examine the assignable causes of adoption, non-adoption, under-utilization and abandonment of the system particularly with respect to the level of patient participation. In general the study would focus on two main stakeholder categories; patients and healthcare providers. As in similar studies, the effectiveness across different patient demographics would be examined and particular attention paid to the differences and similarities between IT literate and other patients as one of the main goals of the PHIM is addressing the technical knowledge barrier to patients' participation. The ease of healthcare providers in interacting with the system in terms of transmitting data and communicating possible corrections as an important factor to the success of the PHIM would be studied using the response-time to data requests, systems interaction and compatibility analysis as well as questionnaires and interview of carefully selected population sample (based on size of organization, specialization, etc). The effect of sharing the results of analyzed IQ issues with concerned organization on subsequently received information would help in determining the effectiveness of the PHIM in helping to improve health IQ at the source.

PHIM helps in conducting comparative analysis of de-centralized PHR (containing longitudinal patient information) and centralized systems like HealthSpace. The level of consumer-centricity may be analyzed using the response-time to patients suggestion/complain about the system design in light of the availability of competitors. Also, the study of the correlation of patient retention to the amount of correction they have effected could also provide information about patients' perception of the value of their participation. One of the final analysis would be the effect of the conceptual integration and longitudinal patient information analysis on increasing patient understanding of their health status and how it can be better managed.

Possible models of a PHIM Financing

Although the financing aspects of the PHIM are not within the scope of this article, we briefly describe the potential ways to make it financially viable. This discussion does not represent a full PHIM financing solution; however it gives an idea of how it can be achieved. The implementation of the PHIM system within a single payer health care system like in Canada and a multi-payer system like in the US would differ for two main reasons namely: access to data and financing. In the former, current central information systems can be implemented to give patients access to real-time and standardized information while the information has to be collected from independent stakeholders in the latter. Moreover, the US system calls for a market based financing with private companies dominating the implementation and the government having a limited role it while the Canadian can be managed through a government sponsored program or through a government and private companies' partnership.

Patients would have access for free to basic functions such as obtaining their complete medical profile information, and reports on data access. However, a small fee could be required to access more elaborate reports like comparing statistics on health care providers and procedures. Other sources of revenue would be to provide datasets to other health care related organizations such as health insurances, pharmaceutical companies, professional groups, practices and research institutes (in the limit of the respect of the HIPAA law), use the PHIM services as the main HIT provider or advertise health care related products to targeted populations. As a measure of public service, the PHIM would provide free access to governmental institutions such as the Center for Disease Control and other federal agencies or public research institutes in order to fulfill their tasks of public health surveillance or public research.

Opportunities and Concerns

The PHIM offers several opportunities to patients and other stakeholders involved in the health information lifecycle. By increasing the patient's role, the PHIM system creates an environment for a comprehensive health IQ improvement. Through its systematic acquisition and analysis of information, the PHIM acts as an IQ buffer that helps both the patient and the information source organizations to achieve a higher IQ level. Because of the internal view of the patient's identity available to the PHIM, information from heterogeneous sources can be linked with less likelihood for errors compared with using record linkage algorithms. Furthermore, by becoming a more visible stakeholder category in the health information lifecycle, patients can be more adequately considered in future changes to the health care system. Generally, the nature of the PHIM relationship to other stakeholders provides opportunities for very valuable joint contributions to an array of health information issues like standardization, improvement of HIT solutions within the industry.

The demystification of health care information by the PHIM would in general make regular patients better health care consumers. For example access to trends in blood analysis can prompt patients to make healthier life style choices. Also by understanding the cost of different procedures patients may be able to make them choose for alternative less expensive treatment procedures or providers. The unified view of patients' health history can help care givers to choose more effective treatment options thereby making limited but valuable resources available to other patients. The PHIM system provides collectors and custodians the opportunity to reduce costs on information management and focus more on their core competencies. In other words, since the PHIM's primary activities involve IQ checks and data standardization, collectors and custodians can reduce their HIT investment footprint by subscribing to the PHIM's services. The more complete and higher quality information available through the PHIMs puts them in a position to help researchers to identify subjects matching specific clinical trial criteria. On the other hand, the PHIM can also alert patients about new research developments relating to their health conditions.

In addition, the PHIM also addresses the issue of leveraging HIT investment for providing medical

research data raised by other researchers like Judd and Kim mentioned [19]. Due to the expected diversity of PHIM information, the PHIM is a very rich source for longitudinal research data. And by following ethical standards and government regulations like the private health information (PHI) aspect of HIPAA, the protection of patients' rights would be automatically ensured.

The biggest concern that we would foresee for the PHIM system is maintaining the data safe and secure. Unlike standalone CDO, HMO or HIO, a single security breach of PHIM information could result in a higher number of damages due to the range of information compromised. While this is a serious concern, it is not unique to PHIM. Organizations like the MIB, financial institutions and federal credit bureaus have been managing similar security challenges for decades. Security standards and practices in organizations with similar risks as well as the security architecture design described by the HITECH Act [34] would provide PHIMs with substantial security options.

CONCLUSION

We have presented the PHIM system as an approach to increasing the participation of patients in the management of health care information, thereby creating an environment for comprehensive IQ improvement. The PHIM is an independent organization specialized in health care information management that would be primarily responsible for helping patients to physically and conceptually unify their health care information as well as better understand it. This active patient participation catalyzed by the PHIM system also increases the feasibility of a comprehensive IQ improvement in health information. By acting as an IQ buffer in the center of the information lifecycle, the PHIM ensures that IQ issues are quickly identified and addressed. In addition, the PHIM represents a cost saving opportunity for other stakeholders by providing specialized information management service. While security is a major concern for the implementation of such a system, already validated architectures of other organizations facing similar threats can be used to mitigate the risks.

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