



Research Briefing

Special Edition: EHRs, PHRs, and Health Care Reform

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Introduction

This is a special edition Ix Research Briefing on electronic health records (EHRs), an important infrastructure component of health care reform.

A portion of the American Recovery and Reinvestment Act stimulus funds will be invested in EHRs. Health information technology (HIT) could play a significant role in moving to an improved U.S. health care delivery system if they are accompanied by changes in the design of care delivery.

While there is a general (albeit not unanimous) consensus that EHRs are desirable, a limited research base is available to understand the effects of EHRs and personal health records (PHRs) on clinical health care quality, patient outcomes, and various processes within the health care delivery system.

Also lacking is a comprehensive documentation of best practices involved in implementing EHRs into a range of health care settings.

EHR Definitions

To some extent, the terms EMR, EHR, and PHR are used interchangeably, although each one is thought to be slightly different. One way of

defining* and conceptualizing the difference is as follows:

EMR	EHR	PHR
An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization.	An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff, across more than one health care organization.	An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

*Definitions above from **John Halamka's "A Healthcare IT Primer post"** on **The Health Care Blog**.

What Exactly is a PHR?

Meanwhile, the Markle Foundation's Connecting for Health Initiative, in 2003, defined the personal health record (PHR) as follows:

"The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. Family members, doctors or school nurses can see portions of a PHR when necessary and

emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access online self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information."

What is a "Tethered PHR"?

To complicate the issue of having a specific agreed-upon definition of a PHR is the issue of if –and how – a PHR is connected to an EHR. A tethered PHR is connected to an EHR; an untethered PHR operates independently of an EHR. The term PAEHR (patient accessible electronic health record) is sometimes used to indicate a tethered PHR. The term PCHR (patient-controlled health record) has been used to indicate an untethered PHR.

PHR Acceptability and Implications

Objectives

To learn more about consumer beliefs and behaviors regarding untethered PHR use and the corresponding policy (and design) implications for successfully implementing PCHRs (patient-controlled health records).

Background

Health information systems are needed not only to support public health monitoring and research, but also un-fragmented health records and engaged and empowered patients. Personally controlled health

records are a special class of PHRs “distinguished by the extent to which users control record access and contents.” Examples include Google Health, Microsoft’s HealthVault and Dossia.

Qualitative research was conducted as part of a formative evaluation of the Dossia PCHR demonstration in the northeastern U.S. Data were collected using focus groups, semi-structured interviews, and analysis of email content over a two-year period (2006-2008).

Findings

Study results indicate low levels of familiarity with PCHRs. Interestingly, results also indicated high expectations for the capabilities of PCHRs. For example, participants had high expectations for systems to provide them with tailored communications. Participants also expected linkages between self-reported data and clinical data.

Overall, participants seemed to overestimate the extent to which their personal health information is available and transferred electronically within IT systems. A common perception among participants was feeling personally excluded from health information systems. The desire to be included and have some degree of control over their health information was a motivator for consumers to adopt and use the PCHR.

Consumer’s biggest privacy concerns related to insurability, denial of employment, and/or denial of care. The use of an audit check appeared to be the most reassuring and accessible way to safeguard privacy and build confidence.

PHR Implementation Strategies

Objectives

To explore issues related to providing patient access to the PAEHR (tethered PHR) and managing the necessary corresponding institutional change.

Ix Implications

It is noteworthy that consumers expect tailored communications based on the data in their PCHRs, as well as linkages between their self-reported data and clinical data. Patients may have unrealistic expectations of the ability of existing systems to provide them with tailored communications. PCHR systems need to be expanded and implemented in a way that facilitates accurate Ix prescriptions.

Predictive modeling, combined with health information, demographic data, and patient preferences can be used to create Ix information triggers. That will help create links for consumers between their PCHRs and tailored educational content to help them make better health decisions and manage health behaviors effectively.

There is also an opportunity to educate clinicians about the role patients may potentially play in increasing the quality of their medical information, if given the opportunity. Accurate information not only enables more accurate tailoring of information, but presumably would increase the accuracy of provider-facing decision support tools and/or quality of care.

Citation

Weitzman ER, Kaci L, Mandl KD. Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design . J Med Internet Res 2009;11(2):e14. <http://www.jmir.org/2009/2/e14/>

Background

Expanding EHRs to include consumer access has the potential to improve patient experience, support patients with chronic conditions, improve transparency, increase referral rates, and enable continuity of care for

patients. However, potential barriers to the adoption of PHRs for both clinicians and patients include privacy and security, change management, a lack of EHR infrastructure, and conversion of clinical data into useful information for average consumers.

Meanwhile, there are few standards and guidelines available to address barriers to the use and clinical adoption of PHRs. To this end, the Canadian Committee for Patient Accessible Electronic Health Records (CCPAEHR) assembled a group of key stakeholders and experts in the field of EHRs and PHRs to explore issues related to providing patient access to the EHR and managing the necessary corresponding institutional change.

Findings

There were several areas of consensus among the expert panel. First, the panel agreed that patient access to personal health information is fundamental to patient engagement and empowerment. Second, patients should be able to add information to their EHR. Finally, they agreed on the importance of providing tailored educational materials to patients to meet their information needs.

There were several areas where there was not common agreement among panelists, the first of which involves a commonly understood definition of EHRs. The second divergence of opinion involved how much of the data patients should be able to access. The third area lacking consensus related to the timing of data; some believed patients should have real-time access to data while others believed that real-time access might cause unnecessary stress to patients who are unable to interpret the information on their own.

Accuracy of Medical Records

Objectives

To determine agreement between patient-reported symptoms of heart disease and the

Ix Implications

Focusing on areas of agreement points to the importance of flexibility and interoperability of EHR systems. Flexibility within systems will allow patients to indicate and receive communications according to their individual preferences or health literacy status. This would also address one of the areas of disagreement about the timing with which patients should receive information. Patients could decide for themselves whether they would like real-time test results, for example, or if they would prefer to schedule an appointment with their doctor to receive and review the results.

Interoperability of EHR systems also has major Ix implications. In addition to supporting continuity of care across settings, information coordinated across/between systems, including patient-generated information, would likely generate more powerfully accurate Ix triggers. Increased interoperability should result in more comprehensive patient data and likewise, more specifically tailored information to help patients make beneficial health decisions.

It is important to note that there was a lack of actual patient representation on this panel.

Citation

Wiljer D, Urowitz S, Apatu E, DeLenardo C, Eysenbach G, Harth T, Pai H, Leonard KJ, Canadian Committee for Patient Accessible Health Records (CCPAEHR). Patient Accessible Electronic Health Records: Exploring Recommendations for Successful Implementation Strategies. *J Med Internet Res* 2008;10(4):e34. <http://www.jmir.org/2008/4/e34>

documentation of these symptoms by physicians in an electronic medical record (EMR).

Background

Early identification of patients at risk for heart disease is critical to its prevention and successful treatment. Natural language processing (NLP) was used to identify symptoms of heart disease (chest pain, dyspnea, and cough) recorded in the text of health care provider clinical notes. Reported symptoms from 1119 adult patients were compared to the symptoms reported in their clinical notes. The study was conducted at the Mayo Clinic, which utilizes a state-of-the-art EMR environment.

Findings

Significant discrepancies were found between patient-reported symptoms and symptoms recorded in their EMRs, with 31% of patients with chest pain, 38% with dyspnea, and 45% with cough not having these symptoms recorded in the clinical notes of their EMR. Although the reasons for these discrepancies have yet to be researched and understood, data accuracy within an EMR cannot be assumed, at least when it comes to patient-reported symptoms of heart disease.

Implications

While there are some limits to how the findings of this study can be generalized to all health care settings, it has special significance given the current federal

mandate requiring all health care providers in the U.S. to begin using EMRs. Given that the purpose of EMRs is primarily to facilitate and streamline care delivery (and secondarily used for clinical research and quality and safety assurance) data accuracy issues must be addressed. The clinical quality issues associated with the lack of proper EMR documentation have yet to be investigated.

Since well-tailored prescription of information (Ix) is heavily contingent upon the data available in EMRs, the processes by which information is collected in the EMR needs to be better understood. Incomplete or inaccurate data in EMRs limits the ability of existing EMR systems to trigger effective information therapy. NLP offers potential for mining qualitative patient data for information triggers, but only to the extent that symptoms have been recorded within the EMR.

Citation

Pakhomov, Serguei V., et al. 2008. Agreement Between Patient-reported Symptoms and Their Documentation in the Medical Record. *American Journal of Managed Care*, 14(8):530-539.

Conclusion

Data Quality

In this preliminary review of recent literature, there appears to be a lack of understanding of issues around data quality on EHR/PHRs. Although this was by no means a comprehensive review, it is interesting to note that while one article focused specifically on the issue of data accuracy, data accuracy issues emerged in the other two articles under sections on privacy and confidentiality.

Both patient and provider education is required to address data quality issues. While providers may fear that allowing patients access to EMR data might increase errors, it is equally plausible that patient

participation will minimize errors that already exist within EMRs.

Best Practices

Another area where Ix may be able to play a role in health care reform is by sharing information therapy best practices. Ix best practices may have direct relevance to guiding the implementation of HIT and EHR systems in a way that will benefit patients.

For example, Group Health Cooperative uses secure email and after visit summaries (AVS) to enhance communication between patients and physicians. Their investment in HIT has been offset by benefits to both patients and physicians. Patients use secure email when

they otherwise would have called or scheduled appointments to ask questions. Also, patients leave their visits with a document, printed out from the EHR, summarizing their most relevant health information and follow-up instructions (the AVS). Providers receive fewer follow-up phone calls since forgotten information is likely recorded on the AVS and other simple questions can be answered via email.

The Institute for Family Health, whose mission is to provide health care to the medically underserved, saw the AVS as an opportunity to establish trust, which was the biggest barrier to effectively providing health care to this population. The AVS is used as

a transparent communication tool to help patients understand their health information, feel included in the health care process, and build trust with their health care providers.

Putting the Focus Back on the Patient

One of the acknowledged limitations in one of the reviewed articles is that the group of “experts” admittedly included minimal patient perspectives. The patient is at the center of information therapy. The patient is also at the center of health outcomes. The success of health care reform will, at least in some part, be based on health outcomes. Ix provides a framework for focusing on patient outcomes.

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