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 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 10

As a new technology PHRs create new benefits and new policy issues.6 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
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 (5/7), 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. 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, and that timeliness of receiving normal laboratory results is important to patients. 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, however some clinicians have more guarded views and experiences. 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, 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
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.\(^{3}\) 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.

### Table 3 Personal health record (PHR) policies

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

**Philosophically relevant notes.
††Regardless of sign off availability based on each specific lab test.
†††Regardless of sign off.
§§Practice level decision making.

### Table 4 Patient-centered policy model

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

**No is the suggested default with patient control over enable or disable. EMR, electronic medical record; PHR, personal health record.

### 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...
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.

Funding Supported by the Commonwealth Fund, a private independent foundation based in New York City. All authors declare that they are independent of funders for this research.

Competing interests None.

Ethics approval Study approval 2007P-000389 was obtained from Beth Israel Deaconess Medical Center Committee on Clinical Investigations, Boston, MA 02215, USA.

Provenance and peer review Not commissioned; externally peer reviewed.

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