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Personal Health Record Systems as Boundary Objects

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Abstract:

Personal health record systems are widely available and regarded as a key element in the push for electronic health records and the meaningful use of technology in medicine. However, the adoption and use of these systems has been much lower than anticipated. While research has investigated the reasons for this lack of adoption, we have no satisfactory answers. As such, we undertook a qualitative research study in a medical clinic setting to investigate them. We focused on identifying how the unique user groups who interacted with these personal health record systems viewed their use and impact. We specifically examined three different perspectives on these systems; physician, patient, and medical staff (e.g., nurses, receptionists). We found that personal health record systems function as boundary objects that reflect significantly different meanings to the various user groups who interact with them. Our results show that patients largely view these systems as non-essential adjuncts to their current care routine, physicians see the systems as tools, and medical staff members view them as an additional task or chore with questionable effectiveness. This new conceptualization of these systems as boundary objects has significant implications for their design and use.

Keywords: Personal Health Record Systems, Boundary Objects, Health Information Systems, Case Study.

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1 Introduction

An electronic personal health record system (PHRS) is:

* A private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. (Jones, Shipman, Plaut, & Selden, 2010, p. 244)

PHRS have become widely available to patients through their healthcare providers. Many such systems are linked to a specific healthcare organization's electronic health record (EHR) system and are known as tethered systems. With a tethered PHRS, patients can access their own records through a secure portal and see, for example, the trend of their lab results over the last year, their immunization history, or due dates for screenings.

PHRS support patient-to-provider communication because they feature a secure message function as a core function and allow patients to engage in more meaningful ways with their own medical decision making. PHRS support better health-related decision making by giving patients access to necessary data in a format they can easily access and understand. Yet, the latest data available indicate that few American adults have adopted computerized PHRS—only about seven percent (Archer, Fervier-Thomas, Lokker, McKibbon, & Straus, 2011) to 10% (Markle, 2011). A recent forecast estimates adoption rates as high as 20 percent for 2016 (Ford, Hesse, & Huerta, 2016), but even that adoption rate indicates current use by only one in five U.S. consumers.

PHRS are not standalone technologies: they exist in a larger healthcare ecosystem. Yet, the PHRS literature has a consumer focus, which its emphasis on penetration rates and reasons for adoption or non-adoption evidences. In fact, the PHRS literature focuses primarily on patient perceptions and the reasons why patients have or have not adopted them (e.g., Agarwal, Anderson, Zarate, & Ward, 2013; Baird, Furukawa, & Raghu, 2012; Do, Barnhill, Heermann-Do, Salzman, & Gimbel, 2011; Vezryidis & Timmons, 2015). This focus on patients derives from the ideal PHRS, which the patient-centered policy model that Reti, Feldman, Ross, and Safran (2010) developed and Sunyaev’s (2013) vision for a patient-centered PHRS exemplify. In this vision, patients do not passively receive care but are instead a member of a healthcare team, and they actively make decisions about their own healthcare services. As Sunyaev (2013, p. 4) states: “A PHR is a part of this healthcare environment, and its task is both to enable the efficient exchange of medical data, as well as to support the interaction between actors”.

The PHRS exchanges data between patients and their physicians and other medical staff, and it supports interaction, especially in the form of communication, between these actors. In fact, physicians and medical staff, such as nurses, pharmacists, and receptionists, work with PHRS every day, although few studies have considered their perspectives. In order to understand why the rates of PHRS adoption remain low, we need to consider the experiences of other PHRS users in the larger healthcare ecosystem and not only those of patients. Some studies have investigated the perspective of healthcare professionals, including physicians (Nazi, 2013; Huba & Zhang, 2012; Vydra, Cuaresma, Kretovics, & Bose-Brill, 2015) and nurses in particular (Lee, Delaney, & Moorhead, 2006; Thede, 2008; Pushpangadan & Seckman, 2015). However, no study that we know about has considered the experiences and perspectives of patients, physicians, and medical staff who use the same PHRS in a single healthcare ecosystem. We can achieve a fuller, holistic understanding of PHRS and why patients are not adopting them by investigating their role in this larger ecosystem and the extent to which they support the exchange of information among relevant actors.

As Nazi (2013) states:

* Although PHRs are designed as consumer-oriented tools, understanding the consumer perspective is necessary, but insufficient by itself. Consumer PHR use also has broad implications for health care providers and delivery systems; however, these have received less attention...PHR use must be examined as a component of health care work, influenced by and influencing organizational actors and their work within the health care ecosystem.

To understand how PHRS operate in a healthcare ecosystem and to explore the reasons for their lack of adoption, we conducted a case study of PHRS use in a regional medical clinic. We interviewed patients,
physicians, and medical staff. As we analyzed our data and considered the relationships among the PHRS users, a theoretical lens emerged that helped us understand what we were seeing: boundary objects. Brown and Duguid (1998, p. 104) define boundary objects as “objects of interest to each community involved but viewed differently by each of them…. Through them, a community can come to understand what is common and what is distinct about another community, its practices, and its world view”. By serving as an information portal that patients, healthcare staff, and physicians can all influence, PHRS serve as boundary objects and help bridge the gaps in understanding about healthcare that exist between these various user communities.

We examine the following research question:

RQ: How do different user groups in a healthcare ecosystem view a PHRS, and how do differing user perspectives affect its adoption and use?

To investigate PHRS perspectives and use, we interviewed physicians, patients, nurses, and other medical staff in a regional healthcare clinic. Our findings support the expectation that different vested groups view PHRS in different ways and that these perspectives affect their use. In the case of patients, our findings suggest that their views of the PHRS directly influence their adoption. Our findings also suggest implications for PHRS design and use.

2 Theoretical Background

This section on the theoretical background of our study has three parts. First, we review the literature on PHRS, which we organize into four categories. Second, we present common perspectives of PHRS. Third, we look at the literature on boundary objects—especially work that has characterized information systems as boundary objects.

2.1 Personal Healthcare Systems

PHRS have the potential to greatly support patient care through enhancing the communication between physicians and patients and by supporting patient decision making for treatment and care. However, this potential is currently not widely recognized although PHRS are widely available. In fact, as many as 70 million Americans may have access to electronic PHRS (Kaelber, Jha, Johnston, Middleton, & Bates, 2008). Yet, many studies, including our own, show that a very small proportion of patients are using these systems despite their advantages. We divide existing empirical studies of PHRS into four categories: 1) studies that survey the intent to adopt PHRS, 2) studies that survey current users, 3) studies that compare users and non-users across the same measures, and 4) studies that investigate the views of healthcare providers.

Empirical studies of the intent to adopt (i.e., future adoption) have uncovered several different factors thought to be important to PHRS adoption and also some key deterrents. The sheer number and variety of factors uncovered, however, made it difficult to synthesize the findings, but one factor that we found across several studies was perceived usefulness (Archer & Cocosila, 2014; Assadi & Hassanein, 2014; Patel et al., 2011; Spil & Klein, 2014). Other studies uncovered deterrents to PHR use, including computer anxiety (Archer & Cocosila, 2014), perceived risk (Spil & Klein, 2014), and system complexity (Assadi & Hassanein, 2014).

Empirical studies that have surveyed current PHRS users have focused on different aspects related to use, which has also revealed a large and varied number of factors. Some findings were common across studies. Some studies have found the perceived usefulness of the PHRS as a reason for its continued use (Day & Gu, 2012; Tulu et al., 2012), specifically in terms of time savings, ready access to lab results, and convenience. These authors (e.g., Day & Gu, 2012; Tulu et al., 2012) also found ease of use as a factor for continued use. However, others have cited a perceived lack of usefulness and a mismatch between system functionality and patient expectations (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010) and a perception that the system in question was difficult to use (Greenhalgh et al., 2010) as a disincentive for continued use. (Other factors that researchers have found to relate to continued use included computer literacy (Day & Gu, 2012), the perceived privacy and security of the system (Burkhead, Schooley, Dawson, & Horan, 2010), the number of visits to the doctor, and improved quality of care (Beckjord, Richis, & Hesse, 2012; Miller, Vandenbosch, Ivaniv, & Black, 2007).

We could find only one study that specifically compared PHRS users to non-users. Emani et al. (2012) surveyed 1500 patients at two medical centers in Massachusetts. They grouped the resulting 760
responses into five categories: innovators, other users, laggards, non-users, and rejecters. They found that non-users were less likely to be computer users than users or rejecters. Non-adopters were also less technologically innovative than users or rejecters. PHRS users perceived greater ease of use and greater relative advantage for PHRS compared to non-adopters and rejecters. In testing a model of the relationship between several factors related to innovation diffusion, the authors found that relative advantage, ease of use, trialability of the PHRS, positive perceptions of privacy and security of the PHRS, computer use, and age were all positively related to the perceived value of the PHRS.

We could only find three studies that investigated the perceptions of PHRS held by healthcare professionals as opposed to patients. Nazi (2013) interviewed 30 U.S. Veterans’ Administration healthcare professionals, healthcare providers (which included physicians), nurses, and pharmacists about their perspectives of PHRS. Her key finding was that these actors—even the provider community—often underused PHRS but that the implementation of secure messaging had dramatic consequences for communication and patient-provider relationships. Nazi posited that healthcare professionals played a crucial role in the successful adoption of PHRS and their use by patients. However, for her study, she did not differentiate between the perceptions of PHRS by the different groups of professionals in her dataset.

Huba and Zhang (2012) interviewed 21 healthcare professionals about their views on PHRS. About half of their informants were not familiar with PHRS, but most of them expressed support for a central repository for patient data. Nevertheless, they also had concerns about the quality and trustworthiness of any data that patients would be able to enter into a PHRS.

Vydra et al. (2015) surveyed 54 physicians at the Ohio State University Medical Center and conducted a focus group with four physicians who had completed the survey. The survey results indicated that the respondents overestimated the amount of time they were logged in to the PHRS each week. Respondents estimated they were logged in an average of 12.5 hours per week when, according to institutional records, they were logged in on average 8.2 hours per week. While the members of the focus group were optimistic about PHRS, they were bothered by the extra time needed to attend to electronic communication, especially since they were not being reimbursed for it. They viewed the PHRS primarily as a supplement to face-to-face care.

Three studies dealt with the perspectives of only nurses on PHRS. In one study, nurses designed and built a PHRS (Lee et al 2006). The authors of the other two studies expressed their views that nurses should be actively involved in designing and developing these systems (Thede, 2008; Pushpangadan & Seckman, 2015).

2.2 Perspectives of PHRS

Researchers have conceptualized computer-based systems in different ways (see Orlikowski & Iacono, 2001), but, in general, in the MIS literature, researchers view such systems as rationally designed “tools” that perform as their designers intend and as their users expect. The PHRS literature is no exception. Indeed, the view of PHRS as “tools” is common in the literature (Assadi & Hassanein, 2014; Beckjord et al., 2012; Burkhead et al., 2010; Dohan, Abouzahara & Tan, 2014; Pushpangadan & Seckman, 2015; Tang, Ash, Bates, Overhage, & Sands, 2006). For example, Spil and Klein (2014) cite the definition of PHR from the Markle Foundation (2003): “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” (p. 3). Garvin, Odon-Wesley, Rudman, and Stewart (2009) write that “The PHR may be an important tool for collecting, tracking, and sharing up-to-date clinical information about an individual’s health or the health of someone in their care”.

The tool view of an information system assumes a rational designer and a rational user. They assume that, if users have well-designed tools and receive proper training, then they should use these tools to their benefit, as designed, and with minimal problems. If true, then why would people who could benefit from PHRS use choose not to use them? The tool view of PHRS is based on a perspective of the patient as a consumer and is not a complete explanation—the tool metaphor may not adequately capture how multiple user groups conceptualize PHRS. Given the differences in physicians’ and patients’ perspectives and roles in a healthcare ecosystem, the PHRS tool physicians envision is likely to differ from the tool that the patient perceives. The perspectives and roles that other medical staff play also differ from those of physicians and patients. Nurses handle patient messages. Receptionists handle patient requests for appointments. Rather than work with a holistic PHRS “tool”, these healthcare professionals work with narrowly defined system functions from their own perspectives, which are not the same as a patient’s or
the physician’s perspective. Differences in perspectives across groups can affect both adoption and use. As Vydra et al. (2015) states:

Low levels of physician awareness and familiarity with PHRs represented significant barriers that may prevent adoption and use. In contrast to the support expressed by patients, physicians expressed more concern about the potential risks of PHRs, notably the potential for parts of the medical record to confuse patients. To achieve widespread adoption of PHRs, the beliefs and attitudes of physicians and patients toward PHRs should be reconciled.

2.3 Boundary Objects

Boundary objects are:

Objects that are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. Like the blackboard, a boundary object “sits in the middle” of a group of actors with divergent viewpoints. (Star, 1989, p. 46)

In her study with Griesemer (Star & Griesemer, 1989), Star adds that boundary objects are “objects which inhabit several intersecting social worlds…and satisfy the informational requirements of each of them” (p. 393). Boundary objects include such things as claims forms (Wenger, 1998), contracts (Brown & Duguid, 1998), specimens and field notes (Star & Griesemer, 1989), ERP systems (Pawlowski & Robey, 2004), and human anatomy simulations (Fleischmann, 2006). Wenger (1998) argues that one could usefully see such artifacts as boundary objects and that designing them involves designing for participation as well as for use. Wenger states: “The office is replete with boundary objects that connect its function with a wide range of communities of practice and constituencies without a specific shared practice” (p. 106). Further, he says: “Connecting the communities involved, understanding practices, and managing boundaries become fundamental design tasks” (p. 108). So while researchers have conceptualized other computer-based information systems as boundary objects (Pawlowski & Robey, 2004; Fleischmann, 2006; Gal, Lyytinen & Yoo, 2008), to the best of our knowledge, they have not yet conceptualized PHRS in this way. The closest we have found is a paper by Saario, Hall, and Pecover (2012), who suggest that electronic health documents (not electronic health records systems) may serve as boundary objects.

However, boundary objects can cut both ways. If designers do not consider the potential boundary-spanning aspects of artifacts when designing them, artifacts may actually work against providing a shared understanding among participating constituencies. Brown and Duguid (1998) discuss how business processes should span boundaries among groups and lead to shared interpretations in organizations, but, instead, they are sometimes intentionally designed to impose compliance and conformity. Fox (2011) reinforces this view of boundary objects’ sometimes having a negative influence, which, in effect, inhibits shared understanding. For example, Prout (1996) argues that the antiseptic techniques that Sir Joseph Lister advocated for surgery acted as inhibitory boundary objects, while aseptic techniques, which doctors widely accepted and implemented in operating rooms, served as facilitative boundary objects.

As an example of boundary objects that span multiple social worlds, consider the case of cybercadavers: software-based simulations of dead bodies that provide options for medical education (Fleischmann, 2006). Fleischmann identifies three overlapping social worlds involved in their design and use: gross anatomy instruction, educational administration, and simulation design (Figure 1). For those in gross anatomy instruction, the primary activity is teaching medical students about human anatomy. For those in educational administration, their concerns are broad and include such issues as medical school curriculum, standardized testing, and accreditation. Simulation designers create new software, and cybercadavers designers create simulations that represent the human body. According to Fleischmann (2006), instructors see cybercadavers as an extremely valuable tool and as providing many advantages over real cadavers. Administrators see them as increasing the efficiency of teaching because acquiring and maintaining real cadavers is a messy and difficult job. Designers see cybercadavers as a way to exercise their craft while also earning academic and professional awards. According to Fleischmann (2006), “As boundary objects, cybercadavers solidify the connection between these social worlds, providing them with common ground for values and knowledges relevant to all three social worlds” (p. 82). Yet, as he also points out, once created, boundary objects do not “passively sit at the intersection…. Instead, they actively reshape relationships within and among these social worlds, shifting alliances, conflicts, and the overall balance of power” (p. 82). Cybercadavers can bring administrators and designers together over the prospect of eliminating actual cadavers. They can bring instructors and designers
together where cybercadavers can be used a supplement to dissection; where the digital complements the actual. Finally, cybercadavers can be the basis for collaboration between administrators (who prefer replacing cadavers and enhancing efficiency) and gross anatomy instructors (who prefer the traditional route of dissection) instead of a source of conflict. With cybercadavers as the boundary object, members of each social world can understand a little more about the other social worlds they interact with in the medical school arena.

Figure 1. Cybercadavers as Boundary Objects (Based on Fleischmann, 2006, p. 82)

3 Materials and Methods

We conducted an in-depth single case study for which we used an inductive, interpretive approach to qualitative research (Klein & Myers, 1999). This approach iterates between data collection and analysis while leveraging the researcher’s knowledge of existing relevant literature (Mason, 2002; Yin, 2009). A single case study is appropriate when the researchers have secured a high level of access to an organization with multiple parties, such as the vested groups who interact with the PHRS, who are informed on one or more aspects of the phenomenon of interest (Yin, 2009; Siggelkow, 2007; Voss, Tsikriktsis, & Frohlich, 2002).

3.1 Site description

Our study took place in a medical clinic in Iowa; we conducted interviews between October, 2012, and April, 2013. The clinic employed more than 200 healthcare providers at the time of our study, including physicians, physicians’ assistants, and nurse practitioners. An additional 1,000 staff roles spanned business, reception, laboratory, and nursing functions. Patients from 10 different communities made more than one million clinic visits annually. The clinic began implementing its EHR system (EHRS), licensed from one of the three leading American EHRS vendors, in 2008. Use of the vendor’s PHRS module began in March, 2010. The initial pilot of the PHRS, involving about 1,000 employees and their families, lasted until October 2010. The clinic made the PHRS, which we call HealthTech here, available to all patients immediately after the trial period. The clinic preliminarily justified the system based on a perceived desire on the part of patients to communicate electronically and securely with their healthcare providers. Patients could sign up when they visited a clinic office. Signing up for and use of HealthTech was free. At the time of writing, over 53,500 or 35 percent of patients had signed up.

Patients used HealthTech either to review information from their charts or to initiate some action that involved contacting clinic employees. For a given doctor’s patients, all PHR messages and prescription refill requests went first to the doctor’s primary nurse. Appointment requests went to receptionists. The
primary nurse, who made sure that prescriptions were refilled and responded to patient questions sent via the PHRS's secure message function, handled most patient requests. In some cases, the primary nurse passed requests on to the doctor for action. Doctors submitted patient information to the EHRS, which then populated the PHRS. They could also introduce special instructions or comments into the PHR after a patient visit, but they rarely initiated contact with patients through the tethered PHRS. Nurses other than the primary nurse could monitor patient messages at select times.

3.2 Data Collection and Analysis

To collect data, we used semi-structured interviews with informants who represented each key user group that interacted with the PHRS. The key user groups we identified were patients, medical staff, and physicians. While there are other important players in the larger PHRS ecosystem, such as clinic administrators, upper management, and IT staff, we focused on representatives of those groups who worked with the PHRS as part of their repeated, routine activities. We conducted 25 interviews (Tables 1 and 2), including one with the clinic’s marketing manager for background information.

<table>
<thead>
<tr>
<th>Informant</th>
<th>Gender</th>
<th>Age</th>
<th>Occupation status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
<td>Male</td>
<td>88</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 2</td>
<td>Male</td>
<td>66</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 3</td>
<td>Female</td>
<td>86</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 4</td>
<td>Male</td>
<td>63</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 5</td>
<td>Female</td>
<td>60</td>
<td>Working</td>
</tr>
<tr>
<td>Patient 6</td>
<td>Female</td>
<td>71</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 7</td>
<td>Female</td>
<td>19</td>
<td>Student</td>
</tr>
<tr>
<td>Patient 8</td>
<td>Male</td>
<td>76</td>
<td>Retired</td>
</tr>
<tr>
<td>Patient 9</td>
<td>Female</td>
<td>71</td>
<td>Working</td>
</tr>
<tr>
<td>Patient 10</td>
<td>Female</td>
<td>56</td>
<td>Working</td>
</tr>
<tr>
<td>Patient 11</td>
<td>Female</td>
<td>42</td>
<td>Working</td>
</tr>
</tbody>
</table>

Table 1. Patient Demographics

<table>
<thead>
<tr>
<th>Informant</th>
<th>Organizational tenure (years)</th>
<th>Occupational tenure (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purchasing director</td>
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<td>18</td>
</tr>
<tr>
<td>Lab director</td>
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<td>3</td>
</tr>
<tr>
<td>Neurologist</td>
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<td>10</td>
</tr>
<tr>
<td>Certified nurse midwife</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>Patient/nurse</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Dermatologist</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Family medicine MD</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Optometrist</td>
<td>13</td>
<td>18</td>
</tr>
<tr>
<td>Receptionist</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Medical office assistant</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Junior receptionist</td>
<td>1.5</td>
<td>5</td>
</tr>
<tr>
<td>Licensed practicing nurse</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2. Physician and Staff Demographics
We used one of three protocols to interview participants depending on their role (see Appendix A). We stopped interviewing respondents when we felt that we were no longer gaining additional new information. We recorded all interviews with the permission of the informants. The interviews ranged from 19-53 minutes with an average length of 31 minutes. The same receptionist transcribed all interviews, and we analyzed them with the support of NVivo version 10. All informants received some compensation for their participation: physicians received US$100, staff received US$50, and patients received US$10 gift cards.

We conducted the study using interpretive field research (Klein & Myers, 1999; Walsham, 2006). This method of case study analysis iterates between data collection and analysis while leveraging the researcher’s knowledge of existing relevant literature (Mason, 2002; Yin, 2009). We designed the study to investigate PHRs in the context of their implementation and to shed light into the process of how different users interact with the system. The data analysis uncovered the key themes, insights, and relationships to existing theory that might help to explain the phenomenon (Miles & Huberman, 1994; Mason, 2002). We conducted the analysis while using the tools of interpretive case analysis and the constant comparative method (Walsham, 2006; Sarker & Sarker 2009).

The data analysis generated 18 emergent nodes that described the interactions of the interviewees with the PHRS. These categories encompassed both system functionality and user attitudes and impacts from interactions with the PHRS. We also used word counts to uncover the prominent themes so that we could best articulate the emerging theory (see Appendix B for a list of the nodes and their descriptions and a work product that involves word counts and a work product that involves text parsing).

4 Results

Our analysis pointed to three very different perspectives of the PHRS. Each vested group had a different vision of the system, its functioning, and its purpose. To illustrate the differences in these views, we use metaphors that capture the predominant perspectives of each group. Patients saw the PHRS as an adjunct, something added to what already existed in their view of medical records and their maintenance. Physicians saw the PHRS primarily as a tool for patients. Medical staff tended to see the PHRS as a chore—additional work that they had to perform as part of their jobs once the clinic had decided to implement it.

4.1 PHRS as Adjunct

When patients adopted HealthTech, they tended to use it to support their current healthcare activities. If patients were already diligently collecting and keeping their medical records, then they used HealthTech as an additional way to support their routine interactions with their healthcare data. Patient 1’s comments illustrate this practice:

Well, the clinic has instituted that new procedure where when you make a visit you get the results on the internet... which is important, for instance lab results. In a day or two I can see what my cholesterol is, what my HDL is, what my LDL...and then if I have any questions as a result of that I can contact my provider and get clarification. I have basically a file of all the results over the years.... But, this new deal with the computer makes it really nice.

If patients were already in constant contact with their physicians and related medical staff, they used the secure message function of the system to communicate even more or to redirect some of the communication through a different channel. One patient used HealthTech primarily as a way to communicate with her physicians and related medical staff. She suffered from several chronic conditions and was bound to a wheelchair. She was in the habit of contacting the clinic frequently with questions and concerns. Since the accident that had disabled her, she had taught herself how to use a computer, and, with HealthTech, she could use the computer as another channel for communication. In fact, she had shifted much of her phone-based communication to the message function of HealthTech:

I don’t use the phone as much. It’s just easier... I emailed my doctor, it was a non-emergency, “Should I get a flu shot sooner or later?” and it came back with a ‘sooner!’ “OK, great.” I wouldn’t have bothered to call the clinic. I have a cell phone that flakes out because of where I live, and it’s something you think about in the middle of the night, that doesn’t do you any good.... The drawback I have with computers and emails is that I would rather email somebody than talk to them. (Patient 5)
Contrast the example of the patient who was heavily invested in the PHRS with patients who rarely used it:

I’ve only looked at it once or twice, to tell you the truth…. I haven’t used it very much. (Patient 2)

Right now I need to try to get back in. I’ve forgotten my password. (Patient 3)

I have logged in, but I don’t use it very often…. but I don’t know what would be included in HealthTech. I guess if I saw everything that was in my medical record I probably wouldn’t know what it all means. (Patient 7)

I like having the accessibility to it. Do I check it regularly? Or do I have a need to use it a lot? No, I’m a very healthy person…. I’m not a fanatic about checking everything…. I can’t say that I’m an avid user of it. (Patient 9)

As the second quote above illustrates, one out of the 11 patient informants could not access their account because of an issue with passwords. The reception staff frequently dealt with password issues as well:

And sometimes they have not logged in so many days or weeks their password expired, and they don’t know how to just click on the “Forget my password” and some generic one—they always call the front desk. (Medical office assistant/receptionist)

I do know that they have a lot of issues where if they forget their password or their username they call us a lot, and there’s buttons there that says, “I forgot my password,” or, “I forgot my username.” And then they would email it to you. Well, a lot of times they’re just like, “Well, I just need a new password, can’t I just get a new password?” I’m like, “Well, you’ve got to click the button”. (Receptionist)

If constant communication was not a key part of a patient’s approach to healthcare, having HealthTech available would not change the quantity or quality of the patient’s interactions with medical providers. In general, the availability of HealthTech extended patients’ ability to do what they were already doing, but it did not substantially change patient actions. Hence, we use the “PHRS as adjunct” metaphor to describe patient views based on defining adjunct as: “something that is joined or added to another thing but is not an essential part of it” (Adjunct, n.d.). The patients we interviewed considered HealthTech as a nice thing to have but not a necessary part of their healthcare.

Note that attitudes towards HealthTech were not necessarily influenced by the severity of the patient’s health situation. While Patient 9 was relatively healthy and saw no real need to use HealthTech in part because of her good health, Patients 3 and 7 suffered from chronic conditions that involved frequent operations and continual monitoring of their situations. Yet neither was very interested in HealthTech or the functionality it offered. HealthTech had extended their healthcare possibilities by presenting them with alternative means of communicating with the healthcare system and accessing their health data, but neither of them saw reasons to engage with these capabilities.

4.2 PHRS as Tool

Physicians viewed PHRS primarily as a tool intended to help patients manage their own healthcare. When asked about the relationship between HealthTech and patient care, the physicians volunteered their tool-based views:

Well, I think that personal health records are a tool that helps to—it’s a venue to help with patient-centered care. I think that it’s a venue to give the patient, to empower the patient with information and to be able to use that information towards either understanding of their condition, understanding what the doctor wants to do, and at the same time to communicate with their physician in a more freely manner, by using personal health records. I think it’s a tool. (Neurologist)

Yeah, I mean I think it’s just one of those things that I think it just gives them one more tool to kind of feel like they have a little bit more hold on what’s going on in their health too, as opposed to it just kind of being, “Oh, it’s just all that stuff that the doctor’s done. I don’t know that much about that…” or that kind of thing. (Family medicine MD)

So personal health record is nothing but a little portion of those electronic medical records, so in general I would say more electronic health records, in general, are an excellent tool….. (Neurologist)
One physician (the dermatologist) identified the PHRS as a very specific type of tool: a database: “So it really becomes kind of a living database of their own history of health, at least since it started.”.

Physicians admitted they had little or no direct access to HealthTech from the patient’s perspective. Of the five physicians interviewed, two did not use it as a patient, two were heavy users, and the fifth signed up as a patient just before the interview. Most had a limited understanding of what the patient saw and did with HealthTech:

> I’ve seen, you know, like the basic things that they have sent to us of this is kind of what the patient can see, but I haven’t done it from the direct patient perspective. (Family medicine MD)
> The nurses usually take the HealthTech messages, and then they talk to us, and send them a message back, or they send me the message. (Certified nurse midwife)
> We don’t have access to HealthTech, as physicians. (Neurologist)
> I may not know exactly, you know, everything about it, but I think compared to the average patient that I take care of, I probably know more than the average patient. (Optometrist)

Although physicians had limited exposure to the patient-facing side of HealthTech, they did have direct interactions with it. Their interactions involved adding to and editing the “after visit summary” (AVS), a document patients received at the end of their visit that summarized what had happened and that contained instructions for the patient to follow. The clinic required an AVS for every patient visit, and, typically, the reception staff printed and gave them to patients when they left. However, patients with HealthTech received the AVS in digital format:

> And for people who don’t have HealthTech access, they get what’s called an “after visit summary”. (Optometrist)
> We don’t need to print it if you have HealthTech. Because it will be on your chart, and that counts towards that after visit summary. So, [the clinic] wants more people using HealthTech so you don’t have to print many of the AVS. (Neurologist)
> I like the idea of an after visit summary. We use them heavily, but I hate printing it because here’s a HIPAA sensitive document we hand the patient, if it gets in the garbage can between here and the front door, you know, whose responsibility is that? We print, I think, on the bottom of all of them, “Delivered to the patient,” so hopefully, it’s not our responsibility. (Dermatologist)

When the physicians talked about the PHRS and their ability to influence the patient through it, they talked about how the clinic had a 48-hour rule for the release of the PHR to the patient.

> After 48 hours the system automatically releases that information. 48 hours is a window that you have, so if something is abnormal, you can tell the patient and contact the patient before the patient goes and sees something is abnormal and doesn’t know what’s going on. So, people like it from that perspective. Also because we have to provide an after visit summary to each patient, and those are also available in HealthTech. (Neurologist)

Between the time of a patient visit and when the AVS was posted to HealthTech, physicians had an opportunity to customize the content of the PHR. They would enter additional instructions and relevant information for the patient to make the contents of the record clearer and more helpful.

> Some of it is automated, what I use that’s sort of my personal input mostly, is in the patient instructions field. For instance, if I use liquid nitrogen on someone I have little boiler plate I can put in the patient’s directions is the post care information for that… If I do a biopsy, the wound care information is there. If I see an acne patient, I have a regular acne handout, I used to have them in files and hand them to all of my acne patients, and now they go in the after visit summary… I write them a note about the results I try to reiterate what we spoke about, but it isn’t automated and part of the lab test report, for instance. (Dermatologist)

HealthTech doesn’t have any additional medical thinking, or information that they may be looking, “Why my doctor is thinking this, or my doctor thought about this”. Et cetera. Now we’re trying to improve that by using the after visit summary and put more patient instructions et cetera there. I usually write down the diagnosis and the patient instructions, so they know what I mean by whatever I said they have… It has information well, which lab work or tests you need to schedule, and they are there. You have information about your condition, because then we
have patient driven information that is available as database, and that is directed towards patients so we take that and we pull it and put it into the patient's after visit summary. (Neurologist)

You know, and so, sure, I mean there’s times where I look at think, “OK, well, that’s going to get sent to them, if I don’t do something directly about it now,” and there might be certain things that I think, “Well, I want to make sure that I get a message to them saying, “This is OK, don’t worry about this,” even if stuff says it’s low or high, or this, that or the other thing. (Family medicine MD)

As the PHR content went into the patient’s chart, physicians were concerned about what went into the record. They were concerned about the legality of the information that was released through the PHRS and about whether or not patients could understand the content. They were also concerned about the legal implications of what information was released to patients in HealthTech. While blood pressure readings and any other quantifiable information were fine to release, results of tests that dealt with such things as sexually transmitted diseases were not. Confidentiality was a major concern:

We’re trying to do it in an appropriate way that takes advantage of the immediacy of that communication, but also respects the confidentiality we have to maintain…. We’re paranoid about confidentiality. (Dermatologist)

The physicians were also concerned about whether patients would be able to easily understand the information in HealthTech. The results of certain procedures, such as Pap smears and colonoscopies, could not be quantified and so were not communicated in HealthTech. Other information would not be relevant if read out of context or might unnecessarily worry patients who did not understand its implications:

[Y]ou have to be careful about the amount of information that you release, particularly because the lack of information can be very confusing. I think genetic testing with genetic results, I think that they should not be available, unless you have seen the doctor, for example. (Neurologist)

I mean I think with anything I think most providers—probably, little bit, every once in awhile—there’s certain things that you probably think twice about, “How am I going to word that, so that if the patient…,” typically because, in the electronic health—or in the stuff like HealthTech—they don’t see all of the documentation that you put. (Family medicine MD)

The physicians saw HealthTech primarily as a tool for their patients, and they accordingly worried about the information they put into the PHRS so that the tool would be used appropriately. They worked to make sure the information HealthTech contained was personalized, legal, and understandable. Like anyone who provides a useful tool to another, they were conscientious about their role in shaping the tool’s utility, ease of use, and proper function. However, they did not believe HealthTech was a “silver bullet”. Like most tools, it would work best when used in the right way and in the right context.

So, people who have no chronic diseases, or they just go for a very punctual reason to see a doctor, and they don’t have to go for the next two, or three, or four years, they don’t really find anything useful in having HealthTech. (Neurologist)

So, I think the population of people who are really going to benefit from HealthTech are parents, people who are getting to the middle age, who are all of a sudden starting to have blood tests, and cholesterol checks, and knowing their laboratory results, because all of those things, of course, are nice to be able to look up—your immunizations, you know. (Optometrist)

Physicians identified overuse as the primary inappropriate use of the PHRS, specifically in terms of patients’ sending too many messages.

I mean there are some patients that will email you five times a day, you know, every day for weeks after an encounter, and… so, while, in general, I’m heartily in favor of that kind of access, there are people who just don’t know how to get to the point and then let it go. (Dermatologist)

Now, it hasn’t overrun me by any means, maybe ten years from now it will be way too much and I’ll be like, “I need to do patient care. I don’t need to be doing emails with patients.”. (Optometrist)
So, maybe a little bit, that they might ask, maybe a little bit more questions, but we don’t get a ton. I mean we definitely have certain patients that use it more than others. (Family medicine MD)

4.3 PHRS as Chore

In general, medical staff did not view HealthTech systemically. Instead, they saw it in terms of specific functions that they themselves had to deal with. For them, HealthTech represented an additional patient contact point, which meant additional work. Hence, the metaphor that best represents their perspective is PHRS as a chore.

Receptionists only dealt with that part of HealthTech that allowed patients to make appointments. The receptionists tended to believe that HealthTech was helpful:

*It helps us to be very quick in getting back to the patient, at least in our department, we have a real good track record of getting back to the patient within the allotted time.* (Receptionist)

But they had issues related to using it:

*I think HealthTech initially slowed the system down somewhat, from the scheduling side.* (Receptionist)

*I would say three—well, four out of ten, out of those four, two would be, “Hey, I sent a question to my nurse this morning and it’s 1:00 PM, and I haven’t heard”. And the other two would be, “I forgot my password… how do I go back?”. (Medical office assistant)*

Receptionists and LPNs (licensed practical nurses) had the task of recruiting patients to sign up for HealthTech, which they saw as one more chore they had to handle. Receptionists and LPNs had to work the recruitment into their regular work routines:

*It’s a little—it was overwhelming at first, because we have these sheets that, on top of doing what we do, we give these sheets out and we have to tell people. You know? So it can take upwards of five minutes to explain it to someone on top of their five or ten minutes that we’re sitting in the room with them…. That being said, it’s also frustrating when they leave it on the table, you know, and walk out of the room.* (LPN)

At this point, the receptionists and LPNs who were encouraging patients to enroll in HealthTech were engaging in selling behavior that had little to do with their regular jobs or with the system. Recruiting was just one additional task they were asked to incorporate into their daily work.

By far the most arduous new task associated with HealthTech was dealing with patient messages. Registered nurses (RNs) received messages sent from HealthTech to which they either answered directly or consulted with physicians about the response. In rare cases, physicians would respond directly. When the RN was off duty or not available, a pool of nurses would monitor patient messages. The nurses saw the benefit in patients’ having the ability to send and receive secure messages:

*And, it’s nice for us, I would rather send a quick email, than wait on the phone for 30 seconds for them to answer their phone, or play phone tag.* (RN)

But the nurses also felt that dealing with patient questions and comments through secure messaging could sometimes be overwhelming. They characterized some patients as writing detailed daily journals or even novels.

*My nurses have some patients who they regretted—this patient shouldn’t be given access to HealthTech they like to write a novel.* (Medical office assistant)

*To a daily journal, some people will tell us about every single thing they did, wishing us a happy whatever holiday it is…. You know, really like using it like a journal. So, in that case you kind of have to say, “Oh man, was that a mistake, giving that to them?”* (LPN)

*I think some of the nurses get frustrated because we get paragraphs of, “Here’s my day, here’s what I had for breakfast…”. So, just the filtering through those—do you really want this in your chart? You know, it’s a whole journal of what’s going on.* (RN)

Despite the role they played in recruiting and in interacting with patients through HealthTech, the staff seemed to have been given little training on the system or its features. When asked directly if they were
provided with any additional training related to the introduction of HealthTech, staff indicated that training was scarce or not provided at all. When asked about specific training on HealthTech, one of the receptionists replied: “I can’t remember. I’m not sure.”.

While members of the medical staff saw the benefits of having a PHRS such as HealthTech available for patients and while they were generally positive about it, HealthTech added to and changed their daily work routines. They tended not to view HealthTech holistically as the physicians did but instead focused on the specific parts of it that they had to deal with as part of their expanded job duties.

5 Discussion

We used three different metaphors to capture the perspectives of three different user groups who interacted with PHRS. Although HealthTech was a single software system, the three groups viewed and used it differently. Patients saw it as an adjunct, just one more thing added to what they already possessed. Physicians primarily saw it as a software-based tool for patients. Medical staff saw it as creating more work/chores that they had to perform.

The PHRS here sat “in the middle” of the different groups of actors who had different views about healthcare and the information systems created to monitor and maintain it (Star, 1989). As a portal, HealthTech provided a way for patients to share their healthcare situations with physicians and other medical staff who communicate back their own perspectives. In addition to being participants in the communication process, medical staff members were also facilitators who intervened in the communication flow between patients and physicians. Yet, patients did not need to understand the prescribed work flow involved in routing their queries through HealthTech in order to participate in and benefit from the process. Similarly, staff did not need to understand how patients conceptualized their personal health situations in order to successfully mediate the passing of queries and responses between patients and physicians. Although physicians were aware of the role played by their primary nurses in HealthTech, they did not need to be aware of how the PHRS touched others in their offices and altered their work responsibilities. For patients, the PHRS acted as a direct boundary between them and the clinic. Everything that a patient submitted through the PHRS went directly to staff members. Staff received all questions and requests that patients directed to physicians, so patient-initiated interactions with physicians were mediated twice: first by the PHRS and then by the staff. Staff responded to questions and requests via the system on behalf of physicians sometimes independently and sometimes after consultation with the physician. For a physician, HealthTech was the ultimate boundary that separated them from patients. However, perultimtate boundaries in the form of the EHRS or the clinic staff also separated physicians from patients. After a patient’s office visit, a physician entered the patient’s information into the EHRS, and a select set of it eventually made its way into the PHRS, although physicians frequently introduced special instructions or comments for the patient into the PHR. When a physician responded to a patient’s request or question, the response went first to the staff, typically a nurse, who then communicated with the patient through the PHRS. From a patient’s perspective, however, the PHRS was the only mediator. Patients did not know what happened to the items they submitted or how they were routed—they only knew that, within 24 hours, they got a response. Physicians and medical staff did not directly work together through the PHRS, but, as the discussion above about work flows indicates, their interactions with the system affected each other’s work.

The situation resembled Wenger’s (1998, p. 106) characterizations of the roles that medical claims forms play except, in this instance, it was the PHRS that “connect[ed] its function with a wide range of communities of practice and constituencies without a specific shared practice”. Like the cybercadavers we mention in Section 2.3 (Fleischmann, 2006), PHRS allow different groups who approach healthcare from very different perspectives to have meaningful discussions over joint areas of interest. Patients and physicians can exchange information about the meaning and implications of a test result, medical staff and physicians can discuss office work flows altered by the introduction of the PHRS and ways to further adapt practice, and medical staff and patients can discuss expectations on both sides about the time frame for a response to a query submitted through the PHRS or the best way to structure a question about a health-related issue. Consistent with how Brown and Duguid (1998, p. 104) define boundary objects, the PHRS acts as an object “of interest to each community involved but viewed differently by each of them”. Our case of PHRS adds to the limited literature on information systems as boundary objects (e.g., Fleischmann, 2006; Pawlowski & Robey, 2004) and demonstrates the usefulness of the theoretical lens for understanding how information systems function at the nexus of multiple and varied user groups.
Applying a boundary object perspective to PHRS has implications for design and use. In terms of design, one needs to remember that PHRS, like many information systems, do not have a single set of users. While PHRS are widely conceived of and sold as tools to support patients, that perception ignores other groups that also use the systems. Physicians and medical staff also use PHRS, although not in the same manner as patients. The expectations for useful, usable, and successful systems differ by constituency. What makes a system useful for one group may cause problems for others. For example, nurses may see a feature that limits the size of messages as a huge improvement given that they monitor them, but some patients may also see it as a serious hindrance. Designers who focus only on the requirements of the nurses might inadvertently worsen the user experiences for patients. Thinking of information systems as boundary objects would help designers better identify each of the relevant user groups. Once they did so, developers could involve representatives of each group simultaneously in the requirements-determination process—whether a joint application design (JAD) effort or an agile-type prototyping exercise. After the designers established requirements and built prototypes, the representatives of each group could change roles in an effort to understand how the system would function, look, and feel for others. In this way, the requirements-determination process itself would act as a boundary object and allow different user groups to better understand each other’s needs and practices.

The role of the PHRS as a boundary object in our context allows for meaningful interactions between different attitudes and interactions (both with each other and with the system) impact system design and ultimately affects the provision and consumption of healthcare.

This view of PHRS as boundary objects in no way negates the vision of the patient-centered approach to healthcare (Sunyaev, 2013) or of the PHRS as a vehicle for promoting patient-centeredness. PHRS allow engaged patients to receive information from their charts, such as lab results and lists of identified medical conditions and summaries of their office visits. Suggestions and instructions from physicians augment the after-visit summaries. PHRS allow engaged patients to ask questions and to seek additional information about their treatment and their conditions. Yet, we must understand the ability of PHRS to empower patients in the context of physician and medical staff perspectives of PHRS and in the context of the health-delivery system that can provide a centralized role for patients (Nazi, 2013; Vydra et al. 2015). To promote the adoption and use of PHRS and to facilitate their best use, scholars need to understand them from the perspectives of all user groups and in the healthcare context in which they are situated as part of a larger ecosystem.

6 Conclusions

We contribute to the health IT domain by introducing the theory of boundary objects to the literature on PHRS. This theoretical perspective is important because the number of constituent user groups and their differing attitudes and interactions (both with each other and with the system) impact system design and use. The role of the PHRS as a boundary object in our context allows for meaningful interactions between user groups but does not require a common understanding of processes or practices related to the work systems or information processing of each group. While this conceptualization of the system does not require one to understand work flows, it does impact both the workload and the flow of work for care providers and patients. The system design impact of these characteristics is a sharp increase in complexity because of the necessity of considering the needs of widely diverse user groups, their level and type of participation with the system, and their basic use. Finally, the nature of the system creates
very different patterns of use. While one group has to use it, another can do so purely voluntarily, and the third can do so in a partially automated manner. However, despite these differences, a small change in usage behavior by one group will likely have a significant and frequently unintended impact on the other groups. Additional training about the design and implementation of the system and about the different ways in which different user groups interact with the system could help citizens of overlapping social worlds understand each other’s perspective.

Traditionally, researchers have conceptualized PHRS as consumer-oriented tools. Returning to the quote from Nazi (2013), while we need such a perspective, it cannot solely explain PHRS because research has paid little attention to the “broad implications for healthcare providers and delivery systems” of a consumer-oriented perspective. The introduction of a PHRS in a healthcare context changes the patterns of behavior of both the intended user group (i.e., patients) and anyone else in the healthcare context whose jobs the new technology affects. Patterns of behavior change again as the various user groups move beyond adoption to routine use. Their interactions with the system affect their interactions with each other both directly and indirectly. Viewing PHRS as boundary objects allow observers to go beyond the traditional conceptualization of PHRS as a tool for patients to a new appreciation of the complexity of its embedded implementation in a particular healthcare context.

For the practitioner audience, our results have relevance as well. Health system administrators focus their efforts on designing health systems to encourage patient involvement in their own healthcare. The results of these efforts often create unintended consequences for the work processes and workloads of physicians and staff. Our results shed light on how system design and implementation can impact the divergent roles that patients, physicians, and staff hold. Conceptualizing the role of the system as adjunct, tool, and chore for the varied user groups provides a useful lens through which healthcare systems designers can analyze the impact of system design and implementation in situ. Additionally, one should consider the nature of these systems as boundary objects when designing and marketing the systems. Our study sheds some light on the nature of the disconnect between the intended use and participation for the patient population and the actual use and participation by the patients who register for accounts. While the health system intends the PHRS to be a useful tool to allow for active patient participation in their healthcare, the patient users simply view it as an alternate means of accessing the same information already available to them.

Like all studies, this one has limitations. First, our focus on a single PHRS in a single location—while in one sense a strength as we describe above—is also a weakness in that our findings have limited external validity. One can extend findings from the study of a single technology in a single organization only so far. However, in this case, one of the United States’ leading health records systems vendors developed the PHRS in question, and it was tethered to one of the most common EHRs in the US. As such, the PHRS was a reasonable surrogate for tethered PHRS that are widely available in the US. Researchers may design future studies to overcome the limitation of a single technology in use in a single site by including multiple case studies and collecting data about multiple PHRS deployed in multiple situations and locations. However, because one typically chooses to use multiple case studies for theoretical replication, one would need a more quantitative approach to greatly extend statistical generalizability.

Second, the participating organization constrained our ability to access participants. We are reasonably confident that our patient interviews were sufficient because we believed we reached saturation by the time we were done, but the study would have benefited from additional physician interviews and interviews with top managers and administrators. Unfortunately, limited access to desirable interview participants is a common limitation for research conducted under these circumstances. Limited access also constrained the materials that we could access in conducting the case study. Yin (2009, p. 102) describes many different resources that one can analyze as part of a case study, including documentation, archival records, interviews, direct observations, participant observation, and physical artifacts. Of these resources, we received permission only to conduct interviews, although we had direct access to the patient-facing part of HealthTech (a physical artifact) because both authors were participating patients in the clinic. In summary, then, future research could involve multiple sites; the participation of more informants in key roles, especially in terms of physicians; the collection and analysis of multiple sources of data; and the development and deployment of a survey instrument for a quantitative approach. In addition to patients, physicians, and healthcare staff, one could interview representatives of other constituent groups such as insurers, policy makers, managers, and information systems specialists in future studies. Additional future research could involve data collection in other contexts such as large
hospitals or private practices, comparisons of various commercially available PHRS, and PHRS comparisons across countries and cultures.

Personal health record systems have the potential to have a big impact on healthcare. In general, they are free to patients, run on established and reliable technology platforms, and can be accessed easily with Web browsers and on smartphones. They represent an easy way for physicians to provide chart information to patients and for patients to communicate with nurses and physicians. Yet, few patients actually adopt PHRS, and fewer still use these systems regularly. If the healthcare community views PHRS simply as tools for patients to use, then the issue becomes one of enticing patients to use the systems more or in different but appropriate ways. However, if the healthcare community recognizes that there are different groups of users of PHRS and that the systems lie at the boundaries of the various groups who use them, then the issues surrounding PHRS become more complex. Seeing them as boundary objects is the first step. In the next step, we need to further explore the implications of such a perspective—a step that invites continued research from the health information technology community.

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References


Appendix A: Interview Protocols

Semi-structured Interview Protocol: Physician

Background information
1. What is your field of specialty?
2. How many years have you been practicing (working in this field)?
3. How many years have you worked at [clinic]?

Context questions
4. Have you had any direct experience with PHRs like xxxxx?
5. How would you rate your interest in the use of PHRs in this organization?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all
6. How would you rate [clinic]’s interest in the use of PHRs?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all
7. How would you rate your interest in the use of patient-centered outcome measures in this organization?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all
8. How would you rate [clinic]’s interest in the use of patient-centered outcome measures?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all

PHR/EHR use questions
9. How long have you been using EHRs like the [EHR vendor] system?
10. Does the use of an EHR allow you to give better quality care to your patients? If so, how?
11. Are you familiar with what data is available to your patients through [EHR vendor’s] PHR system?
12. Are you comfortable with the information that is available to your patients through the PHR system?
13. Did the implementation of the PHR system change the way you put notes or other data into the EHR system?
14. Do you encourage your patients to use the PHR system that is available to them? Do you rely on someone else to do this (i.e., your nurse or front-office staff?)
15. Is there specific information you would like your patients to know in regards to decisions they must make about their medical care? If so, is it available to them in the PHR system?

16. Do you use xxxx or Microsoft's HealthVault yourself? If so, what do you think of its functionality? Ease of use? Usefulness?

**Patient-centered care questions**

17. How do you define patient-centered care (PCC)?
18. How important is PCC as an element of healthcare delivery quality?
   i. Extremely important
   ii. Important
   iii. Neutral
   iv. Unimportant
   v. Not at all

19. Do you feel that you understand what your patients expect in order for them to feel that they have experienced patient-centered care during an office visit? If so, what is it?

20. Can you think of a patient interaction that you considered as being particularly successful in terms of resulting in patient-centered care? If so, can you describe it for us?

21. Can you think of a patient interaction that you considered as being particularly unsuccessful in terms of resulting in patient-centered care? If so, can you describe it for us?

22. What percentage of your patient interactions do you consider to have been truly patient-centered?

23. Do you feel that your perception of what is patient-centered care differs from what your patients perceive as a patient-centered interaction? If so, why?

**Relationship between PHR and PCC questions**

24. Do you find that PHRs encourage patient-centered practices during your clinic hours?
25. Can you give an example of a time when a PHR facilitated a patient-to-provider interaction that improved the patient’s health outcome?
26. Do your patients ask more questions once they start using their PHR? If so, are they the ‘right’ questions from your perspective?
27. Do you feel that increased information exchange is an important aspect of providing PCC?
28. How would you define patient-centered communication?
29. Does the use of PHRs improve patient-centered communication in your practice?

**Semi-structured Interview Protocol: Patient xxxx User**

**Background information**

30. What is your profession?
31. Do you mind telling us your age?
   i. 18-30
   ii. 31-40
   iii. 41-50
   iv. 51-60
   v. >60

32. What is your ethnic background?
33. Do you have any chronic health conditions that require constant monitoring or attention? If so, what are they?
34. How well do you understand your medical condition(s)?
   i. Extremely well
   ii. Well
   iii. Adequately
35. How many times have you seen your current primary care physician?
   i. 0-5
   ii. 6-10
   iii. 11-15
   iv. 16-20
   v. >20

Context questions

36. How would you rate your interest in the use of a personal health record system like xxxxx to manage your health information?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all

37. How important is the degree of patient-centered care displayed by your healthcare providers? (i.e., how much consideration is given to your needs and opinions as a patient)
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all

PHR/EHR use questions

38. Why did you choose to sign up for the xxxxx application offered by [clinic]?
39. How familiar are you with the data available to you through xxxxx?
40. Are you satisfied with the information that is available to you through xxxxx?
41. Is there additional data you would want to be available? If so, what?
42. How often do you use xxxxx? What’s the main thing you use it for?
43. What parts of xxxxx do you really like? What parts do you really dislike? Is there another function you’d like to see added to xxxxx?
44. Do you think xxxxx is easy to use? Are there any changes you would like to see made to xxxxx that would make it easier to use?
45. How did you find out about xxxxx? Why did you start using it?
46. Where do you use xxxxx primarily? On a computer at home? Somewhere else? Do you have the smartphone app?
47. If you had to pay to use xxxxx would you still use it? If so, how much would you pay?
48. Have you ever heard of Microsoft’s HealthVault? Would you ever use a personal health records system like HealthVault?

Patient-centered care questions

49. How do you define patient-centered care (PCC)?
50. How important is PCC to you as an element of healthcare delivery quality?
   i. Extremely important
   ii. Important
   iii. Neutral
   iv. Unimportant
   v. Not at all
51. What behaviors you expect to experience in a healthcare delivery setting in order to feel that you have experienced patient-centered care?

52. Can you think of a physician (or other healthcare professional) interaction that you considered as being particularly successful in terms of resulting in patient-centered care? If so, can you describe it for us?

53. Can you think of a physician (or other healthcare professional) interaction that you considered as being particularly unsuccessful in terms of resulting in patient-centered care? If so, can you describe it for us?

54. Do you feel that your perception of what is patient-centered care differs from what your physicians (and other healthcare professionals) perceive as a patient-centered care? If so, why?

**Relationship between PHR and PCC questions**

55. Do you find that your use of xxxx encourages patient-centered care between you and your care providers during clinic visits?

56. Can you give an example of a time when xxxx facilitated an interaction between you and your provider that improved your health outcome?

57. Do you ask more questions since you started using xxxx? If so, are they usually questions about healthcare options or about how to use xxxx?

58. Do you feel that increased information exchange between you and your care provider is important? Does xxxx encourage this information exchange?

**Semi-structured Interview Protocol: Patient: Non-user**

**Background information**

59. What is your profession?

60. Would you mind telling us your age?
   i. 18-30
   ii. 31-40
   iii. 41-50
   iv. 51-60
   v. >60

61. What is your ethnic background?

62. Do you have any chronic health conditions that require constant monitoring or attention? If so, what are they?

63. How well do you understand your medical condition(s)?
   i. Extremely well
   ii. Well
   iii. Adequately
   iv. Not well
   v. Not at all

64. How many times have you seen your current primary care physician?
   i. 0-5
   ii. 6-10
   iii. 11-15
   iv. 16-20
   v. >20

**Context questions**

65. How would interested are you in keeping track of your personal health information?
i. Extremely interested  
ii. Interested  
iii. Some interest  
iv. Very little interest  
v. Not at all

66. How important is the degree of patient-centered care displayed by your healthcare providers? (i.e., how much consideration is given to your needs and opinions as a patient)?
   i. Extremely important  
   ii. Important  
   iii. Some importance  
   iv. Very little importance  
v. Not at all

PHR/EHR use questions

67. What method do you use to track and store your personal medical information?
68. Have you heard of a personal health record (PHR)? If so, what is it? Have you ever heard of xxxx? Of HealthVault?
69. Do you have a computer at home and access to broadband Internet service? Do you have a smartphone?
70. Would you be willing to use a PHR if it were offered by your medical care provider? Why or why not?
71. Has your doctor or anyone else at [clinic] mentioned xxxx to you?
72. Are you familiar with what data is available to you through xxxx?
73. Do you see any benefits in using a computer-based system to manage your personal health records? Do you see any disadvantages?
74. Why have you chosen not to use the xxxx system? What would it take for you to start using a system like xxxx?

Patient-centered care questions

75. How do you define patient-centered care (PCC)?
76. How important is PCC to you as an element of healthcare delivery quality?
   i. Extremely important  
   ii. Important  
   iii. Neutral  
   iv. Unimportant  
v. Not at all
77. What behaviors you expect to experience in a healthcare delivery setting in order to feel that you have experienced patient-centered care?
78. Can you think of a physician (or other healthcare professional) interaction that you considered as being particularly successful in terms of resulting in patient-centered care? If so, can you describe it for us?
79. Can you think of a physician (or other healthcare professional) interaction that you considered as being particularly unsuccessful in terms of resulting in patient-centered care? If so, can you describe it for us?
80. Do you feel that your perception of what is patient-centered care differs from what your physicians (and other healthcare professionals) perceive as a patient-centered care? If so, why?

Relationship between PHR and PCC questions

81. Would it be beneficial to you to have more information before your office visit in order to encourage patient-centered care?
82. Can you give an example of a time when information you had about your own health status was used during an office visit with a medical provider that improved your health outcome?
83. Do you think you would ask more questions about your treatment if you had easy access to your own health information?
84. Do you feel that increased information exchange between the patients and care providers is important?
85. Would having a PHR like xxxxx encourage you as a patient to engage in this information exchange?

Semi-structured Interview Protocol: Allied Health

Background information
86. What is your job title and responsibilities?
87. How many years have you been working in this role?
88. How many years have you worked at [clinic]?
89. We know that [clinic] has implemented the Electronic Health Records system developed by [EHR vendor]. How much time have you spent using [EHR vendor] EHRs?
90. What's your opinion of the [EHR vendor] system?
91. What do you think the relationship is between EHR use at [clinic] and the quality of care provided to patients?

Context questions
92. Have you had any direct experience with Personal Health Records (PHRs)? Which ones? As part of your job? As a patient?
93. How would you rate your interest in the use of xxxxx in this organization?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all
94. How would you rate [clinic]'s interest in the use of xxxxx?
   vi. Extremely interested
   vii. Interested
   viii. Some interest
   ix. Very little interest
   x. Not at all
95. How would you rate your interest in the use of patient-centered outcome measures in this organization?
   i. Extremely interested
   ii. Interested
   iii. Some interest
   iv. Very little interest
   v. Not at all
96. How would you rate [clinic]'s interest in the use of patient-centered outcome measures?
   vi. Extremely interested
   vii. Interested
   viii. Some interest
   ix. Very little interest
   x. Not at all
PHR/EHR use questions

97. About what proportion of [clinic]'s patients do you think use xxxxx? What do most of them use it for? Is there one part of it that they seem to like the most? Is there a part they seem to dislike?

98. Do you think patients find xxxxx easy to use? Are there things [EHR vendor] could do to make xxxxx easier to use?

99. Are you familiar with what data is available to patients through xxxxx?

100. Are you satisfied with the information that is available to patients through xxxxx? Why or why not?

101. Is there additional data you would want to be available? If so, what?

102. Did the implementation of xxxxx change the way you put notes or other data into the [EHR vendor] EHR system? Why or why not?

103. Do you encourage patients to use xxxxx? Why or why not?

Patient-centered care questions

104. How do you define patient-centered care (PCC)?

105. How important is PCC as an element of healthcare delivery quality?
   i. Extremely important
   ii. Important
   iii. Neutral
   iv. Unimportant
   v. Not at all

106. Do you feel that you understand what patients expect in order for them to feel that they have experienced patient-centered care during an office visit? If so, what is it?

107. Can you think of a patient interaction that you considered as being particularly successful in terms of resulting in patient-centered care? If so, can you describe it for us?

108. Can you think of a patient interaction that you considered as being particularly unsuccessful in terms of resulting in patient-centered care? If so, can you describe it for us?

109. Do you feel that your perception of what is patient-centered care differs from what your patients perceive as a patient-centered interaction? If so, why?

Relationship between PHR and PCC questions

110. Do you find that xxxxx encourages patient-centered care between care providers and patients during clinic visits?

111. Can you give an example of a time when xxxxx facilitated a patient-to-provider interaction that improved the patient’s health outcome?

112. Do patients ask more questions once they start using xxxxx? If so, are they the questions about healthcare options or about how to use xxxxx?

113. Do you feel that increased information exchange between the patients and care providers is important? Does xxxxx encourage this information exchange?
Appendix B: Research Products

NVivo Nodes

We label the nodes with the most references “descriptions” (Figure B1). While we clearly label the descriptions from doctors and from staff, the descriptions from patients make up the “[name redacted] descriptions” node. These three nodes have the most references because they became the focus of our work as we analyzed the interview data. The other 15 nodes represent themes that emerged as we looked across the interview data: access to results, email questions, data repository, and so on. These themes looked promising but never developed in a substantial way. Many of the other nodes were based on themes that received even less attention: barriers to use, HealthVault (we asked everyone about it but almost no one had heard of it), prescription refills, and speed. In hindsight, it makes sense that we could categorize most of the content of the interviews as descriptions of the PHRS because we focused on trying to understand what PHRS are, how people use them, and how they think about them.

Once the three major nodes had emerged, we analyzed the contents associated with each one in turn. We include part of one of our work products that dealt with staff descriptions of the PHRS to show how we systematically analyzed the content (see Figure B2).

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1 We have redacted the name of the PHRS.
Lab Director:

Well, all of our lab results file into [redacted] after three days, after they’ve been reviewed by the doctor then they file in. So, if patients call, say, “I’m looking for my whatever test result,” and then I’ll say, “Do you have [redacted]?” And if they say yes I say, “I would suggest you go to your [redacted] and look at your results there, and then if you have questions then you can send your provider an in basket message.”

I think it’s wonderful. Like I said, it cuts down the — not that we don’t have patient contact, but it cuts down on those kind of unnecessary phone calls, where people are just wasting results.

— it makes our life — it takes just some of that extra busy work —

Nurse (at [redacted]):

We will communicate with the physicians sometimes after hours by using that system.

We e-script prescriptions that the doctors don’t have a chance to send over after hours, if a patient calls and needs something, we’ll actually e-script it over to a pharmacy through the [redacted]. So, there’s a lot of good advantages to it.

[redacted] nurses spend a lot more time explaining that, especially the ones that have a lot more knowledge of it. In fact, I actually pulled my personal [redacted] so other nurses could see what it is that their patients will be seeing on the other end of it. So that, you know, physicians had no idea what the patient side of it is

I mean it still allows us as healthcare providers to decide what information is out there for them versus, you know, if they have a really bad result, obviously you’re not going to allow EPIC to post that, you want to make that phone call.

I think it decreases the number of phone calls, allowing the nurses and the doctors to care for the patients that are in the office a little more effectively.

Lead receptionist:

But, as far as [redacted], with us. I think that it’s very … it helps us to be very quick in getting back to the patient, at least in our department, we have a real good track record of getting back to the patient within the allotted time, because there are time slots where we have said, you know, “We will get back to you within two days if you’re requesting an appointment,” we always get back to them within four hours in our department.

In dealing with prescription refills and requesting appointments, mainly those are the two items I think that they use it most for. The requests for appointments would come to the receptionist, the request for prescriptions would come through to the nurse, directly.

Figure B2. Segment of Work Product Related to Staff Descriptions of the PHRS
Word Count Summary

Through NVivo, we generated word counts for each user group: physicians, patients, and medical staff (Figure B3). Each count contained 1000 words. We do not reproduce them here. Some of the words counted were names of the PHRS, the PHRS vendor, the clinic, the city the clinic is located in, other regional place names, and people’s names. Given the extent of the counts and the sensitivity of some of the contents, we instead have included one of our work products that we used to compare and contrast the user groups.

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<th>No. of Doctors</th>
<th>Usage Count</th>
<th>No. of Staff</th>
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<td>Patients used 'job' as in 'good job;' for doctors &amp; staff, it meant work</td>
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<td>Patients used 'work' as a verb; for doctors, it was sometimes about labor; for staff, about labor half the time</td>
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Figure B3. Spreadsheet Summary of Word Counts from NVivo Analysis
About the Authors

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