November 2013

PHR Ignite

Stakeholder Interview Summary

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1. INTRODUCTION

In the first phase of the Personal Health Record (PHR) Ignite project, our two-state team reviewed secondary resources to assess and summarize the published literature on key aspects of the PHR landscape nationally and specifically for Utah and New Mexico. In completing the environmental scan, we identified limitations in the published information currently available. In this report, we supplement the findings of the environmental scan with primary sources: interviews with key stakeholders to further clarify the barriers and opportunities for further PHR adoption in these two states.

2. METHODS

Information for this report was gathered through a variety of approaches that differed across stakeholder groups. In all cases, interviews and discussions were documented, common themes identified, and key messages and findings summarized in this report. With the exception of the consumer interviews and comments from two clinics in Utah, all stakeholder observations relate to Health Insurance Portability and Accountability Act (HIPAA)-covered PHRs rather than non-HIPAA covered PHRs.

2.1 Consumers

For the Utah assessment, we obtained a range of consumer opinions through three separate strategies. First, we reviewed an existing data source: consumer opinions gathered between 2011 and 2012 as part of a series of statewide consumer focus groups conducted to assess consumer attitudes toward Utah's Clinical Health Information Exchange (cHIE). Many of the ideas that participants expressed in these groups related to PHRs, and we reviewed and included these comments in this report. Second, *HealthInsight* Utah convened eight consumers, in two groups, to determine their use of and attitudes toward PHRs. Finally, we conducted four individual interviews with expert consumers/consumer advocates. About half of these consumer interviewees suffered from a chronic disease. For both the group discussions and individual interviews, we described the concept of HIPAA and non-HIPAA-covered PHRs, and at times, we asked consumers to compare their perceptions of the two. Of the eight group participants, three (and one participant's spouse) used a PHR. All of these were HIPAA-covered PHRs for large health systems, which could be described as traditional patient portals that display some aspects of the electronic health record (EHR) and do not permit user-entered data. Non-users were aware of these PHRs but had not used them. No one used a non-HIPAA-covered PHR.

In New Mexico, consumer interviews focused on groups and individuals most likely to need more access to their health information. We conducted interviews with seniors and a cancer survivor group. In the cancer survivor group, 9 individuals took part in the group discussion (6 women and 3 men). Six were cancer survivors and 3 were caregivers. In addition, 14 attendees of an aging conference were interviewed individually (13 women, 1 man). All but one was between the ages of 40 to 65.

2.1.1 Providers

We gathered broad input from health care providers in both states through a variety of approaches. In New Mexico provider groups interviewed included the following organizations:

- A rural health clinic (had a PHR);

- Two pediatric practices (no PHR);

- A large primary care association representing 33 community health systems and more than 120 clinics (19 of the systems offer a PHR or are in the process of implementing one);

- The university-affiliated network of 30 primary and specialty clinics (University of New Mexico, offers a PHR); and

- A specialty practice with 15 clinics across the state, Eye Associates of New Mexico (has a PHR).

Information from the above providers was gathered strictly through one-on-one interviews with leaders within each organization.

Similarly, key informants were identified within primary care clinics in Utah and were interviewed for this assessment. These organizations included five independent primary care clinics located along the urban corridor surrounding Salt Lake City, all of which offered a HIPAA-covered PHR system. Of the five EHR systems used in these clinics, four EHR systems are used widely across the United States and one was a Utah-based vendor. Four of the EHR systems offer a HIPAA-covered PHR (patient portal) developed by the parent vendor organization for use by the clinics and their patients. One EHR system does not have its own patient portal but the EHR vendor has contracted the use of a patient portal by a different vendor. However, the patient portal is integrated to the EHR, making it a tethered PHR.

In addition to these clinics, representatives from hospitals and physician organizations were interviewed during a group meeting convened under the Utah Health Information Network (UHIN) Clinician Community advisory group, which includes representatives from major health care systems as well as independent and specialty groups. Organizations that contributed to that discussion included:

- The University of Utah Hospital and Clinics (offers a PHR);

- St. Marks Family Practice (in the process of implementing a PHR);

- Emergency Group Physicians (affiliated with a PHR through a hospital system);

- Intermountain Healthcare Physicians (affiliated with a PHR through a health system);

- Representation from the Utah Medical Association, and;

- Independent General Surgeons.

Information that could not be gathered during the course of the group meeting, such as usage data, was acquired through follow-up phone calls.

We also conducted individual interviews with the four main hospitals and one independent rural hospital that service the Utah population. The hospital systems included:

- Intermountain Healthcare Hospitals;
- IASIS;
- HCA;
- University of Utah Hospitals; and
- Beaver Valley Hospital (rural).

The hospital groups all had PHRs in place and were in varying stages of deploying their patient portals; some were quite mature while others were just in the development stages. Hospitals that were interviewed in the New Mexico market were part of systems with primary care associated clinics and one system also included a payor group. All of these payors had PHRs, with the exception of the Utah Medicaid program:

2.1.2 Payors

In both states, the team interviewed prominent health care payors for this assessment. In Utah, information was gathered during a group meeting convened by UHIN, and included both public and commercial payors comprising the vast majority of covered lives in the state:

- Utah Medicaid;
- University of Utah Health Plans;
- Deseret Mutual Benefits Association;
- Educators Mutual;
- Regence Blue Cross Blue Shield of Utah;
- SelectHealth and;
- Public Employees Health Plan.

Similar to the clinician meeting, specific information that could not be gathered during group discussion was acquired through follow-up communications.

In New Mexico, information was gathered through two in-depth interviews with leaders with prominent payor organizations: Blue Cross Blue Shield (BCBS) of New Mexico and Presbyterian Healthcare Services. Both payors currently offer a PHR.

3. FINDINGS

While the information gathered for this report was drawn from convenience samples, information was surprisingly consistent across interviewees and across states. In this section we combine the New Mexico and Utah findings for each stakeholder group where appropriate, and compare and contrast findings when differences were noted.

3.1 Consumer Attitudes

3.1.1 Ownership and Usage

In Utah, approximately half of the lay consumers and the consumer advocates had personally used a PHR. Both in their personal usage and in thinking about their representative populations, consumer advocates expressed many similar thoughts to those of the consumers.

Similarly, consumers interviewed in New Mexico had varying degrees of familiarity with PHRs and patient portals; some consumers in the group had actually used PHRs while others were familiar only with the concept of PHRs.

Predictably, consumers who were not technologically savvy had limited interest in a PHR. Most PHR group participants were reasonably comfortable with the idea and/or practice of using a traditional patient portal. The PHR users logged in only after provider appointments, usually to check laboratory results. Another user used the PHR to send secure messages to his doctor. Users particularly liked how quickly they got laboratory results and that they were able to check for errors in their record.

In New Mexico, most users accessed the PHR following an appointment. One large hospital and clinical system required users to provide identification in person and register; users then received a login and password via e-mail. Users most frequently used the PHR to access laboratory or other test results. Some systems allowed for secure messaging to providers. Many systems had not enabled that feature, although consumers reported that they would like the PHR to offer secure messaging.

Benefits: A More Complete Record

Consumers in both states also expressed a desire to have access to all of their medical data in one place. One advocate for rural populations in Utah underscored the need for comprehensive records because some people must travel great distances for care, and they tend to see providers in different health care systems. He also observed anecdotally that rural facilities were less likely to have functioning coordinated EHRs, even within the same system or even the same building. In New Mexico, the Primary Care Association supports 19 different systems all using the same EHR. Several of the federally qualified health systems

have multiple sites where the EHR is used across the clinics that are part of the same system; however, interoperability between the organizations is still lacking.

Benefits: Track Health Over Time

Consumers also highlighted the ability to track care over time as a key benefit—specifically, the ability to view lab results, track medications, immunizations, previous providers, and dates of procedures. With this capability users would know when it was time for another screening test. Consumers felt that PHRs could be especially useful for relocation and for seniors and their caregivers who need to keep track of many medications and procedures. One participant said he compared the most recent and earlier results: "With [my PHR] the way they have it you can go back 3 months, 6 months, 9 months, a year to see what you're doing. Matter of fact, I've done that before to see how I was compared to last time on my A1C, for example." One person in New Mexico also underscored the value of having a historic view of his lab results.

Benefits: Time Saving

Another common benefit identified in the New Mexico consumer interviews was the potential for PHR technology to reduce the amount of time spent on personal and phone interaction with a clinic/provider. Interviewees considered the ability to refill prescriptions to be one of the more desirable and time-saving functions of these systems. Other desired functions were the release of lab results and accompanying information through the PHR that might reduce return visits to the clinics. Among those who had used a PHR previously, interviewees found that email alerts were incredibly useful to let them know when additional health information was added to their portal. Those who did not have experience with using their PHR expected that they would use this functionality in the future.

Benefits: Improve Doctor-to-Doctor Communication

Consumer interviewees in both Utah and New Mexico felt that PHRs could improve doctor-to-doctor communication. A few participants who were not technologically savvy still thought that their doctors would be able to communicate more effectively, even though they themselves were not interested in viewing their records. In other words, they preferred that their various medical records not be isolated within a specific provider system because such "silo-ing" of data could compromise care, but they did not think they would access that record given the opportunity. In contrast, one participant had two PHRs for different health systems, but she did not find the duality inconvenient. However, she did want the providers in the different systems to be able to communicate more conveniently. Overall, participants had mixed ideas about transfer of medical information. Some wanted control over any sharing of records between providers while others trusted providers to share their data appropriately. These comments suggest that while some participants would be satisfied with a health information exchange (HIE) solution, others could benefit from a patient-mediated

solution, such as a PHR that allowed them to share certain kinds of information with whom they chose.

Benefits: More Complete and Accurate Record

Consumer advocates in Utah alone noted that non-HIPAA-covered PHRs in particular could help patients have a more complete and accurate record because information could be collected in one place and checked for errors. However, as noted below, they had reservations about this type of PHR, particularly related to the underlying motives of the companies that offer them.

Barriers/Concerns: Health Literacy

Although interviewees identified lab information as a potential means to reduce interaction time, they were also concerned about the release of this information via the portal. One interviewee in New Mexico stated that she did not want to have access to lab results prior to seeing/communicating with her doctor because she did not have the level of knowledge to properly interpret the results and did not want to worry unnecessarily about what such results might mean. On the other hand, several interviewees found their lab results easy to interpret as either normal or out-of-normal range.

Barriers/Concerns: Lack of Awareness

Consumers identified lack of awareness as a key barrier. Several consumer participants in Utah had been only peripherally aware of the PHR and had not thought to access it. This sentiment came up in the New Mexico interviews as well: consumers noted a general lack of education about what PHRs are, what they can do, and how they can help patients. In Utah, participants also suggested that providers could do more to encourage use—for example, by handing out cards or leveraging staff to set up accounts while patients are waiting to see the physician. One participant in Utah suggested that "it would be beneficial at assisted living facilities or senior centers to have a spot where people could go in and a navigator would help seniors access their health records."

Barriers/Concerns to Use: Time Required/Difficulty

Another area of concern related to the difficulty of consolidating information in a patient-controlled PHR. Participants in the New Mexico interviews raised this issue, especially related to the needs of health care consumers who require medical services from many different providers and settings of care. These consumers said they had significant difficulty in consolidating all of their health information into their PHR from former providers and insurers. They spent a prohibitive amount of time populating and maintaining the extensive and complex health information in their PHRs. Utah consumer advocates echoed this sentiment: they worried about the feasibility of PHRs that required users to manually enter their information. Participants were concerned that consumers most in need of care

management due to illness, advanced age, or other disadvantage would be the most likely to feel overwhelmed by trying to manage their data.

Barriers/Concerns: Direct to Consumer Marketing

By and large, participants in Utah did not trust the non-HIPAA-covered PHRs, even though some saw value in the ability to gather all records in one place. They were concerned about commercial interests gaining access, resulting in targeted advertising, for example. Several people claimed they always or usually read the terms and conditions for websites. One Utah consumer was curious about this kind of PHR after the discussion and intended to look into them further. Of note, the Utah participants expressed this sentiment, but the New Mexico participants did not.

Barriers/Concerns: Accuracy

Although Utah consumer advocates viewed a more accurate record as a benefit of patient-mediated PHRs, in both states many interviewees expressed serious concerns about the accuracy of information contained in PHRs. In Utah, consumers cited examples of requesting medical records (in paper form) in the past and finding "gross inaccuracies." A few participants wanted to be able to edit their record themselves, but most wanted a simple process by which they could request their provider to make changes. Some distrusted records they had not seen and did not want records shared between providers owing to fear of errors. These comments all suggest that consumers want to have access to a PHR that is connected to provider EHRs.

Consumers in New Mexico echoed the concern about accuracy. Interviewees noted that if a provider relied solely on the information contained in doctors' notes and did not ask the patient for clarification, mistakes or misinterpretations could occur.

Barriers/Concerns: Privacy

Interestingly, Utah consumers frequently expressed concern about privacy, but New Mexico consumers did not explicitly mention it. Both in actuality and in perception, privacy was an important issue among Utah consumers. Advocates felt that consumers would be concerned about personal embarrassment that could result if information were shared, including with family members, for example, about illegal drug use or homosexuality. They noted that consumers might worry about employers, insurance companies, and other private interests accessing their information. They might also worry that the opinion of another physician would be held in higher esteem than their own, that errors would be perpetuated, or that they might be denied care based on information in their record. One advocate suggested that a PHR could be more of a skeleton, an outline that indicates what kind of information was included but omitted details such as test results. Another had the unique perspective that it was "scary to depend on a provider to collect and maintain that data for me" because it could be easily lost and, therefore, consumers would have more personal responsibility for

maintaining their medical record. For records that might be shared between providers, some Utah consumers wanted to be able to suppress parts of the information, especially about sensitive topics. Many wanted to give consent before records were shared. All of these consumer preferences could fit well with a non-HIPAA-covered PHR that would allow the user to decide what data to share and with whom.

Barriers/Concerns: Security

Similar to the issue of privacy, security of medical records in general was a serious concern for Utah consumers, but less so for New Mexico interviewees. Utah consumers worried about government access to records, due either to perceived ineptitude or malicious intent. General comments about hacking were common, with some concerns about identity theft. A few participants expressed concern about the ramifications of electrical problems. Some said they wanted nothing to do with electronic medical information, but for most participants the perceived advantages of health information technology outweighed their concerns. One participant said, "I guess I am willing to give up some freedom for efficiency but that is a big concern." Security was both a concern and a barrier for several Utah consumers; some said their concern would actually prevent them from using a PHR altogether, but most participants thought the benefits outweighed the disadvantages.

Barriers/Concerns: Access to Technology

The consumer interviews revealed that access to computer technology and high-speed internet was a concern in both states. Given New Mexico's digital divide, consumers not surprisingly noted lack of consistent high-speed internet connectivity as a lingering barrier. Similarly, group interviewees in Utah reported that access to the internet and lack of technology proficiency were barriers, and related to these issues, they also identified age as a barrier.

Barriers/Concerns: Lack of Engagement in Health

In Utah, a few consumers resisted the idea that they should be engaged in their own health care, including accessing their medical information through a PHR. These consumers preferred to take a more passive role and to trust the provider to manage their information and tell them what they needed to do. Encouraging PHR usage among people with these perspectives would be a challenge.

Functionality Desired: Range of Needs

Consumers in both states expressed a desire for a range of functionalities. Some said they wanted to see more of the provider's notes in their record; others were satisfied with the current level of detail. Another suggested that providers might want to note and/or communicate certain information to each other but would not want to share it with a patient (such as if a patient is regularly seeking pain medication).

A few consumers were interested in being able to add their own contributions to the record; others did not see value in that functionality. Consumer advocates in Utah also wanted records be more searchable and chronological, to have better capability for handling scanned images, to include over-the-counter medications, and to have links to medical education websites.

Both Utah and New Mexico consumers expressed the key desire for a more complete record that incorporates data from multiple providers and that could be transferred from provider to provider if they needed to switch to a new physician—particularly if that physician was in a different geographical location. Utah consumers also saw value in portability of records for travel or relocation.

Related to this need, consumers also sought a PHR that could include data from non-Western medical providers (i.e., holistic medical providers). They also wanted the ability to document treatment preferences, including nutritional interventions and information.

A few participants expressed the desire for patient-mediated information exchange only, by using a flash drive, bracelet, or wallet-sized card. Many felt that access to records would help them better manage their health; for example, they could review care plan notes and be informed about their medication allergies. They felt they could also avoid duplicate tests and procedures if they had access to the original test results. Others wanted the ability to have prescriptions refilled and to request appointments via the portal.

All of the Utah users interviewed were very enthusiastic about the ability to view their records and felt that the PHR helped them manage their health and health care.

Summary

For the most part, consumers in both states saw the benefits of having a PHR; they also recognized the limitations of siloed data and some were interested in adding data themselves. Utah consumers were notably distrustful of non-HIPAA-covered PHRs, which could be a significant barrier to encouraging their adoption, especially through government-led efforts. Understanding barriers to adoption—such as technology proficiency, time required, and security and privacy concerns—will be important to facilitate adoption. Increased awareness of PHRs, in-person assistance for gaining access, and careful explication of the security that is in place will also be essential to expanding consumer use of PHRs.

3.1.2 Providers—Hospitals

Usage/Penetration

Penetration statistics were requested from all Utah hospitals interviewed, and three hospitals ultimately provided these data. One large hospital system reported that it has

approximately 25% penetration in terms of active users, with no clear patterns apparent between demographic characteristics of patients and associated usage. However, a representative from this hospital system noted that, "individuals that are accustomed to doing business on the internet have no trouble using the portals, and appear to have an expectation that their data is online." In its experience, this hospital system noted that usage does not depend on age: as many patients in the senior citizen age group use the portal as those in other age groups. In addition, parents and caretakers of aging parents/adults actively use the hospital portal for care management.

Health status does appear to influence use in this hospital system's experience, and the more medically complicated the patient, the more likely the person is to engage with the PHR for health management purposes. "Some may be disappointed that things are not further along for getting data from disparate health care systems to interface with each other," noted the representative from this hospital system.

Another large academic health system in Utah, which includes a medical group, hospitals, and clinics, reported that 58% of patients had used its PHR. The health system recently deployed a financial tracking feature for patients, and they have experienced an overall increased usage as a result. The system has not initiated an educational campaign for the new service, so they are very hopeful that with additional marketing, this new feature will further boost utilization. See Table 3-1 for a detailed utilization report for this hospital system.

Marketing/Education

One key strategy for introducing patients to hospitals' PHR systems includes engaging patients when an ambulatory service is provided. One hospital system interviewed uses this strategy. The education is brief because of time constraints during a hospital encounter. Patients are given literature on how to use a PHR and its benefits. This education is provided on an ongoing basis, even when official marketing campaigns may have subsided.

Barriers/Concerns: Lack of Integration

One barrier to further adoption of hospital PHRs is the disconnect between systems offered by the doctor and by the hospital, which creates gaps in knowledge and adds to patient confusion. The doctor may or may not have access to the information in the hospital patient record. (The doctor may have admitting privileges to the hospital, but may not have access to the patient's information electronically.) Vendors that have promised connections with doctors and hospitals are not delivering, according to the Utah hospitals we interviewed. Hospital groups currently in the process of implementing EHR systems with PHR capabilities expressed disappointment. The systems currently offered provide a minimal functionality, mostly based on Meaningful Use criteria, rather than afford integration sought by providers and patients alike.

Table 3-1.   Utilization of PHRs in Large Utah Health System

Feature	Hits	% Hits By Module	Unique Users	% Users By Module	Avg. Hits Per Unique User
Messaging	80,053	16.33	7,938	58.45	10.08
Lab Tests - View List	57,334	11.69	7,459	54.92	7.69
Lab Test - View Results	40,452	8.25	7,109	52.34	5.69
Medical Advice Request	16,325	3.33	4,699	34.60	3.47
Preventive Care	15,282	3.12	6,118	45.04	2.50
Medications	13,830	2.82	5,224	38.46	2.65
Problem List	12,509	2.55	5,100	37.55	2.45
Result Component Graphing	10,693	2.18	2,944	21.68	3.63
Account Inquiry	10,577	2.16	4,291	31.59	2.46
Immunizations	10,044	2.05	4,578	33.71	2.19
Allergies	9,832	2.01	4,526	33.32	2.17
HB Account Details	9,036	1.84	4,019	29.59	2.25
Upcoming Appointment - View Details	7,978	1.63	3,285	24.19	2.43
Encounter Details	7,641	1.56	2,121	15.62	3.60
Health Summary	6,987	1.43	3,825	28.16	1.83
Terms and Conditions	6,940	1.42	3,696	27.21	1.88
Patient Entered Flowsheet	4,122	0.84	74	0.54	55.70
Hospital Statement Details	3,789	0.77	1,347	9.92	2.81
Medical Histories	3,454	0.70	2,295	16.90	1.51
Account Payment	3,175	0.65	1,302	9.59	2.44
Request Appointment	3,073	0.63	1,557	11.46	1.97
Recent Payments	2,416	0.49	854	6.29	2.83
Proxy Access (View)	2,119	0.43	919	6.77	2.31

Barriers/Concerns: Workflow and Implementation Challenges

One specific hospital is currently deploying their PHR and reports that the vendor they selected did not consider the workflow issues thus creating implementation challenges. Related to this issue, hospitals, particularly in rural areas, may not have dedicated staff to help patients with PHR signup and related questions. Currently, intake/registration staff members are required to be technology consultants to those who are curious about the portal, which takes time away from patient care.

Barriers/Concerns: High Costs, Low Usage

A representative from a rural hospital voiced his concern that the anticipated benefit from the implementation of the portal has never been realized. Specifically, very few patients use the hospital's PHR. The administrator from this rural hospital was disappointed that the actual adoption was not what he had hoped, even after significant promotion of the system. "Time and resources were wasted in this implementation," stated this administrator.

3.1.3   Providers—Clinics

Usage

Identifying the usage of PHRs (HIPAA-covered) among the patients and providers was a challenging task; clinics had very rudimentary processes to generate reports on usage. Some clinics could generate reports indicating patients' use of the PHR for each provider, but some could only generate limited usage reports. The usage rates among the clinics included in this phase of the study ranged from 0.5% to 20%. Among the New Mexico clinic organizations we interviewed, only the specialty clinics had utilization numbers available. At this organization, 22,000 patients have been given enrollment education forms, temporary passwords, and temporary usernames to log in to the clinics' PHR. This number constitutes approximately 10% of the overall patient volume. Another large clinic system in New Mexico reported that 2,644 patients had created logins to date (a small proportion of their total patients). Of this number, only 40% actually logged on to access their portals after their accounts were created.

We were able to glean limited information regarding the characteristics and usage patterns of patients who used these PHR products. Interestingly, most of the patients who used the PHR in one clinic were diagnosed with multiple conditions, and many of these diagnoses included mental health conditions such as bipolar disorder, hypochondria, and anxiety.

One Utah clinic provided more detail on functionalities that PHR patients used. This two-physician family practice clinic reported that approximately 7% of its patients used the clinic's PHR; the majority of the interaction (85%) consisted of messages to the clinic (see Table 3-2).

Marketing/Education

Four clinics that we interviewed actively implemented processes to improve awareness and adoption among patients and providers of the tethered PHR. The front-desk staff introduced patients to the PHR and also helped patients create user accounts. The clinics that actively promoted their PHR invested time in training their staff and providers (MAs, MDs, RNs) to use it. The accounts were created at the time patients signed up during office visits or on their own after office visits. All clinics required patients to activate their accounts by accessing an email as a means to provide the required level of authentication. In one clinic,

during the implementation, all staff wore t-shirts that advertised their portal in an attempt to prompt patients to ask questions about the PHR. Most of the clinics distributed fliers to patients that provided instructions on using the PHR and specified a few key functionalities that the patients would find useful. Some clinics tried to increase adoption by informing patients that they could access their laboratory results if they logged into their PHR account. Similarly, patients were told that communicating with providers would be faster if they used the PHR instead of the phone. In one clinic, the EHR set up alerts to notify providers if a patient had not yet signed up for a PHR account. The front-desk staff and the providers used this information to ask patients for their email address and encourage them to sign up and use the PHR.

Table 3-2.   Utah Clinic Portal Audit

Event	Mar13 – Aug13 (2013)	
Total patient visits to clinic	6,410	
Non-staff login to portal	460	7.176%
Portal audit event	Hits	Utilization
Registration success	170	36.957%
Existing patient ID verification	29	6.304%
New patient ID verification	4	0.870%
Medication renewal request	9	1.957%
Referral request	3	0.652%
Demographic update	20	4.348%
Secure message to provider	26	5.652%
Secure message to patient from clinic	389	84.565%

One specific clinic system, which is part of a larger integrated health system, promoted its PHR by adding billing and benefits information and giving members online access to eligibility, out-of-pocket costs, estimation of benefits, and the ability to communicate with customer service experts online.

Finally, one large system in New Mexico recently launched an extensive media campaign promoting its PHR through TV, billboard, and print materials.

Existing Functionalities

We found that functionalities available to patients and providers varied across clinics. Most clinics could choose the functionalities that they wanted to provide in their PHR for the patients. Therefore, two clinics using the same EHR system and the same PHR product could have different functionalities, which is part of the customization allowed in the systems.

Functionalities available in the PHRs that we surveyed in Utah included:

- Problem list

- Allergies

- Vital signs

- Health maintenance and trackers

- Procedures

- Prescriptions and refill requests

- Laboratory results

- Radiology

- Family history

- Social history

- Provider messaging

- Request for appointments

- Paying bills

During our discussions, we found that each clinic had an interesting story to tell about these functionalities. We summarize a few of these atypical findings below:

- *Permissions granted to the patients*: The levels of permission granted to the patients regarding view and edit privileges varied across clinics. In one clinic, patients could view and edit a considerable amount of their health care information, including medications, procedures, medical history, and family history. The majority of the clinics allowed patients to edit information that they typically would provide during an office visit, such as family history, social history, etc.

- *Integration between the PHR and EHR*: More than half of the PHRs evaluated in this phase of the study were fairly well integrated with the corresponding EHR systems. Patients could edit their information and, depending on the type of information, the updated information was automatically updated or populated in the EHR, or an indicator (e.g., a different font color) alerted the provider that the patient had updated that specific data. In the latter situations, the provider could either accept or reject the modifications that patients made.

- *Laboratory results*: Although most PHRs allowed patients to view their laboratory results, one clinic did not provide this functionality. The laboratory results were shared within the PHR as an attachment. It is possible that providers were wary of patients seeing the results before the providers could notify them.

- *Appointment requests:* In one Utah clinic, MAs and the front-office staff were very diligent in reviewing the requests patients made for appointments within the PHR. However, they soon realized that scheduling an appointment for the same day the request was received resulted in several missed appointments. This situation occurred because most patients did not log back into the PHR the same day and, hence, missed appointment scheduling notifications. One provider in New Mexico echoed these concerns. He was hesitant to allow visit scheduling via the PHR and felt it would be difficult to maintain a clinical schedule because patients would not know what types or duration of appointments to schedule.

- *Integration with a non-HIPAA covered PHR:* Two clinics supported their patients in populating a non-HIPAA covered PHR (e.g., Microsoft HealthVault [HV] in both cases). They provided their patients with either a Continuity of Care Record (CCR) or a

Continuity of Care Document (CCD) that the patients could upload to their Microsoft HV account. One clinic had a direct connection with Microsoft HV that allowed patients to click on a specific icon within the HIPAA-covered PHR to transmit the files to their HV accounts (although that connection is currently disabled).

Benefits: Distributes Educational Materials

Clinic organizations in both states expounded on the many benefits of PHRs. Many cited the ability to provide their patients with patient education as a key benefit. Those that did not currently offer a portal mentioned that they would like to have this functionality. One such provider that is debating the purchase of a PHR stated, "A lot of times, I give patients education and they leave it in the parking lot. This leads to a lot of calls afterwards asking about the information that was provided. This would save me time in that I wouldn't have to keep doing the same thing over and over." Another organization indicated that the clinical summaries provided through the portal constitute some of the most useful education they give to patients. Because the EHR incentive program is required to give clinical summaries to patients for more than half of their patient encounters, this organization found that their portal helped to meet this measure. Additionally, patients that actually want a copy of their clinical summaries are more likely to log in to access these documents. This process helps avoid privacy breaches because it reduces the number of clinical summaries (that normally contain protected health information) that would otherwise be thrown away in the waiting room trash receptacle.

Benefits: Saves Time

The New Mexico clinic organizations cited another benefit of PHRs: the ability for patients to input useful information for the provider/organization, such as insurance information, demographic data, social history, diagnosis history, medication, and surgical history. One provider estimates they would eliminate up to 15 minutes per patient at the time of registration by asking patients to enter their insurance information via the PHR prior to the patient encounter. Multiple interviewees mentioned two other benefits of patient interaction via PHRs: prescription refill requests and scheduling. One large New Mexico provider cited the benefit of the ability to triage messages and to identify relevant information to assemble for the provider before the provider answered the patient.

Benefits: Reduces Redundant Care

Provider interviewees also indicated that they would be willing to accept health record information from other settings of care via the patients' untethered PHRs. However, the majority of the interviewees wanted to specify that they would only do so if the information seemed to originate from a legitimate source. One provider, a pediatrician, that does not currently use PHR technology for the clinic indicated that pediatricians do not typically like to rerun many tests on their child patients, especially if these tests involve needles. She thought that most pediatricians would accept such information given the above

specifications. One rural New Mexico clinic was exception to this viewpoint: this clinic indicated that most providers would want to run their own tests unless the procedure was not covered by the patients' insurance.

Benefits: Helps Patients/Caregivers Coordinate Their Own Care

Another benefit for one particular clinic is the ability to help patients who change locations frequently to coordinate their own care. One rural New Mexico clinic near a military base noted that many of its patients are active-duty military and are often deployed around the world, which made accessing medical records challenging until the clinic implemented a PHR. Deployed individuals and their families are now able to log in and view their health information from anywhere in the world as long as they have internet access.

Another practice indicated that its patient volume consisted of children from homes with divorced parents who did not effectively communicate. This provider indicated that a patient portal would help parents coordinate the care of the child, especially if the parents were not on speaking terms.

Barriers/Concerns: Provider Resistance of Technology

Most of the clinic staff we spoke to had very positive feedback on using PHRs as part of the routine workflow to communicate with patients. However, they mentioned a few barriers. First, some providers have not fully embraced online technology for patient communication. One staff member said, "providers do not like the subtle pressure of giving medical advice via an electronic medium. They would rather suggest that the patient make a face-face appointment to discuss their problems."

Barriers/Concerns: Misaligned Financial Incentives

A second barrier is that providers typically do not get paid for the time they spend communicating with patients using the PHR. Concerns about payment were expressed in both states. Although some clinics tried to adopt a payment model that allowed providers to bill for each problem discussed, implementing this system was cumbersome since patients did not request a communication for each problem but rather described their various problems in one communication. Despite these barriers, some providers found that sharing laboratory results with patients via the PHR was very useful but some providers still preferred mailing hard-copy results to patients.

Barriers/Concerns: Setup and Maintenance Costs

In both states resources for the initial setup and the required infrastructure to use it correctly were primary barriers. In two cases, provider interviewees expressed displeasure with the time and cost of PHR maintenance. The first group indicated that significant staff time is required both to monitor the information that is uploaded to the portals and to grant patients access to the system. The PHR implementation at one organization required

retraining medical records staff to monitor and respond to portal activity, which in turn led to additional time requirements and higher costs. A second clinic group had to train 20 employees to maintain a centralized call center to help with system maintenance. Originally, this organization thought that the vendor would handle this type of support line; however, once the portal was operating, they learned that <u>they</u> had to provide the support.

Barriers/Concerns: Accuracy of Patient-Entered Data

Some clinicians were not enthusiastic about a patient-maintained health record because they felt medical information should be validated by providers to ensure accuracy and validity. A community patient portal could be a possibility if clinicians or other medical service providers supplied the patient information to the portal.

Barriers/Concerns: Security

In New Mexico, providers expressed concerns with the privacy and security associated with the use of PHRs. Although these organizations did not specify their concerns with security, they seemed to indicate that they were simply leery of how well the PHRs safeguards truly secured protected health information.

Barriers/Concerns: Patients' Ability to Use PHRs

Another commonly cited negative aspect of PHRs was the patient population's ability to actually use the technology. Most organizations discussed this concern, but each described different reasons for this opinion. In some cases, reliable high-speed internet access was a large barrier for the patient population. Two reasons were cited for this lack of connectivity: (1) the location itself had poor broadband connectivity, and (2) patients in that area did not possess a high level of health or computer literacy and/or have computers available for use. In Utah, some providers noted that patients could not remember their passwords and that the initial process to set up accounts was fairly cumbersome. These issues also affect the need for availability of technology staff to assist patients.

In addition to these challenges, providers expressed concerned that patients would automatically receive abnormal/flagged lab results before the provider had the opportunity to review the results and provide the patient with appropriate interpretation. More than one interviewee reported that providers in their area predicted their patients would turn to an online Web search to determine what is "wrong with them," which could potentially cause unneeded panic/stress. Along these same lines, providers worried that patients may not use the messaging function in the PHR appropriately. For example, absent an EHR, a patient experiencing chest pains would typically go immediately to the local hospital's emergency department; however, instead of seeking this care, the patient might try to use the direct messaging capabilities of their physician-provided PHR to find out what might be wrong.

In New Mexico, a number of the providers interviewed also discussed their concern about their Spanish-only speaking patients who may not be able to interpret the information provided through the PHR. This concern is significant in New Mexico because many residents speak Spanish as their primary language.

Functionality Desired

Clinicians identified the following gaps in the functionality available today and functionality that is needed:

- Granularity on the preferred contact method for different types of information (labs results, clinical reminders, etc.)

- Patient education. Clinicians want to push education to the PHR

- Mass mailings to request patients to review immunization records

- Graphical immunization charts

- Image results that can be shared with the patient

- Ability to build custom forms

- Providers list, personal preference, and proxy

- Ability to send a letter for clinical alerts (reminders) for scheduled and unscheduled messages

- Interactive care plan that allows patient to add weight, glucose numbers

- Reminder for upcoming appointments

Summary/Lessons Learned

Most clinic representatives realized the importance of allowing patients to view their data through a PHR, but some providers mentioned that they were wary of data that came from patients and would be hesitant to offer patients edit privileges. A few of the clinics who had actively pushed for PHR implementation stated that good workflow processes for patient training and signup are essential. Providers echoed many of the concerns articulated by patients related to privacy, security, and technology/health literacy.

3.1.4 Payors

Usage/Penetration

PHRs associated with payors appear to have higher utilization than provider or hospital portals, perhaps reflecting patient demand for billing information.

Payors in the two states differed in their willingness to provide usage data for this report. Utah payors were more open about their utilization statistics; New Mexico payors tended to view that information as proprietary.

In Utah, utilization reflected the differing maturity of the PHRs examined and ranged from zero to 40%. Among those with fully implemented PHRs, payors reported that usage ranged from 20% to 40%, with a mean frequency of access of once a month.

More than one payor reported that utilization appeared to increase during open enrollment. Users (employees) used the system to re-enroll or change their preferences. One payor with a more mature system offered very detailed statistics for this project, which are summarized in Table 3-3.

Both commercial payors interviewed in New Mexico provided absolute numbers of users, but did not provide penetration numbers expressed as a percentage of covered lives. One reported that approximately 20,000 "signons" had been registered by their PHR; however, this number represented unique visits rather than unique patients. The second payor—which included a health plan, a large hospital system, and a clinical network—had 40,000 system users and is adding members at a rate of about 3,000-4,000 users per month. By the end of the year, the payor expects 100,000 users because they recently started a robust marketing campaign to encourage more portal access throughout the state.

Education/Marketing

Payors used a variety of approaches to entice members to use their PHRs. Some subscribers were notified or educated about the PHR via marketing and outreach campaigns, sometimes timed with the launch of their product. Others payors encouraged use by providing monetary incentives if the subscriber used the PHR to participate in wellness programs.

Another payor was able to drive more traffic to its PHR by discontinuing delivery of paper-based explanation-of-benefits forms. Finally, one payor has attracted visitors by offering member discounts with featured vendors such as food companies, fitness/weight loss organizations, and complementary medicine services.

Table 3-3.   Utah Payor Access Counts from 8/1/2012 to 8/31/2013

Portal Status (Number of Portals)	Female			Male			Total		
	Member Count	% of Total Members	Average of User Access Count	Member Count	% of Total Members	Average of User Access Count	Member Count	% of Total Members	Average of User Access Count
Activated	1,370	5.90	9	580	3.00	9	1,950	4.60	9
<18	102	0.40	5	90	0.50	4	192	0.50	4
18—29	359	1.60	9	76	0.40	6	435	1.00	9
30—60	570	2.50	10	268	1.40	10	838	2.00	10
>50	339	1.50	10	146	0.80	13	485	1.10	11
Activation Code Generated First Time but Not Used	771	3.30	—	371	1.90	—	1,142	2.70	—
<18	123	0.50	—	83	0.40	—	206	0.50	—
18—29	188	0.80	—	48	0.20	—	236	0.60	—
30—60	224	1.00	—	118	0.60	—	342	0.80	—
>50	236	1.00	—	122	0.60	—	358	0.80	—
Inactivated	250	1.10	0	135	0.70	0	385	0.90	0
18	14	0.10	0	12	0.10	—	26	0.10	0
18—29	31	0.10	—	11	0.10	—	42	0.10	—
30—60	77	0.30	0	43	0.20	1	120	0.30	1
>50	128	0.60	0	69	0.40	—	197	0.50	0
Non-Standard Status	2	0.00	1	2	0.00	1	4	0.00	1
<18	2	0.00	1	2	0.00	1	4	0.00	1
Patient Declined	723	3.10	—	419	2.20	—	1,142	2.70	—
<18	83	0.40	—	63	0.30	—	146	0.30	—
18—29	129	0.60	—	33	0.20	—	162	0.40	—
30—60	204	0.90	—	132	0.70	—	336	0.80	—
>50	307	1.30	—	191	1.00	—	498	1.20	—

(continued)

Benefits

Payors identified several benefits accruing from PHR implementation. A key benefit for one payor was that consumer satisfaction scores rose following implementation. The same payor reported a decrease in unnecessary visits and overall phone calls to the organization after the PHR launch. This payor attributed the change to improved communication flow because patients used the messaging feature of the PHR instead of phone calls.

Additionally, this organization has benefitted from using the PHR to focus on preventive care. It offers educational resources such as modules for chronic disease maintenance and includes tools such as health assessments, diet and exercise tracking, incentives for goal achievement, and health coaching. Preventive care is a continuing goal for most payor organizations, and this group has benefitted from using PHRs to advance these initiatives.

Barriers/Concerns: Support Provider/Patient Relationship

One payor felt it was absolutely critical to integrate the PHR with the provider and patient experience. This payor had previously offered an untethered PHR that they subsequently discontinued because a standalone product did little to foster the patient/provider relationship.

Barriers/Concerns: Some Patients and Providers Will not Use PHRs

One interviewee stressed the importance of understanding that patients and providers are at different stages in their willingness to use a PHR. Some will be early adopters and high utilizers, and others will be more resistant. This variability in customer PHR use is to be expected. This payor felt that, over time, this variability will shift as PHR use becomes more commonplace and fits better with patient lifestyles and clinical flow.

Functionalities/Functionality Gaps

The PHRs are mainly "view only" for the claims data. The exception for the view only would be enrollment or wellness data that the user enters. Data from these portals cannot be shared with outside entities or downloaded.

The payor PHRs tend to focus exclusively on claims data, explanation of benefits, provider search functionality, open enrollment, and life change updates (marriage, divorce, or birth of children), but many payors are beginning to add health education resources and more robust health management features as noted above. Other features that Utah payors reported are:

- Retirement tools
- Eligibility tools
- Appointment scheduling features

- Provider ratings
- Health care management alerts

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Summary

Compared with provider PHRs, payor PHRs appear to have higher utilization, perhaps highlighting consumer demand for easily accessible claims/financial data. Payor PHRs that marry health-related content with claims data may have an advantage: they may be able to reach more individuals with preventive/wellness messages than traditional methods.

4. CONCLUSIONS

Although offerings and usage patterns differed across provider types, all stakeholders interviewed, by and large, saw value in having a PHR available to patients. One notable finding was that consumers were less familiar, and in some cases, less trustful of PHRs with no connection to their provider (such as stand-alone PHRs like HealthVault). Providers, payors, and consumers all noted limitations that would prevent a significant number of patients from using a PHR (technology access, health literacy, time required, familiarity with the tool, etc.). Similarly, all stakeholders noted the need for PHRs to support, rather than detract from, the patient-provider relationship. Providers especially want the PHR to facilitate more effective, efficient work flow. Both providers and patients view the PHR as a way to be more efficient in communications by reducing phone calls, phone wait time, and unnecessary appointments. Usage statistics gathered from several providers support this statement (see Tables 3-1 and 3-2): they show messaging is among the top three most utilized features. Both patients and providers had lingering concerns about confusion that may arise from lab or test results appearing in a PHR without explanation from a care provider. At the same time, patients found this feature highly valuable.