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Implementing an Interoperable Personal Health Record in Pediatrics: Lessons Learned at an Academic Children's Hospital

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Summary

This paper describes the development of an innovative health information technology creating a bidirectional link between the electronic medical record (EMR) of an academic children's hospital and a commercially available, interoperable personal health record (PHR). The goal of the PHR project has been to empower pediatric patients and their families to play a more active role in understanding, accessing, maintaining, and sharing their personal health information to ultimately improve health outcomes. The most notable challenges proved more operational and cultural than technological. Our experience demonstrates that an interoperable PHR is technically and culturally achievable at a pediatric academic medical center. Recognizing the complex social, cultural, and organizational contexts of these systems is important for overcoming barriers to a successful implementation.

Keywords

HIT; PHR; pediatrics; children's hospital

Introduction

This paper describes the development of a bidirectional link between the electronic medical record (EMR) of an academic children's hospital and a commercially available, interoperable personal health record (PHR). The dual purpose of the project was: 1) To allow for the electronic transmission of patients' personal health information (PHI) from the hospital's EMR directly to the patient's secure, online PHR in order to empower patients, their families, and community providers to access and share medical data more easily and efficiently; and 2) to allow hospital physicians to view patient-entered observations of daily living (ODLs) in the PHR through the hospital's EMR.

Background

Currently, there are two main types of electronic PHR systems: Tethered systems and interoperable PHRs.[1] The key difference between tethered and interoperable PHRs involves who controls or "owns" the patient's personal health information (PHI); in tethered PHRs, the healthcare provider or health institution does while, in interoperable systems, the patient is the owner. Tethered PHRs, which are essentially extensions of the provider's or health system's EMR, function primarily to allow the patient to view information that is stored in the EMR and to communicate via email or online appointment systems with their provider. Because these tethered systems are so intrinsically tied to the specific health care provider's EMR, patients cannot share their information electronically with outside

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providers, and cannot automatically import data from external sources. Interoperable PHRs, on the other hand, can offer patients more control and ownership of their PHI. These systems are interfaced to a provider's EMR in such a way that information can electronically flow from the EMR to the PHR while giving ultimate control of the data to the patient once it arrives in their account. The ability to automatically download data saves the patient from the potentially time-intensive task of manually entering all of their information, and electronic linkages to multiple providers, health systems, and pharmacies allows all relevant PHI to reside in one easily accessible and shared location. Health care providers have successfully implemented both tethered PHRs[2][3][4][5] and interoperable systems[6][7][8] for their patients.

Early studies suggested that PHRs can empower patients by making their health information more accessible and portable, allowing them to take a more active role in their health care. [9] Interoperable PHRs allow patients to consolidate their health information in one secure online repository of information while also allowing them to add basic health indicators or ODLs, such as blood pressures, seizure diaries, or weight measurements, which their physicians can monitor between regularly scheduled clinic visits.[10] Patients can choose to share this integrated, comprehensive source of health information with health care providers and/or family members of their choice, potentially bridging gaps in understanding, promoting more effective patient-provider dialogue, and improving care coordination for patients seeing multiple providers.[11] In all, PHRs have the ability to consolidate and give the patient access to their health information which can make the information more useful to the patient and allow them to play a larger role in their health care.

Approach to PHR Implementation at LPCH

The Lucile Packard Children's Hospital at Stanford (LPCH) made a critical decision to implement a bidirectional, interoperable PHR for our patients and families. As a major referral center for complex and severely ill children, the hospital and clinics are often just one of many places in which our patients receive health care. For example, over 90% of patients who receive care at LPCH have a primary care provider (PCP) outside of LPCH, and many have had hospitalizations or procedures performed in other tertiary care settings. In addition, LPCH receives patient referrals from over 30 states, so providing clinical data access regardless of location or source is critical to meet patient needs.

In this context, LPCH leadership decided that an interoperable PHR might be more immediately useful for patients given that data portability and the ability to share vital information with other providers were major concerns for families. In addition, since LPCH treats children and adolescents, as these youths grow older and begin to leave home for college or work, they often transition to different caregivers. The interoperable PHR allows the patient to retain access to their health information even after they have stopped receiving treatment at LPCH, thereby easing their transition. LPCH also viewed the ability to have updated records if the patient returned to LPCH as both an efficiency and care quality improvement. A commitment to improving the overall health and health outcomes of complicated pediatric patients across their various settings of healthcare and across age groups motivated LPCH leadership to initiate and support this project.

Prior to this project, families often described having their children's medical histories and information scattered across various healthcare settings, including PCPs' offices, local community hospitals or emergency rooms, and at LPCH. Their only option for creating a comprehensive medical history involved contacting each institution, negotiating the release of medical information process at the different medical records departments, and collecting the information in a folder or binder that was somewhat portable and (hopefully) accessible

at a time of need. In the best care scenarios, parents describe carrying an “executive summary” page describing the child’s health history and needs, medications, and instructions in case of emergency. However, there was a growing interest among many parents in consolidating these records into an electronic format.

Further, any physician-requested laboratories performed at institutions closer to patients’ homes or ODLs that patients or family members were to document often wound up on stray pieces of paper. In such non-standard and unorganized formats, the information was often unavailable when clinicians needed it most for making important health decisions with patients. By creating a bidirectional link between the Children’s Hospital’s EMR and an interoperable PHR, we have been able to provide patients the ability to electronically access and control their health information stored in the hospital’s EMR, while also allowing them to seamlessly share the observations documented outside the hospital with their care teams.

Challenges of PHR Implementation at LPCH

Others have identified a number of challenges to the successful implementation of PHRs, including: creating a usable sign-up process,[12] deciding which information to release,[13] deciding who should have access to the information,[14][15] and fitting the system appropriately into the clinician’s workflow.[16] At LPCH, we found that our most notable challenges were not technological, but rather operational and cultural. The three major challenges we faced in implementing this project were: 1) Finding the most appropriate primary party to administer, support, and maintain the project upon technical completion (“business owner”); 2) negotiating the different organizational expectations and cultural differences of the hospital and the software company providing the PHR; and 3) implementing the bidirectional flow of data from the PHR to the hospital’s EMR in a way that would improve clinical care and outcomes.

Finding a department willing to serve as the primary party responsible for administering, supporting, and maintaining the project upon completion (the “business owner”) was a foundational effort for starting the project. Ultimately, the Health Information Management Services (HIMS) Department emerged as the most logical owner given their expertise in release of medical information (ROI) issues at the hospital and their vision that wide adoption of a PHR system might facilitate a more efficient, timely, and patient-friendly mechanism for release of vital medical records. We believe that HIMS leadership and the framing of the PHR as an ROI paved the way for broader acceptance of the PHR project within the hospital administration and among the physician leadership, as well as for future projects in which access to hospital-based PHI will need to be managed.

The second major challenge during this project involved negotiating the cultural and organizational differences between an academic children’s hospital and the software company providing the PHR. Unlike previous large hospital IT projects (eg the EMR), the initial software vendor providing the PHR does not specialize in developing and implementing medical technologies in the enterprise setting, but rather focuses on creating consumer-oriented tools. The hospital’s expectations of solid timelines for new releases and API tools bumped up against the consumer software company’s more fluid and organic product development culture. Additionally, the software company’s desire for rapid deployment and patient adoption of the PHR conflicted with the hospital’s need for a conservative approach to ensure that the new technology would do “no harm” and not have any unexpected “side effects” for patients, physicians, or the institution as a whole.

The best approach to dealing with these organizational differences was not obvious and tested the strength of the partnership at various stages of the project. In the end, open, ongoing, face-to-face communication and negotiation at multiple levels of each organization

helped to ensure that each understood the needs, concerns, and capacities of the other. Recognizing the need large health-care institutions have for concrete roadmaps and robust commitments to the ongoing development of products, the software company began providing the hospital's project team with early releases of new software and informing hospital information services (IS) leadership about new plans and directions in advance of any public announcements. In turn, the hospital began providing constructive feedback that prioritized suggestions and enhancement requests while acknowledging that differences in priorities and timelines would not necessarily jeopardize the partnership.

One final issue that has not been resolved to date has been the viewing of patient ODLs from the PHR from within the hospital EMR. Creating a unique bidirectional flow of data and allowing care teams to monitor patient-entered data in between clinic visits was a critical part of the hospital's original vision for the PHR project. In particular, physicians and care teams for patients with active, evolving ongoing problems (e.g. post-transplant, post-NICU stay), have been particularly hopeful about the potential for this sort of electronic communication "back to the physician." However, while the software company and hospital PHR teams worked together successfully to develop this functionality, widespread adoption is likely to require a significant realignment of physician incentives to encourage use between patient visits.[7]

Early Feedback on the PHR Pilot at LPCH

Currently, the PHR project at LPCH is in a pilot phase that invites patients and families from specific clinical subspecialty programs to enroll, thus targeting children with special health care conditions that would especially benefit from this intervention. The signup process involves a face-to-face explanation of the potential benefits and risks of enrolling, hands-on registration, and brief tour of features of the PHR with an associate hired by the IS department. We have also engaged a cadre of "Physician Liaisons" representing each of the Centers to provide input on design elements and relevant ODLs for their patient groups, feedback on utility of the PHR in improving healthcare provision and health outcomes in various clinical settings, and suggestions for innovative and potentially high-impact ways of taking advantage of the bidirectional transfer of information that the EMR-PHR link currently allows.

Despite the reportedly high levels of enthusiasm and optimism generally expressed by patients and families towards PHRs, overall uptake of these systems has been relatively modest nationwide.[17][18][19] At LPCH, we chose to take a cautious approach to patient enrollment in an attempt to maximize early feedback. As of April 2011, we had enrolled approximately seventy LPCH patients in the PHR pilot. Immediately after initial enrollment, we request online feedback about the enrollment process and users' expectations for the system. Subsequent months' feedback surveys include questions about the usability and usefulness of the PHR, data integrity and accuracy, ease of ODL tracking within the PHR, and PHI from the EMR that the patients find most useful. Unpublished data from our internal QI/QA efforts (Table 1) demonstrate that 84% of patients have found the enrollment process easy, 56% have stated that their method for tracking and managing PHI has significantly improved, and 44% have said that the most useful data they have received in the PHR has been the ability to view lab test results.

We expect that useful data about the effects of the PHR on health outcomes and on patients' satisfaction with their relationship with the hospital and their care teams will require more time. We have also developed tools to assess physician acceptance, use, and impressions of the PHR, including frequency of accessing patient PHRs and perceived impact on quality of patient care and health outcomes.

Once the pilot phase of the project concludes, we expect to reevaluate how well the combination of our software platform and implementation approach has met patient and family needs. In the future, members of the project team hope to expand enrollment to all patients, including adolescents. This group is perhaps the population most likely to benefit from the PHR project because of their journey toward independent self-management, though including this population is challenging because of significant confidentiality and privacy issues.

Conclusions

Implementation of this innovative but relatively untested PHR project has required a paradigm shift for the hospital and the IS department. The overarching goal of the PHR project has been to empower pediatric patients and their families to play a more active role in understanding, accessing, maintaining, and sharing their personal health information in order to ultimately improve health outcomes. Making PHI more “portable” has been an important goal for all healthcare consumers in this country since the Health Information Portability and Accountability Act of 1996 (HIPAA); however, a special need and urgency exists for pediatric populations who change providers more frequently than adults. Targeting patients in addition to providers as the main users of this technology introduces a new and completely different set of requirements that must be addressed in order to ensure the success of the PHR. Our experience shows that implementation of an interoperable PHR is technically and culturally achievable at an academic medical center. We anticipate that other organizations will likely face challenges similar to the ones we have described, but that proactive, open, and ongoing communication between hospital and software company teams will help overcome the inevitable issues that will arise. Recognizing the complex social, cultural, and organizational contexts of these systems is important for overcoming barriers to a successful implementation.

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Table 1

Early PHR survey feedback

Assessment	Very Difficult	Difficult	Somewhat Easy	Easy	Very Easy
Ease of Enrollment	0% (0/19)	11% (2/19)	5% (1/19)	37% (7/19)	47% (9/19)
	Not at all improved	Improved very little	Somewhat improved	Improved	Very much improved
PHR improved management of child's healthcare?	0% (0/9)	11% (1/9)	33% (3/9)	44% (4/9)	11% (1/9)