**Governance for Personal Health Records**

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**Abstract** Personal health records (PHR) are a modern health technology with the ability to engage patients more fully in their healthcare. Despite widespread interest, there has been little discussion around PHR governance at an organizational level. We develop a governance model and compare it to the practices of some of the early PHR adopters, including hospitals and ambulatory care settings, insurers and health plans, government departments, and commercial sectors. Decision-making structures varied between organizations. Business operations were present in all groups, but patients were not represented in any of the governance structures surveyed. To improve patient-centered care, policy making for PHRs needs to include patient representation at a governance level.

**Introduction**

Before the development of electronic storage methods, medical records were handwritten documents used primarily by clinicians and administrators. The development of electronically stored medical records has made medical information more readily available to a wide range of users, including patients. Electronic personal health records are software applications that patients can use as “communication hubs” to access and use information from their medical record and other resources. While the specific definition of a personal health record (PHR) is still evolving, the underlying concepts supporting patient involvement and shared medical records date back to the 1970s, and studies indicate that sharing the record tends to improve communication between doctor and patients.

By empowering patients as active participants in their own health care, PHRs offer the promise of reducing medical errors, improving disease management, and reducing the overall costs of health care. Fulfilling this promise will require more than just information access; it will also entail using PHRs as transformational agents that can enable self-management by patients and improve patient-physician collaborations.

In the United Kingdom (UK), the National Health Service (NHS) is currently implementing HealthSpace as a national PHR platform. The UK market for personal health records is relatively new compared to the United States (US), where personal health records are gathering momentum due to employers requesting that health plans include PHRs, healthcare reforms positioning PHRs as solutions, and the market entry of well known providers Google and Microsoft.

Despite these developments, there has been little discussion and no published research about the governance structures that might best serve PHRs at an organizational level. Similar to PHRs, regional health information organizations (RHIOs) exchange health data amongst a range of stakeholders. A 2005 article describing several large established RHIOs outlines governance structures none of which clearly include patient representation then or now. More recent RHIOs such as the BronxRHIO in New York support a consumer position on the board. The information in PHRs is potentially sensitive, available instantly online, and may include patient-entered data. The transfer of this information to patients creates issues that are specific to PHRs and therefore warrant a well-organized governance group. Issues to be resolved include how parts of the medical record such as the clinical notes (often viewed as a summary and prompt for the physician only), and the full problem list (often viewed as containing information better hidden from the patient, such as the diagnosis of mental illness), should be made available to patients, and under what conditions can patient-entered data be used for research.

In this paper, we examine organizational roles that we consider appropriate for a governance structure that has final decision-making authority for PHR policies. We create a governance model as a minimum structure for an organizational PHR (Table 1). We do this by adapting to a PHR environment the five functions from the United States Agency for International Development governance template. We retain four of the five functions: 1) information/assessment capacity; 2) policy formulation and planning; 3)
Table 1 ■ Proposed Governance Structure

<table>
<thead>
<tr>
<th>Function</th>
<th>Role</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>• Information/Assessment Capacity</td>
<td>Chief Information Officer¹</td>
<td>Organizational overview of information capacity, strategy, and health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>information legislation</td>
</tr>
<tr>
<td>• Policy Formulation &amp; Planning</td>
<td>Medical Informatician²</td>
<td>Awareness of local and national PHR trends, overview of local users and</td>
</tr>
<tr>
<td></td>
<td></td>
<td>their needs, IT and systems architecture advice</td>
</tr>
<tr>
<td>• Social Participation &amp; Responsivity</td>
<td>Patient³</td>
<td>Representing the views of patients as PHR users</td>
</tr>
<tr>
<td>Accountability</td>
<td>Business Operations⁴</td>
<td>Organizational accountability for cost benefit analysis, risk management and</td>
</tr>
<tr>
<td></td>
<td></td>
<td>marketing</td>
</tr>
<tr>
<td>• Clinical Leadership</td>
<td>Clinician⁵</td>
<td>Facilitate the patient-clinician-organization interface, provide clinical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>leadership</td>
</tr>
</tbody>
</table>

¹May also include a chief medical information officer (CMIO).
²Medical informatics involves “all aspects of understanding and promoting the effective organization, analysis, management, and use of information in health care”.¹⁵
³Patient as a consumer and PHR end user.
⁴Primarily administrative and non-clinical.
⁵Registered medical practitioner in clinical practice.

social participation and responsiveness; 4) accountability. We remove regulation because regulatory control is incorporated as an integral part of the other four functions. Clinical leadership is added as a fifth function because, as already discussed, PHRs are tools for patient-clinician collaboration and so clinicians need to be engaged as key stakeholders. These five functions allow broad comparability with other governance models, yet retain specificity for health information technology. In addition to the role of clinician, we ascribe four other roles to the key PHR functions that we have determined. These are a CIO, medical informatician,¹¹ patient, and business operations specialist. We differentiate a CIO from a medical informatician. A CIO has enterprise wide responsibility and may not have specific knowledge of contemporary clinical informatics and trends. We then compare our model with current governance structures in a range of settings.

Methods

Between October and December 2007, we conducted in-depth semi-structured interviews in purposively selected organizations that represent US-based PHR settings.²² Within each setting, an organization with >10,000 registered users (users who had actively logged in to the PHR) on or before January 1, 2007, was identified by literature, web search and personal communications. Hospital settings were associated with a main hospital campus, and the campus was stratified by communications. Hospital settings were associated with a 2007, was identified by literature, web search and personal who had actively logged in to the PHR) on or before January 1, 2007, was identified by literature, web search and personal respondents kept. Accuracy was achieved by post-interview respondent validation including sign off on the data set, titles and organizational names. In each setting we then grouped and matched the governance roles with the roles in our model.

Results

Governance structures varied in all of the settings, as shown in Table 3. The number of roles in each governance body varied between 3–15 people and included CEOs, librarians, and chaplains. The most senior executive officers were a CIO, CFO, and CEO with the greatest cluster of these in the large hospital setting. The role of business operations was the most common and was present in all of the governance bodies. Within business operations, the roles varied from senior management CEOs and CFOs to member services representatives, with information systems and information technology the most common. The ambulatory care setting PAMF (Palo Alto Medical Foundation) had the most business roles (eight), and the medium-size hospital BIDMC the least (two). Among other clinical roles, the ambulatory care setting was also the only one to include a nurse. The commercial organization Medem had the most people representing large nationwide organizations such as the American Medical Association and the Cancer Society. The commercial organization also had the most medical/legal representation with state and national liability representation. Organizations sharing business similarities, such as the hospitals BIDMC and BWH, had different governance structures. Comparing all roles with the five in our model indicated the most consistent was business operations, which were present in every setting. This was followed by clinicians in six of the seven, and informaticians and CIOs in three. No organization included a patient representative in its governance structure.

Discussion

We found in our survey a wide range of governance structures across all of the settings. There are several possible explanations for this. The first is that different structures reflect different healthcare settings. The VA has wide representation consistent with government PHR bodies.²⁶ Medem is a commercial platform and its awareness of commercial risk may be reflected by the inclusion of two liability specialists. However, similar healthcare settings such as the hospitals BWH and
BIDMC had vastly different structures. Although a range of different governance structures may be appropriate for different settings, we believe the five components in our model should be common to all.

Another possible explanation is that the governance structures may be functionally more similar than they structurally appear. Under this supposition there is more commonality if the governance group is redefined to take into account advisory groups and subcommittees. Some of the organizations such as VA, PAMF, and Kaiser have extensive advisory hierarchies supporting the main governance body while others receive more limited advice. We believe advisory support has a place but should not be more elaborate than needed for the purpose.27

Divergent governance structures may also reflect the fact that one governance role is fulfilling several functions, such as when a clinician or CIO is also an informatician. For example, the percentage of organizations with informaticians in the PHR governance structure would be increased if the CMIO at Palo Alto Medical Foundation were also recognized as having an informatician role. It is a limitation of this study that we assigned single roles based on job-titles, rather than examining the functions performed by the individuals in their jobs. The possibility of multiple roles may be small at the organizations studied however, with no respondent identifying this at post interview follow-up. In any event, even if multiple roles were present, no role directly represented a patient. In our model we remove the potential for dual roles by requiring each role be lead by a different person. We believe this is important to bring specific focus and expertise to each role.

We did not examine all PHRs, and the study design excluded those with small user numbers. This creates a tendency to over represent large health system, EMR populated platforms. This is a limitation of our study. We are not aware of any PHR governance structures where a patient is included, although they may exist.

Personal health records are communication tools between clinicians and patients. Clearly both these parties are important stakeholders. While clinicians are represented in most governance bodies - patients are not. We believe patients need to be directly represented at a governance level. Indirect representation through clinicians or advisory support groups is not enough—patients need to “be at the table.” An argument often raised is the difficulty of deciding who represents a patient. It is not the purpose of this paper to enter this debate, but we note two points that provide some guidance and suggest this is not an insurmountable barrier. First, most US health organizations have ethics committees that require a community member.28 Second, a US federally mandated PHR workgroup, the American Health Information Community—Consumer Empowerment Workgroup, has patient representatives from the National Patient Advocate Foundation, Office of Minority Health, and the Office for Civil Rights.28

Table 2 - Purposively Selected Interview Settings

<table>
<thead>
<tr>
<th>Setting</th>
<th>Medium Hospital</th>
<th>Large Hospital</th>
<th>Ambulatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization</td>
<td>BIDMC1</td>
<td>BWH2</td>
<td>PAMF3</td>
</tr>
<tr>
<td>Implemented</td>
<td>1999</td>
<td>2002</td>
<td>2000</td>
</tr>
<tr>
<td>Registered</td>
<td>35,000</td>
<td>38,000</td>
<td>96,000</td>
</tr>
<tr>
<td>Interviewee</td>
<td>Chief Information Officer</td>
<td>Chief Information Officer</td>
<td>Chief Medical Information Officer</td>
</tr>
</tbody>
</table>

1Beth Israel Deaconess Medical Center, CareGroup Healthcare, Boston, MA.
2Brigham and Womens Hospital, Partners HealthCare, Boston, MA.
3Palo Alto Medical Foundation, Palo Alto, CA.
4Aetna, Hartford, CT.
5Kaiser Foundation Health Plan, Oakland, CA.
6Medem, San Francisco, CA.
7Veterans Health Administration, Seattle, WA.

Table 3 - Governance Structures

<table>
<thead>
<tr>
<th>BIDMC</th>
<th>BWH</th>
<th>PAMF</th>
<th>Aetna</th>
<th>Kaiser</th>
<th>Medem</th>
<th>Veteran Affairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steering Committee</td>
<td>CIO1</td>
<td>CIO</td>
<td>CIO &amp; CFO</td>
<td>CMIO2</td>
<td>1 Clinician</td>
<td>5 Clinicians</td>
</tr>
<tr>
<td>- CIO</td>
<td>- 2 Clinicians</td>
<td>- 2 Business Ops (CEO3 &amp; CFO)</td>
<td>- 6 Clinicians</td>
<td>- 1 Business Ops</td>
<td>- 2 Business Ops</td>
<td>- 1 Informatician</td>
</tr>
<tr>
<td>- 2 Informaticians</td>
<td>- 2 Business Ops</td>
<td>- 8 Business Ops</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>- Business Ops2</td>
<td></td>
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</tbody>
</table>

1Chief Information Officer.
2Business operations includes managers, directors, VPs and representatives of: IT, IS, Marketing, Communications, Clinical Operations, Projects, Programs, Legal Services, National & State Liability Organizations, Medicare, Technical Development, Member Services, Planning.
3Chief Executive Officer is considered part of business operations.
4Chief Financial Officer is considered part of business operations.
5Chief Medical Information Officer is considered to perform many of the same functions as a CIO.
6Includes 1 registered nurse clinician.
Conclusion

In summary we believe that the policy process for personal health records can be improved by having a minimum PHR governance structure. A governance structure should accurately reflect and serve a purpose. The broad purpose for personal health records is to facilitate communication between clinicians and patients. We propose a governance model with five functions and roles that recognize clinicians and patients as key stakeholders and include them as members. Further work needs to be done to explore how changing PHR governance structures affects policy processes and eventual policy outcomes. This could include qualitative assessment of patient governance representation as it relates to organizing meetings, participation in discussions, public dissemination of information, and patient contribution to final policy decisions.

References

18. Bernardt M, Gunning L, Quenstedt M. Patient’s access to their own psychiatric records. BMJ 1991;303:967.