Improving personal health records for patient-centered care

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ABSTRACT

Objective To assess the patient-centeredness of personal health records (PHR) and offer recommendations for best practice guidelines.

Design Semi-structured interviews were conducted in seven large early PHR adopter organizations in 2007. Organizations were purposively selected to represent a variety of US settings, including medium and large hospitals, ambulatory care facilities, insurers and health plans, government departments, and commercial sectors.

Measurements Patient-centeredness was assessed against a framework of care that includes: (1) respect for patient values, preferences, and expressed needs; (2) information and education; (3) access to care; (4) emotional support to relieve fear and anxiety; (5) involvement of family and friends; (6) continuity and secure transition between healthcare providers; (7) physical comfort; (8) coordination of care. Within this framework we used evidence for patient preferences (where it exists) to compare existing PHR policies, and propose a best practice model.

Results Most organizations enable many patient-centered functions such as data access for proxies and minors. No organization allows patient views of clinical progress notes, and turnaround times for PHR reporting of normal laboratory results can be up to 7 days.

Conclusion Findings suggest patient-centeredness for personal health records can be improved, and recommendations are made for best practice guidelines.

INTRODUCTION

Personal health records (PHRs) are software applications that patients can use to communicate with their clinician, to enter their own health data, and to access information from their medical record and other sources.^{1–3} Uptake of this new technology in the United States is modest,^{4,5} but increasing due to employers requesting that health plans include PHRs, healthcare reforms positioning PHRs as solutions, and the market entry of Google and Microsoft.⁶ By facilitating online access to medical information, and activating the patient in knowledge based collaborations with clinicians, personal health records are envisaged as having a key role in patient-centered care.^{7,8}

As a new technology PHRs create new benefits and new policy issues.^{9–11} Organizational policies for PHRs directly affect the impact of PHRs on the patient-centeredness of care, one of six dimensions of quality identified by the Institute of Medicine (along with safety, effectiveness timeliness, efficiency and equity).¹² We surveyed 10 topical PHR issues in a purposive sample of seven institutions representing a spectrum of early adopter PHR providers. We then

assessed policy patient-centeredness of these policies utilizing a framework of care that includes: (1) respect for patient values, preferences, and expressed needs; (2) information and education; (3) access to care; (4) emotional support to relieve fear and anxiety; (5) involvement of family and friends; (6) continuity and secure transition between healthcare providers; (7) physical comfort; and (8) coordination of care.¹³ Within this framework we used evidence for patient preferences (where it exists) to compare existing PHR policies, and propose a best practice model.

METHODS

The interview schedule in table 1 shows 10 cornerstone PHR issues identified by literature,⁹ web search, and personal communications. These are grouped into data access, data content, data control, data re-use, advertising, emergency access, and communication. In this framework proxies are people who are granted personal health record access by patients, and minors are defined by legal definition in each jurisdiction. Data control allows patients to control who views certain subsets of their data. "Break the glass" functions allow identifiable health providers not otherwise explicitly specified by the user, to access personal health record information in medical emergencies.

Site selection and data collection

Between October and December 2007, as part of a wider study exploring PHR governance,¹⁴ we conducted in-depth semi-structured interviews in organizations purposively selected to represent a variety of PHR settings⁵ in the USA with established user bases. The settings were medium and large hospitals, ambulatory care facilities, insurers and health plans, government departments, and commercial PHR sectors. The user base was set at >10 000 registered users (users who had actively logged in to the PHR) on or before January 1, 2007. Organizations were identified by literature, web search, and personal communications. Hospital settings were associated with a main hospital campus, and the campus was stratified by inpatient beds into medium (<499)¹⁵ and large (≥500).¹⁶ Small hospitals were not sought as they were less likely to be able to afford health information technology (IT),¹⁷ and to have the required user numbers.

Table 2 shows the characteristics of each setting. Interviews were conducted by SR.

Within each organization, a senior management person recognized by the organization as having PHR expertise was invited to participate or recommend a more suitable participant. Interview

Table 1 Interview schedule

PHR issues	Categories
1. Can patients authorize another person(s) as a proxy for PHR access?	Data access
2. Are minors able to access their PHR?	Data access
3. Are patients able to view full EMR clinical progress notes?	Data content
4. Can patients view an EMR full diagnosis list?	Data content
5. Can patients control who sees what PHR data?	Data control
6. Is patient self-entered PHR data able to be used for research purposes?	Data re-use
7. Does 3rd party health related web based advertising occur on the PHR website?	Advertising
8. Is there a "break the glass" function allowing PHR information to be available in emergencies?	Emergency access
9. From when normal laboratory results are available to clinicians, how soon are they available to the PHR?	Communication
10. What is the policy timeframe for clinicians to respond to patient PHR emails?	Communication

EMR, electronic medical record; PHR, personal health record.

questions were framed around 10 current PHR issues previously described. The interview was structured in format and the questions were asked as they appear in the interview schedule shown in table 1. There were five face-to-face interviews and two telephone interviews. Interviews lasted 45–180 min with detailed field notes kept. Accuracy was achieved by post-interview respondent validation including sign off on the data set, titles, and organizational names.

RESULTS

Table 3 shows organizational responses to the ten PHR issues.

Among those organizations where the examined functions are applicable to their population, for example access for minors is not relevant to Veteran Affairs, and where the functions exist and are by policy enabled or disabled, we found that most organizations support data access for proxies (6/7), data access for minors (4/5), restricting third party website advertising (6/7), and preventing re-use of patient self-entered data (5/5).

Some organizations enable emergency "break the glass" functions (3/7), patient access control over subsets of their data (2/7), and views of a full electronic medical record (EMR) diagnosis list (4/7). One organization filtered out their patients' mental illness diagnoses.

All organizations with access to laboratory data make that data available to patients, but the time frame in which data is released varies. Communicating normal laboratory results to patients ranges between simultaneous clinician and patient availability (2/6), to a default 7-day delay regardless of clinician sign off (1/6). The remaining time frames (3/6) are between

these points, with these organizations also providing for immediate release on clinician sign off. Clinician turnaround response time to electronic patient messaging varies between 24 and 48 h (2/6), within 72 h (2/6), or is completely discretionary (2/6).

No organization enables patient views of clinical progress notes.

DISCUSSION

This study shows a wide range of PHR policies across early adopter organizations in 2007. This variance can be explained by inter-state, organizational, and personal preference factors. For example, access for minors is governed by legislation at the state level. The availability of normal laboratory results is an inherently organizational decision, and clinician response times to patient emails is largely left to individual clinician preference.

Observing the wide range of policy responses, we seek to stimulate discussion toward standardizing guidelines by proposing a "best practice" model that seeks to maximize the patient-centeredness of PHRs. We develop a patient-centered policy model informed by concepts of patient empowerment and full control of the personal health record.^{18, 19} Where evidence exists, we note patient preferences for various policies, and where the evidence is less clear, we offer suggestions based on broader principles for patient-centered care previously described. Table 4 shows a proposed patient-centered policy model derived from these principles.

In our survey, policies vary for patient access to normal laboratory results. Some personal health records make normal laboratory results simultaneously available to patients and clinicians. Others have delays based on clinician sign off that can extend up to 7 days. There is evidence that physicians support direct reporting of normal laboratory results to patients,²⁰ and that timeliness of receiving normal laboratory results is important to patients.²¹ Given that clinicians still review all laboratory results, we see no substantive advantages in delaying release of normal laboratory results to patients.

Electronic messaging has been reported by patients as being one of the most useful features of a PHR,⁷ however some clinicians have more guarded views and experiences.²² A decade ago it was noted that as patient messaging increases, the response time may need to change from a standard 2–3-day turnaround,²³ but our results show that clinician turnaround times have generally not shortened. No clear guidelines exist, however it is our view that if PHR messaging is to be a legitimate supplement to clinic telephone calls, then similar communication protocols will need to be applied. For example, the communication pathway for practices wishing to incorporate PHR messaging will need to include timely messaging checks. We propose a one-business day practice response time that at a minimum, acknowledges receipt

Table 2 Purposively selected organizations and interview settings

	Medium hospital	Large hospital	Ambulatory	Insurer	Health plan	Commercial	Government dept
Organization	BIDMC*	BWH†	PAMF‡	Aetna§	Kaiser¶	Medem**	Veteran Affairs††
Established	1999	2002	2000	2007	2003	1999	2003
Users	35000	38000	96000	>800000	1.6 million	500000	500000
Interviewee	Chief Information Officer	Chief Information Officer	Chief Medical Information Officer	Head of eHealth Product	SVP Quality & Clin Systems Support	Chief Executive Officer	Director of Medical Informatics

*Beth Israel Deaconess Medical Center, Boston, Massachusetts.

†Brigham and Women's Hospital, Boston, Massachusetts.

‡Palo Alto Medical Foundation, Palo Alto, California.

§Aetna, Hartford, Connecticut.

¶Kaiser Foundation Health Plan, Oakland, California.

**Medem, San Francisco, California.

††Veterans Health Administration, Seattle, Washington.

Table 3 Personal health record (PHR) policies

	Categories	BIDMC	BWH	PAMF	Aetna	Kaiser	Medem	Vet Affairs
1. Patient proxies enable PHR access	Data access	Yes	Yes	Yes	Yes	Yes	Yes	No
2. PHR access for minors	Data access	NA*	No	Yes†	Yes†	Yes†	Yes†	NA*
3. Patient views EMR clinical notes	Data content	No	No	No	NA‡	No	No	No
4. Patient views full EMR diagnosis list	Data content	Yes	No	Yes	No§	Yes	Yes	No
5. Patient control of information access	Data control	No	No	No	Yes	No	Yes	No
6. Research using patient self-entered data	Data re-use	No	No¶	No	No	No¶	No	No
7. Third party PHR web advertising	Advertising	No	No	No	Yes	No	No	No
8. Emergency "break the glass" access	Emergencies	No	No	Yes	No	Yes	Yes	No
9. Normal lab results PHR availability	Communication	Stat**	Stat-day 2††	Sign-day 5	NA‡	Sign-day 2	Sign	After day 7‡‡
10. Clinician response to patient emails	Communication	<72 h	NA§§	24–48 h	NA‡	24–48 h	NA§§	<72 h

*Predominantly adult medical services.

†Parent proxy while a minor.

‡No relevant notes, investigations or messaging.

§Filtered for mental illnesses.

¶Patients are unable to self-enter data.

**Stat is immediately and sign is when the results are signed off by a clinician.

††Regardless of sign off availability based on each specific lab test.

‡‡Regardless of sign off.

§§Practice level decision making.

BIDMC, Beth Israel Deaconess Medical Center; BWH, Brigham and Women's Hospital; PAMF, Palo Alto Medical Foundation; EMR, electronic medical record.

of the message, indicates proposed actions by named parties, and provides a likely timeframe to completion.

Emergency access to health information has long been held out as a pivotal expectation of personal health records by patients and clinicians.^{24–26} The majority of institutions surveyed do provide "break the glass" features that patients could enable or disable. We believe "break the glass" functions represent one of the most important alignment and visions of patient-centered care and personal health records.

By the standards we propose, PHRs of the surveyed organizations support patient-centered care to varying degrees. All the functions of an ideal patient-centered model are collectively visible across organizations, except for patient access to clinical progress notes. While patients have the right to obtain copies of their records under US law,²⁷ providing online access to clinical notes still remains at the discretion of clinicians and organizations. Many have expressed concerns about the potential consequences of making clinical records available to patients.^{28–29} Some have been concerned that because clinical notes are intended more for personal recall^{30–31} and professional communication, they may be ill suited (eg, confusing, worrisome) for communication with patients.³² However, in one study patients valued access to clinical notes even when technical jargon made parts of the notes hard to understand.³³ These patients valued

transparency as much as the information content of the note, and did not want access to the actual clinical note to be supplanted by access to a simple patient-oriented visit summary. Overall, given the lack of demonstrable benefit in providing online access to clinical notes, there has been little interest in the practice.⁹ In spite of the concerns of some (not all) clinicians,³⁴ the fact remains that many patients desire online access to their clinical progress notes,³⁵ and online representations of clinical progress notes must faithfully reflect the original source data.³⁶ We believe restricting access to clinical records is antithetical to principles of patient-centeredness, and we suggest that further work be done to educate and support clinicians with best practice medical record documentation, and that further studies be undertaken to examine the consequences of large-scale, personal health record patient access to clinical progress notes.

This study has some limitations. It was conducted at the end of 2007 and the functionality of personal health records can change rapidly over time. This was demonstrated in the speed with which PHR functions were changed when incorrect or inappropriate institutional claims data was incorrectly migrated into a public personal health record.³⁶ In this context, while we acknowledge that this study is a snapshot in time, the 10 items examined are policy issues that are fundamental to PHRs now and in the foreseeable future.³⁷ We develop a patient-centered model with full patient empowerment, acknowledging that patients differ in their desire for access to, control of, and participation in information sharing and decision making.^{38–41} One can envisage a continuum of patient control with our model representing one end of the spectrum. We did not examine all PHRs but purposively focused on larger, more experienced early adopter organizations and it was not our intention to be comprehensive. The study design excludes organizations with small user numbers and this creates a tendency to over-represent large health system PHRs that utilize information held in underlying electronic health records. However, we believe that the recommendations for best practices are appropriate for smaller sites as well.

CONCLUSION

Personal health records are important tools for patient-centered care. We inform the discussion by describing what PHR policies currently exist, and establishing a policy position for full patient empowerment. Further work is required to develop these

Table 4 Patient-centered policy model

PHR issues	Categories	Patient-centered policies
1. Patient proxies enable PHR access	Data access	Yes
2. PHR access for minors	Data access	Yes
3. Patient views EMR clinical progress notes	Data content	Yes
4. Patient views EMR full diagnosis list	Data content	Yes
5. Patient data control of information access	Data control	Yes
6. Research using patient self-entered data	Data re-use	No*
7. Third party PHR web advertising	Advertising	No*
8. Emergency "break the glass" access	Emergency access	Yes
9. Normal lab results availability	Communication	As soon as available to clinician
10. Clinician response to patient emails	Communication	<24 h

*No is the suggested default with patient control over enable or disable.

EMR, electronic medical record; PHR, personal health record.

concepts into national guidelines, including exploring the consequences of opening clinical progress notes to patients, enabling “break the glass” access in emergencies, and developing rule sets for patient messaging turnaround times.

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