Sociotechnical Challenges of Developing an Interoperable Personal Health Record

Lessons Learned

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Keywords

Personal health records, medical records, information systems, sociotechnical analysis

Summary

Objectives: To analyze sociotechnical issues involved in the process of developing an interoperable commercial Personal Health Record (PHR) in a hospital setting, and to create guidelines for future PHR implementations.

Methods: This qualitative study utilized observational research and semi-structured interviews with 8 members of the hospital team, as gathered over a 28 week period of developing and adapting a vendor-based PHR at Lucile Packard Children's Hospital at Stanford University. A grounded theory approach was utilized to code and analyze over 100 pages of typewritten field notes and interview transcripts. This grounded analysis allowed themes to surface during the data collection process which were subsequently explored in greater detail in the observations and interviews. **Results:** Four major themes emerged: (1) Multidisciplinary teamwork helped team members identify crucial features of the PHR; (2) Divergent goals for the PHR existed even within the hospital team; (3) Differing organizational conceptions of the end-user between the hospital and software company differentially shaped expectations for the final product; (4) Difficulties with coordination and accountability between the hospital and software company caused major delays and expenses and strained the relationship between hospital and software vendor.

Conclusions: Though commercial interoperable PHRs have great potential to improve healthcare, the process of designing and developing such systems is an inherently sociotechnical process with many complex issues and barriers. This paper offers recommendations based on the lessons learned to guide future development of such PHRs.

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1. Background

An increasing amount of attention has recently been focused on popularizing personal health records (PHRs) in the United States. Over \$19 billion from the American Recovery and Reinvestment Act (ARRA) was allocated for the improvement and expansion of the nation's computerized medical records [1, 2]. Part of the ARRA, the Health Information Technology for Economic and Clinical Health (HITECH) Act specifically calls for healthcare providers to demonstrate the "meaningful use" of systems that can "provide patients with timely electronic access to their health information" [3].

Many hospitals aim to utilize PHRs as one important component for demonstrating "meaningful use." Generally defined, PHRs are electronic systems aimed at empowering individual patients by allowing them to access, update and share their own health information presented in an easily understandable fashion. "Tethered" PHRs allow patients to view their health information stored in the electronic medical record (EMR) of their healthcare provider, but do not allow patients the ability to change the content or add new information. By contrast, "untethered" PHR systems are wholly created and maintained by the patient utilizing commercially available software or web applications. Between these two extremes, "interoperable" systems incorporate features of both tethered and standalone systems. Interoperable systems combine the ability to of tethered systems to connect directly to a hospital's EMR with the user interface of a standalone system, allowing the patient to create, store and edit their health information as well as share it with other providers.

All of these PHR systems encourage patients to play a more active role in their healthcare by giving them more responsibility for maintaining a healthy lifestyle and managing their chronic diseases, and thus may provide a cost-effective way to improve the quality of the patient care [4–8]. Private organizations such as the Markle Foundation and the Robert Wood Johnson Foundation are sponsoring programs like the Blue Button Challenge [9] and Project Health Design [10] which focus on supporting the development and adoption of PHR systems. PHRs are also gaining popularity within the healthcare and medical informatics community for their potentially transformative effects on the nature of healthcare in the United States [11, 12].

Despite the great potential of PHRs, levels of adoption and usage have been relatively low in the United States [13, 14]. Over the past several years, researchers in the field of medical informatics have repeatedly called for a better understanding of the barriers to the development and use of these systems [6, 7, 13]. To date though, the design process itself has not been reported on in the literature on PHRs. Most studies focus on an evaluation of the PHR itself – the end result of the process – and the features and functionality of the PHR, as well as user-satisfaction with these systems [8, 15–21]. In almost all cases, the focus of the studies is on the final system and not *how* it was produced. However, understanding the process by which these systems are developed and implemented can allow stake-holders to more effectively and consistently produce successful systems [22, 23].

Importantly, obstacles to developing successful PHRs are not solely technical in nature, but also have organizational, cultural, and legal dimensions. Researchers have used the term "sociotechnical" to describe these complex issues dealing with the interconnected nature of society and healthcare technology [24–30]. These issues emerge most clearly during the process of change, as the social context in which a technical system is built and implemented impacts the final product, just as the technology can reshape the social relationships in that context [31–34]. Fields such as Design Science Research (DSR) have emphasized the importance rigorously studying the organizational factors inherent in the process of developing innovative technological systems [35]. Thus, in order to adequately comprehend the nature of the barriers facing a successful PHR implementation, it is necessary to analyze the *sociotechnical* aspects of the design and development *process* [25].

2. Methods

The fieldwork for this project was conducted at Lucile Packard Children's Hospital at Stanford University (LPCH), an academic hospital focused on the treatment and care of babies, children, adolescents and expectant mothers. LPCH is presently a 303 bed quaternary care children's hospital of which 225 non-obstetric beds are located on the main campus. In 2009, LPCH built on its experience

with clinical informatics projects [36, 37], by beginning the process of implementing a vendor-based PHR system (Google Inc., Mountain View, CA) that can be interoperable with multiple commercially-available EMR systems, including the system (Cerner Corporation, Kansas City, MO) used by LPCH. This hospital was one of the first children's hospitals to begin implementing an interoperable PHR, and this is one of the first studies of such a system. Unlike PHR systems that are tethered to a particular institution's EMR, such as PAMFOnline at the Palo Alto Medical Foundation [8, 38–40], or My HealtheVet at Veterans Affairs hospitals [16, 17], and that have served as the basis of most past studies of PHR systems, an interoperable PHR offers the potential advantage of data portability and patient ownership of their data.

However, interoperability in this case also presented unique challenges. Although the main features of the PHR have been developed by a large software vendor, actually implementing the PHR system at LPCH required much more than a simple purchase. The PHR used by LPCH was originally built by the vendor to function as an untethered system. In order to achieve interoperability, the PHR implementation team had to work with both hospital staff and the vendor to integrate the PHR software with the EMR at the hospital. In contrast, if the team had implemented a tethered PHR, the system would have been designed from the beginning to work with the specific EMR in place. Thus, developing this interoperable PHR required a significant level of coordination and cooperation between hospital and vendor. The research in this paper took place while the team at the hospital was working to develop the pilot release of the PHR in order to test the system before releasing it hospital-wide.

Grounded research methods were used to identify and analyze the sociotechnical factors that influenced the process of designing and implementing a 3rd-party PHR system at the hospital from the early stages of the process. Because many of the most critical factors shaping PHR development are sociotechnical in nature, emerging from the interactions between social and technological factors, they can only be elucidated through qualitative research and analysis that arises organically from the context of those interactions [41, 42]. Additionally, as one of the first studies to prospectively observe the creation of a PHR in real-time, rather than relying solely on interviews and observations conducted after a system is complete, this approach was uniquely able to examine the development *process* as it unfolded.

The researchers conducted observational research at the hospital for 28 weeks, from August 2009 through May 2010, by sitting in on weekly design team meetings. These meetings were regularly attended by 6-12 hospital employees, consisting of various project and department managers, technical and legal personnel as well as physicians. No representatives from the vendor organization attended the meetings on a regular basis, although there was consistent contact between representatives of the organizations to discuss issues as they occurred. Observational research conducted by GG enabled the researchers to assess the interactions among hospital team members during the course of the project and allowed the researchers to identify themes that were explored in more depth in interviews [43]. The researcher who sat in on the meetings was purely an observer and did not participate in the decisions or discussion of the team with respect to the PHR project. Semi-structured interviews were conducted by GG over the course of these 28 weeks with eight team members from the hospital who were chosen to provide a wide range of perspectives on the project and included team members who either attended the design team meetings on a regular basis or were part of the leadership overseeing the project. The interviews lasted between 30-60 minutes, and allowed the researcher to explore themes and topics that emerge throughout the interview while still covering the themes identified in advance [44].

The interviews were audio-recorded and transcribed and field notes were gathered from the observational research, resulting in over 100 single-spaced pages. Using a grounded theory approach, themes were identified by GG in collaboration with AD and RS as they emerged rather than trying to fit the evidence to fall into predetermined categories [45–47]. The questions asked in each interview were motivated by the themes that cropped up during the observation as well as in previous interviews (see ►Appendix 1 for a sample interview schedule). After the conclusion of the fieldwork at LPCH, the themes from the observation notes and interview transcripts were then manually coded and organized thematically. Passages, quotations, sentences or even phrases were assigned one or more brief coding words or phrases which assigned them to a particular thematic area. To analyze the results, the researchers sorted the coded passages into thematic groups, and those groups which re-

curred repeatedly formed the framework for the Results Section of the manuscript. Representative quotations and anecdotes were used to provide illustrative detail for the different themes [41, 48]. The research protocol was approved by the Institutional Review Board of Stanford University, and all interview subjects signed consent forms.

3. Results

Some of the biggest obstacles that the development team at the hospital faced during this project were not technical, but were organizational or cultural in nature. Interviews and observational research revealed four major themes, as discussed below.

3.1. The Value of a Multidisciplinary Team

"The group is what has made the project." This sentiment was expressed by many members of the hospital team. The hospital team encompassed a broad range of expertise, including members with clinical, legal and product management backgrounds as well as technical experts. This diverse assemblage allowed the hospital team to foresee and overcome sociotechnical issues and challenges that may have been overlooked if the team had been composed solely of technical developers.

Including team members with clinical expertise – including nurses, physical therapists, and physicians – meant that they were able to recognize that some features of the PHR that might be perfectly logical from a software-engineering perspective made no sense clinically. For example, the PHR was designed to display lab test results in alphabetical order. However, when a physician orders a group of lab tests to be run, the results are grouped by category. Blood tests are grouped together (e.g. white cell counts, platelets, etc.) so that test results can be viewed in context with other related results. With the alphabetization of lab test results, white blood cell counts could be far removed from platelet counts, disrupting the context and clinical usefulness of the data and thus hindering patients from properly understanding their health information. As one member of the hospital team with a clinical background put it, this "is totally ridiculous for the way medicine is practiced, because all of a sudden you get a Chem-23 [battery of blood tests] and instead of it being in the normal pattern we're used to seeing it, it's exploded into alphabetical format, which changes everybody's ability to process that data." By including team members with a clinical background, the hospital team was able to ensure that the PHR was appropriate for the context in which it would be used.

The situation was similar for team members with other areas of expertise, including those with legal and product management backgrounds. For example, a team member with legal experience was present at many of the team meetings and helped the team avert potential legal issues. The team was able to recognize very early on in the process that there were many legal issues surrounding releasing certain pieces of health information to the profiles of children who are between 12 and 18 years of age. With this information, the team was able to appropriately configure the PHR to not transmit information to the profiles of children in this age range. Without considering a legal perspective from the beginning, the team very easily could have developed a PHR that was technically functional, but legally inappropriate because it would automatically import the patient's information, regardless of their age.

The hospital team also consulted with the families and caregivers of children who received treatment at the hospital throughout the process. For example, feedback was gathered through meetings with the hospital's Family Advisory Council (FAC), composed of the family members of patients who had received care at LPCH. Further, after this research was collected and the hospital entered into the pilot implementation phase of the project, one member of the FAC became a permanent member of the hospital PHR team. Additionally, gathering feedback from patients and families about the PHR in the form of surveys and a focus group was a vital part of the pilot implementation. The families' suggestions to improve the PHR were relayed back to the PHR vendor. The multidisciplinary nature of the hospital team allowed it to more effectively address the diverse suggestions and needs of the families, and to foresee and overcome a wide range of sociotechnical challenges.

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3.2. The Challenges of a Multidisciplinary Team

Although this broad range of expertise could be complementary, it did not necessarily encourage the team to develop cohesive goals or visions for the project. In fact, each team member at the hospital had different views about the goals and end-users of the PHR. Between the eight different hospital team members interviewed, six different goals for the PHR were given (\triangleright Table 1). Some goals were emphasized far more than others, and at times the team members simply disagreed. In general, team members agreed upon four goals, but did not give all of them equal priority:

- 1. *Patient Empowerment* was an important goal for 7 of 8 interviewees. As one interviewee stated, "the key point of [the PHR] would be that patients will have more control of their…health record."
- 2. *Portability* was an important goal for 5 of 8 interviewees. As one explained, "our main business objective is to allow the patient to take that data anywhere, and for us to get that data from anywhere."
- 3. *Providing physicians with a view of the PHR* was an important goal for 5 of 8 interviewees. One noted that the PHR is "going to offer a…venue for our patients to get data about themselves back into…the hands of the providers electronically."
- 4. *Technical Functionality* was volunteered as an important goal by only 2 of 8 interviewees. This suggests that many members of the team either took this for granted or were simply far more concerned with the social impact of the system.

Team members actually disagreed about two of the goals for the system:

- 1. *Providing "a patient's complete record*" was a goal for half of the interviewees. However, three of the team members did not mention this goal, and one explicitly disagreed. As this interviewee noted: "some things...we're legally not able to provide to them electronically. And other things...are just not quite easily portable whether it be their X-rays or everything."
- 2. Attracting patients to the hospital was a goal for one team member, who stated that "if you're comparing a hospital which provides this kind of functionality with another hospital with equal quality, but without this functionality, a patient will choose one with this functionality." But, another team member explicitly stated that it should not be a goal: "I don't see it as being a major driving force for …patients to go their doctor and say I have to go to Packard…because they have this PHR thing." The majority of the team members (6 out of 8) did not mention this goal at all.

Hospital team members also focused on different end-users: almost all agreed that clinicians as well as patients and their caregivers were end-users, but a significant fraction identified a very different group, network administrators (> Figure 1). Additionally, team members offered disparate criteria for what would make the project "successful" (> Figure 2). Such incongruities can lead to inefficiencies in the design process as hospital team members work in divergent directions. Additionally they also may contribute to miscommunication with the vendor.

3.3. Differing Organizational Conceptions of the End-Users

"This is a hospital, it's not an IT company." Hospital team members often distinguished their own sense of identity from what they perceived in the software vendor. Indeed, because the hospital and software vendor are two very different organizations with differing goals and missions, individuals within those organizations worked on the PHR differently, and held distinctive visions for the PHR.

Perhaps most strikingly, the organizations held different definitions of the end-user. The software vendor focused primarily on "the consumer," whereas the hospital focused on "the patient" and "the physician." There is a subtle, but important difference between viewing the consumer versus the patient or physician as an end-user. Consumers are envisioned as individuals who exercise free market choices; hence the software company emphasizes "the value of consumers being able to own, use, manage and share their medical data online with whomever they choose" [49]. By contrast, when hospital team members emphasize that "everything is focused around the patient and the patient's care," they invoke a more specific set of social relationships, which includes physicians, as well as the patient's family. The "consumer" may not be the "patient" at all; for example, a PHR might be con-

trolled by the patient's parent or guardian. In this case, it would not be legal for the hospital to release some information (such as an adolescent's sexually transmitted infection [STI] testing results).

Additionally, the hospital wanted the PHR to provide physicians with information entered by the patient and by other health care providers outside of the organization, making the physician one if its end users. But since the vendor did not initially envision physicians as an important group of endusers, its initial software did not allow physicians affiliated with the hospital to automatically and easily view a patient's PHR. One hospital team member stated that the software vendor has "yet to care about the physicians, the people that actually need to consume the information." Though the PHR vendor eventually contracted with a third-party vendor to build a physician viewer interface, this ended up delaying the project, and the viewer proved to be cumbersome and limited in usefulness.

In short, different conceptions of the "end user" illustrate how cultural differences between the hospital and the vendor can shape the process of developing a PHR, as well as the end product.

3.4. Difficulties with Coordination and Accountability

"They're the kid with the ball and we're just...fortunate to be playing with them in the same court. But it's their ball; they can do what they want with it." Hospital implementation team members and leadership voiced a sense that they were not treated as full partners by the PHR vendor, suggesting persistent difficulties in communication and coordination around key decisions. Different goals for the PHR project and a lack of clear communication or formal business agreement between the vendor (which offered the PHR product for "free") and the hospital caused delays in the project and tensions as the organizations worked in different directions.

In part due to the lack from the very beginning of a contract specifying expectations and deliverables between the vendor and hospital, several key pieces of functionality that the hospital expected to be in the PHR product were not present. For example, though the hospital placed an extremely high priority on having a physician viewer, the vendor did not. The initial PHR also lacked the ability for patients or caregivers to see comments about their lab results. Without these comments, the patient or caregiver would see numerical lab results, but might not have any idea what that number meant. Because the hospital and the vendor did not initially formalize an agreement defining the expectations for the work to be done by each partner, communication challenges were compounded by a lack of accountability. Once the hospital team finally articulated features that they felt were essential, they were forced to wait months for the vendor to update the PHR with those features. One hospital team member recalled that the PHR implementation "was supposed to be one of those six-week kinda things," but the pilot phase took over one year to go live and faced numerous delays and timeline pushbacks while different features of the PHR were sorted out and corrected. Without an explicit timeline or mechanism for ensuring accountability, the team at the hospital found themselves waiting months for the vendor to make the appropriate changes to the PHR – while still expending resources to keep the project going.

4. Discussion: What Process Leads to a "Successful" PHR?

These findings provide insights for developing "successful" PHRs that may not be developed solely by studying end products. In fact, this analysis demonstrates that every actor participating in this PHR implementation – both on an individual and an organizational level – had different criteria for defining the success of the implementation. For the vendor, user satisfaction and improved health-care are one more way of boosting traffic to their website and encouraging users to purchase services offered by the company [50]. The hospital is primarily concerned with enhancing the health care experience of patients, and otherwise improving health outcomes.

Even within the hospital, team members held differing views of success. When asked how they would judge the success of the PHR, the eight interviewees volunteered five different outcomes (\triangleright Figure 2). Though they agreed on some criteria, no two interviewees had the same set of criteria. Furthermore, even criteria that everyone agreed on – such as "usage" – are somewhat ambiguous because of different conceptions of the user. Thus, the training and experiences of each individual working

on the project also influenced how they worked on the product and which aspects of the system they consider important.

When individuals and organizations frame technological systems differently, they may work against each other unwittingly. These findings corroborate previous studies of the process of implementing large technical systems in healthcare settings, which have demonstrated that the interaction of social and technical factors crucially shapes the implementation [51]. Such sociotechnical factors, ranging from cultural differences that shape organizational conceptions of technology and the necessity for clear communication [52, 53], to the value of a multidisciplinary development team [30, 54, 55], are critical factors in the design and implementation of health information technology.

This study extends these results to the development of an interoperable PHR and demonstrates that these sociotechnical factors are critical for PHR implementations. Interoperable PHRs require a significant degree of coordination between vendor and health care institution that tethered or stand-alone PHRs do not need. Hence, the sociotechnical factors become especially important for these types of systems. Further, this work adds to the existing literature regarding implementations of health information technology by highlighting both the challenges and value associated with a multidisciplinary team as well as extending these findings to the development of a vendor-based interoperable PHR. In all, the most important take-away from this experience is that developing a large technical system like a PHR is much more than just a technical challenge; it also involves the careful consideration of sociotechnical issues throughout the development process.

Although the qualitative approach employed in this study can provide unique insights, researchers acknowledge limitations to such methods, which are intrinsically situational [56–58]. In this case, the interviews were conducted only with members of the hospital team, which may contribute to a somewhat one-sided view of the interactions between the hospital and the software company. Additionally, although team members were encouraged to be completely honest, and confidentiality was assured, team dynamics and individual interviews may have been subtly influenced by knowledge of the present research project. While only one author (GG) coded the field notes and transcripts, two other authors (AD and RS) discussed on a regular basis the analysis of those codings and independently agreed upon the resulting themes. Finally, the specific issues identified here emerged from the implementation of a specific commercial interoperable PHR system at one children's hospital; an examination of a different vendor-hospital interaction might yield somewhat different issues.

Nonetheless, this research provides good reason to anticipate divergent goals and expectations in implementations of PHRs, and suggests the value of corrective action. Since LPCH is one of the first hospitals in the nation to implement an interoperable vendor-based PHR system, this study should enable smoother and more successful interoperable PHR implementations in the future. The analysis outlined above suggests several "best practices" for similar future PHR implementations as summarized in \triangleright Table 2.

5. Conclusion

Since this research was conducted, the hospital completed the initial PHR development and recruited approximately 70 patients and their families to participate in a pilot program to use the system. The initial feedback from users concerning the system was positive. Overall, they were very pleased with the interoperable aspects of the system, such as their ability to view their health information from LPCH and add their own information as well. Many of the features that users felt could be improved, such as the alphabetical display of lab test results, were features that had already been identified by the project team as targets for ongoing work. However, in June 2011, Google, the vendor of the PHR, publically announced that they were going to sunset the PHR due to low uptake and adoption rates [59]. The sociotechnical challenges identified in this study may explain the reason for the lack of adoption by other healthcare institutions. The lessons learned from this implementation might help other vendors and hospitals avoid some of the pitfalls encountered in this project and product. LPCH is currently reevaluating its options and strategy for proceeding forward, but is still firmly committed to providing technology to patients and their families that offers easy, online access to their health information.

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Interoperable personal health records have the potential to transform and improve healthcare in the United States. However, developing and integrating these systems into a hospital setting is a complex process with many sociotechnical variables to be accounted for. Our work should be used to help guide future interoperable PHR implementations by making the teams aware of the obstacles inherent in the development and implementation process and providing recommendations for how these obstacles might be overcome. Future work should be done to analyze more PHR implementations in order to make more broadly generalizable conclusions. Further research must also be done to assess the impact of interoperable PHR systems on improving healthcare outcomes.

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Clinical Relevance Statement

This study adds to the growing literature confirming the notion that the creation of technical systems like an interoperable PHR is a complex, sociotechnical process. Successful implementations of such systems should acknowledge this complexity and account for it through the use of a multidisciplinary project team and open lines of communication and coordination between the parties involved.

Conflict of Interest Statement

None of the authors have any conflict of interest, financial or otherwise, relevant to the conduct or reporting of this study.

Protection of Human and Animal Subjects

The study was per-formed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects, and was reviewed by Institutional Review Board of Stanford University.



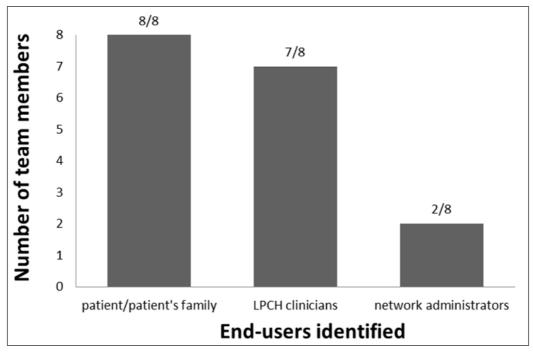


Fig. 1 The different groups of end-users mentioned as important by hospital team members during interviews. These demonstrate the varying conceptions of the PHR project between different team members.

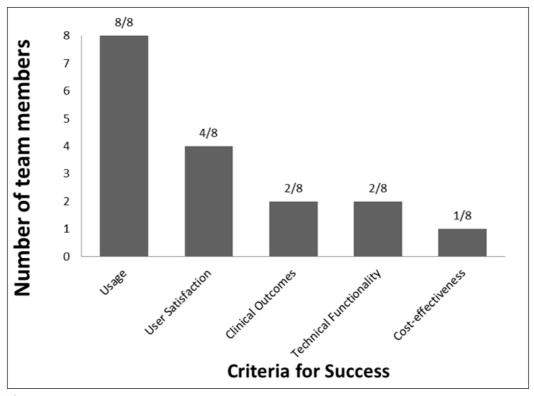


Fig. 2 The varying definitions of success noted by members of the hospital team during interviews. These illustrate the different visions that team members had for the PHR.

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 Table 1 Differing goals for the project between hospital team members. The results in this table illustrate the different visions that members of the same hospital design team have for the PHR.

Inter- viewee	Patient Empowerment	Portability	Physician View	Complete Record	Attracting Patients to Hospital	Technical Functionality
1	Yes	DNM	DNM	DNM	DNM	Yes
2	Yes	DNM	Yes	No	DNM	DNM
3	DNM	DNM	DNM	DNM	Yes	Yes
4	Yes	Yes	DNM	Yes	DNM	DNM
5	Yes	Yes	Yes	Yes	DNM	DNM
6	Yes	Yes	Yes	Yes	DNM	DNM
7	Yes	Yes	Yes	No	No	DNM
8	Yes	Yes	Yes	DNM	DNM	DNM

Yes=mentioned positively as a goal; No=mentioned negatively as something that should not be a goal; DNM=Did Not Mention in their interview.

 Table 2 Recommendations for future implementations. Recommendations derived from the results of this research to aid future healthcare organizations in implementing an interoperable commercial PHR.

Type of Issue	Recommendation		
The Value of a Multidisciplinary Team	 The healthcare organization should include team members with a broad range of expertise, including members with: health informatics expertise clinical expertise legal expertise product management expertise 		
The Challenges of a Multidisciplinary Team	 The project team within the healthcare organization should aim for agreement on key design issues for the system to ensure team members do not work in opposing directions. Key issues may include: different priorities for key functionalities of the system different overarching goals for the system different measures of success 		
Differing Organizational Conceptions of the End-User	• The healthcare organization should communicate with the PHR vendor the required functionality of the system based on their expectation of end-user needs		
Difficulties with Coordination and Accountability	• The healthcare organization should establish a formal agreement with the PHR vendor regarding responsibilities, expectations and timelines for the project		

References

- 1. White House: The White House Homepage [Internet]. Washington D.C.: The White House [updated 2010 August 30]; Health Care. [updated 2010 August 30; cited 2010 August 30]. Available from: http://www. whitehouse.gov/issues/health-care
- U.S. Department of Health and Human Services. American Recovery and Reinvestment Act Implementation Plans [Internet]. Washington D.C.: U.S. Department of Health and Human Services; 2010 June [cited 2010 August 30]. Available from: http://www.recovery.gov/Transparency/agency/Re covery%20Plans/HHS%20Recovery%20Act%20Plan%20-%20June%202010.pdf
- 3. Blumenthal D, Tavenner M. The "Meaningful use" regulation for electronic health records. N Engl J Med 2010; 363: 501–504.
- 4. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc 2008; 15(1): 1–7.
- Britto MT, Wimberg J. Pediatric personal health records: current trends and key challenges. Pediatrics 2009; 123 (Suppl. 2): S97-S99.
- 6. Ahern D, Kreslake J, Phalen J. What is eHealth (6): Perspectives on the evolution of eHealth research. Journal of Medical Internet Research 2006; 8(1): e4.
- 7. Council on Clinical Information Technology. Policy statement using personal health records to improve the quality of health care for children. Pediatrics 2009; 124(1): 403–409.
- 8. Horan TA, Botts NE, Burkhard RJ. A multidimensional view of personal health systems for underserved populations. J Med Internet Res 2010; 12(3): e32.
- 9. Health 2.0 LLC: Blue Button Challenge [Internet]. San Francisco: Health 2.0 LLC; 2010 [cited 2010 August 30]. Available from: http://health2challenge.org/blog/blue-button-challenge/
- 10. Robert Wood Johnson Foundation: Project HealthDesign [Internet]. Madison (WI): Robert Wood Johnson Foundation; 2010 [cited 2010 August 30]. Available from: http://www.projecthealthdesign.org/
- 11. Detmer D, Bloomrosen M, Raymond B, Tang PC. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak 2008; 8: 45.
- 12. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006; 13: 121–126.
- 13. Kaelber, DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). J Am Med Inform Assoc 2008; 15(6): 729–736.
- 14. Steinbrook, R. Personally controlled online health data the next big thing in medical care? NEJM 2008; 358(16): 1653–1656.
- 15. Reti SR, Feldman HJ, Ross SE, Safran C. Improving personal health records for patient-centered care. J Am Med Inform Assoc 2010; 17: 192–195.
- 16. Nazi, KM. Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users' characteristics, needs, and preferences. J Am Med Inform Assoc 2010; 17: 203–211.
- 17. Nazi, KM, Hogan TP, Wagner TH, McInnes DK, Smith BM, Haggstrom D, et al. Embracing a health services research perspective on personal health records: Lessons learned from the VA My HealtheVet system. Journal of General Internal Medicine 2010; 25(Suppl. 1): S62–S67.
- Kim MI, Johnson KB. Personal health records: evaluation of functionality and utility. J Am Med Inform Assoc 2002; 9: 171–180.
- 19. Lee M, Delaney C, Moorhead S. Building a personal health record from a nursing perspective. Int J Med Inform 2007; 76(Suppl. 2): S308–S316.
- 20. Maloney FL, Wright A. USB-based personal health records: next term an analysis of features and functionality. Int J Med Inform 2010; 79(2): 97–111.
- 21. Do NV, Barnhill R, Heermann-Do KA, Salzman KL, Gimbel RW. The military health system's personal health record pilot with Microsoft HealthVault and Google Health. J Am Med Inform Assoc 2011; 18(2): 118–124.
- 22. Madon T, Hofman KJ, Kupfer L, Glass RI. "Implementation science." Science 2007; 318: 1728–1729.
- 23. Goldstein MK. Using health information technology to improve hypertension management. Current hypertension reports 2008; 10(3): 201–207.
- 24. Ash JS, Berg M, Coiera E. Some unintended consequences of information technology in health care: the nature of patient care information system-related errors. J Am Med Inform Assoc 2004; 11(2): 104–112.
- Wears, RL, Berg M. Computer technology and clinical work: still waiting for Godot. J Am Med Assoc 2005; 293(10): 1261–1263.

- Sittig DF, Ash JS, Zhang J, Osheroff JA, Shabot MM. Lessons from unexpected increased mortality after implementation of a commercially sold computerized physician order entry system. Pediatrics 2006; 118(2): 797–801.
- 27. Ash JS, Sittig DF, Dykstra RH, Guappone K, Carpenter JD, Seshadri V. Categorizing the unintended sociotechnical consequences of computerized provider order entry. Int J Med Inform 2007; 76(suppl. 1): 21–27.
- 28. Harrison MI, Koppel R, Bar-Lev S. Unintended consequences of information technologies in health care an interactive sociotechnical analysis. J Am Med Inform Assoc 2007; 14(5): 542–549.
- 29. Shen B. Bio-socio-technical underpinnings of participatory medicine. J Participat Med 2009; 1(1): e7.
- Goldstein MK, Coleman RW, Tu SW, Shankar RD, O'Connor MJ, Musen MA. Translating research into practice: organizational issues in implementing automated decision support for hypertension in three medical centers. J Am Med Inform Assoc 2004; 11(5): 368–376.
- 31. Pinch T, Bijker W. The social construction of facts and artefacts: or how the sociology of science and the sociology of technology might benefit each other. Social Studies of Science 1984; 14(3): 399–441.
- 32. Jasanoff S, editor. States of knowledge: The co-production of science and social order. Routledge and Kegan Paul; London: 2004.
- 33. Taylor P. Building on construction: an exploration of heterogeneous constructionism using an analogy from psychology and a sketch from socioeconomic modeling. Perspectives on Science 1995; 3: 66–98.
- 34. Orlikowski WJ, Gash DC. Technological frames: making sense of information technology in organizations. ACM Transactions on Information Systems 1994; 12(2): 174–207.
- 35. Hevner A, March S, Park J, Ram S. "Design science in information systems research," MIS Quarterly 2004; (28:1): 75–105.
- 36. Bernstein JA, Imler DL, Sharek P, Longhurst CA. Improved physician work flow after integrating sign-out notes into the electronic medical record. Jt Comm J Qual Patient Saf 2010; 36(2): 72–78.
- 37. Longhurst CA, Parast L, Sandborg CI, Widen E, Sullivan J, Hahn JS, et al. Decrease in hospital-wide mortality rate after implementation of a commercially sold computerized physician order entry system. Pediatrics 2010; 126(1): 14–21.
- 38. Tang PC, Black W, Buchanan J, Young CY, Hooper D, Lane SR, et al. PAMFOnline: integrating EHealth with an electronic medical record system. AMIA Annu Symp Proc 2003: 644–648.
- 39. Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. Health Aff (Millwood) 2005; 24(5): 1290–1295.
- 40. Tang PC, Lee TH. Your doctor's office or the Internet? Two paths to personal health records. N Engl J Med 2009; 360(13): 1276–1278.
- 41. Strauss AL. Qualitative analysis for social scientists. Cambridge, MA: Cambridge University Press, 1987.
- 42. Ash J, Berg M. Report of conference track 4: socio-technical issues of HIS. Methods Inf Med 2003; 69: 305–306.
- 43. Forsythe DE. "It's just a matter of common sense": ethnography as invisible work. Computer Supported Cooperative Work 1999; 8: 127–145.
- 44. Emerson R, et. al. Writing ethnographic fieldnotes. Chicago: University of Chicago Press, 1995.
- 45. Glaser BG, Strauss AL. The discovery of grounded theory: strategies for qualitative research. New York: Aldine De Gruyter, 1967.
- 46. Strauss AL. Corbin J. Basics of grounded theory methods. Beverly Hills, CA.: Sage, 1990.
- 47. Corbin J, Strauss AL. Grounded theory research: Procedures, canons and evaluative criteria. Qualitative Sociology 1990; 13: 3–21.
- 48. Weiss, Robert S. Learning from strangers. New York, New York: The Free Press, 1995.
- Spector A. Update from the Google Health Team. 2010 March 1 [cited 2010 August 30]. In: The Official Google Blog [Internet]. Mountain View (CA), Google, Inc. Available from: http://googleblog.blogspot. com/2010/03/update-from-google-health-team.html
- 50. Giustini D. How Google is changing medicine. BMJ 2005; 331: 1487–1488.
- 51. Berg M. "Implementing information systems in health care organizations: myths and challenges." Int J Med Inf 2001; 64: 143–156.
- 52. Lorenzi, Nancy M, Riley, Robert T. Organizational issues = change. Int J Med Inf 2003; 69(2–3): 197–203.
- 53. Lorenzi, N M, Riley, R T. Managing change: an overview. J Am Med Inform Assoc 2000; 7(2): 116–124.
- 54. Thursky KA, Mahemoff M. "User-centered design techniques for a computerised antibiotic decision support system in an intensive care unit." International journal of medical informatics 2007; 76(10): 760–768.
- 55. Ash JS, Fournier L, Stavri PZ, Dykstra R. Principles for a successful computerized physician order entry implementation. AMIA Annu Symp Proc 2003: 36–40.
- Finkel SE, Guterbock TM, Borg MJ. Race-of-interviewer effects in a pre-election poll: Virginia 1989. Public Opinion Quarterly 1991; 55: 313–330.

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- 57. Forsythe DE, Buchanan BG, Osheroff JA, Miller RA. Expanding the concept of medical information: An observational study of physicians' information needs. Computers and biomedical research, an international journal 1992; 25(2): 181–200.
- Forsythe DE. Using ethnography to investigate life scientists' information needs. Bull Med Libr Assoc 1998; 86(3): 402–409.
- 59. Brown A, Weihl B. An update on Google Health and Google PowerMeter. 2011 Jun 24 [cited 2011 Jun 24]. In: The Official Google Blog [Internet]. Mountain View, CA: Google Inc. c2011. Available from: http://goog leblog.blogspot.com/2011/06/update-on-google-health-and-google.html

Appendix 1 – General Interview Schedule

Background

- How long have you been working at LPCH?
- What kind of background do you have that is relevant to your work on this project? Have you ever done anything similar?
- Can you please give me a general overview of the system, focusing on what you believe to be the key, defining features and characteristics?
- Could you walk me through the overall process of implementing this system, starting from the beginning and continuing onto the future directions for this project?
- Please explain your role in the implementation of this system.
- Could you please describe what you felt to be the most important factors that the team considered in order to shape the implementation of the system?

Challenges

- What was your involvement in the decision to choose Google as the provider?
 - Then →How was the decision made to go with Google as opposed to another vendor's software or creating a LPCH specific PHR?
- How would you describe the relationship that the LPCH team has with Google?
- What role has Google assumed in this process? Is it the same or different from what you originally thought their role would be?
- What are Google's strengths and weaknesses? LPCH's strengths and weaknesses?
- In your opinion, what were the major obstacles that impeded the successful development and implementation of this system? How were they overcome?
- What aspects of the implementation process would you change or like to improve?
- What aspects of the implementation process did you feel were successful or very effective?

Intended Outcomes

- What is the purpose of the system and who was in charge of defining this purpose?
- Who are the intended end-users of this system?
- How do you see the end-users actually using this system?
- Do you think that use of this system will change the role of the patient or the way the patient behaves? How about the physician?
- What kind of effects do you anticipate this system having upon the way patients view healthcare at Sacred Heart? The way physicians practice?
- What kind of role have patients with little technical background played in the design process?
- Who is responsible for keeping the interests of the patients in mind over the process?
- What kind of a role have physicians played in the design process?
- By what criteria will you judge whether the system is successful or not?
- Is there anything I haven't covered yet that you feel might be relevant or important to my study?