

Who should have access to my personal health record? Patients' perspectives

Kaitlin Light Costello, MLIS, Barbara M. Wildemuth, PhD

University of North Carolina at Chapel Hill, NC

Abstract

This paper investigates what potential users of personal health records (PHRs) think about allowing people access to their PHRs. As part of a larger study on the needs and requirements of PHR users, semi-structured interviews were conducted with 43 potential PHR users. The study participants discussed four groups that might have access to their PHRs: physicians, pharmacists, family members, and insurance companies. They talked about the benefits and drawbacks of each group viewing their PHRs and/or adding information to the records. The variety of their responses indicates the necessity for a tiered access system, where different people would have different levels of access to the PHR. In most cases, the patient would specify and maintain these access levels, although some participants preferred that physicians control access.

Introduction

Many people would like access to their own health records; some of these people would also like the ability to share their health information with others, depending on the identity of the recipient.¹ Sharing health records may have several motivations, including: facilitating caregiving, especially for dependents; improving quality of care; aiding communication between patients and care providers; and streamlining records maintenance activities, such as pharmacists viewing and adding prescription records.²⁻⁵ In addition to allowing individuals to access their own health records, personal health records (PHRs) can enable sharing records with others. However, studies have uncovered several potential concerns with using PHRs for sharing health information, including issues with inaccurate data; fear of discrimination, especially for insurance purposes; the belief that the records might upset patients, especially if they receive a difficult diagnosis or test result from their PHR; and the concern that people may not understand their records.⁵⁻⁷ Although these studies have been valuable, none have yet asked potential users about access rights within their ideal PHR system. Could tailored access controls let users enjoy the benefits of sharing health data, while avoiding some of the major concerns patients and physicians have about sharing PHRs? Understanding what kinds of access users want for their PHRs will aid in the development of design guidelines for PHRs, promoting the construction of effective and usable PHR systems for the future.

Definitions and Research Questions

There are many definitions of PHRs. Most of these definitions discuss three common attributes: what information the record contains, the source of that information, and the functions afforded by the PHR.⁸ The individual patient is always a key feature of PHRs. Usually they are the primary creator of the records held in the PHR, although they do not have to be the sole records creator.⁹ The presence of the patient as an active participant in record creation and use distinguishes PHRs from electronic medical records (EMRs), which are created and maintained by care providers and may not be accessible to patients.²

We define PHRs as records that are kept by an individual to keep track of their health status, changes in their health, medical treatment that they have received, and other aspects of their health or health care. This definition is based on several previous studies on PHRs and borrows heavily from the American Health Information Management Association definition published in 2005.¹⁰ Most PHR definitions do not indicate who might have access to the PHR, aside from the patient. Other potential users include care providers, caregivers, pharmacists, employers, government agencies, and insurers.⁹ To better understand patients' perspectives on PHR access, we investigated the following research questions:

1. Who should be able to access an individual's PHR?
2. With what kinds of access are potential users comfortable?
3. What concerns do potential PHR users have about others' access to their PHRs?

Methods

These questions were addressed within an interpretive research paradigm. We targeted four groups of potential PHR users: parents with young children, adults with chronic diseases requiring self-management, adults caring for older family members, and older adults. An announcement was sent to a listserv at the University of North Carolina at Chapel Hill to recruit participants in these four groups. When a participant in one of these groups replied, we scheduled a time for a private interview.

We conducted 43 semi-structured interviews in April and May of 2006. At the beginning of each interview, we provided participants with our definition of a PHR, outlined above. Participants were offered \$25 for their time. The interview questions asked about what current methods, if any, participants used to manage their health records; what types of data they might want to keep in an electronic PHR; the circumstances under which they would create, maintain, and use a PHR; who they thought should have access to their PHR; the range of uses they perceived for their PHR; and other issues related to PHRs, such as security and privacy.

The interviews were audiotaped and transcribed. Participants were assigned pseudonyms for the purposes of reporting our conclusions. The transcribed interviews were analyzed qualitatively using Nvivo version 7. Open coding, an inductive process where codes are derived from the data themselves, was used to aggregate responses and isolate themes from the interviews.¹¹

Results

Since none of the participants had used a PHR system, their perspectives on PHR access were informed by their past experiences with paper health records, electronic medical records maintained by their physicians, and other computerized records systems like online banking. The participants often used these examples as analogies when describing their ideal PHR system.

Our reported results are based on the participants' comments related to PHR access (i.e., viewing the records and adding information to the records). The results are organized in terms of the four groups that might have access to PHRs, aside from the patients themselves: physicians, pharmacists, family members, and insurance companies.

Physicians

Viewing: The participants often distinguished between different types of physicians, indicating that general practitioners or primary care providers should have the capability to view most of the PHR while specialists should have a more restricted view. Most participants were interested in allowing care providers to view some records in their PHR, indicating that physician-accessible PHRs would make doctors' visits and other interactions easier for all involved parties. Many discussed the potential for PHRs to streamline routine processes such as discussing their medical history or current medications with the doctor.

Many participants also discussed situational sharing: allowing providers to view their PHR during particular events or in specific instances. Usually, these providers were specialists or emergency doctors instead of primary care physicians (PCPs). Joan wanted specialists to have access to her entire PHR while she was being treated: "If I was under the care of a doctor for a particular illness," she said, "I would say 'OK, you can look at everything, because who knows what might affect, contribute to, or be affected by it.'" Kail wanted healthcare providers to have access to his PHR during medical emergencies: "as long as the people who are managing my healthcare when I'm unconscious have quick access to that data... that's fine with me." Others discussed allowances for traveling, particularly if they have a health emergency while out of town. Since situational sharing was often limited by time, some participants indicated their desire to place a time limit on these sharing permissions: "I want my doctors and their assistants [to have] access with permission that can be revoked, maybe by time," Edouard explained.

Adding: Participants often assumed that physicians would enter data into the PHR, either manually or automatically. In this case, access to those records was seen as a way for patients to take ownership of their health. As Megan said, "I'd like to be able to, if I'm curious, go in there and take a look and see how I was feeling two years ago, and see if there were trends." Although some participants were aware that they could currently request their medical records from physicians, this process was described as excessively frustrating and difficult. People also discussed information added by providers as trustworthy, although

some were concerned about the accuracy of these records. Several participants were interested in allowing doctors to add private notes to their PHRs – notes that the patient could not see, but that would be available to care providers. As Megan explained, “I know that they [already] write some notes that are really just intended for themselves and the nurse and so if they’re not comfortable putting all of those in I don’t have a problem with it.”

Family members

Viewing: Our participants discussed family members accessing their PHRs in caregiving situations. Granting access to a specific person or select group of people was important to Mike, who said, “I think that, at least having one designated person who is able to access that record, if not one, two, or three, would be key.” Presumably this would benefit him in situations where he could not manage his own care. People were often happy to give access to family members, especially spouses. No one expressed reservations about sharing their health records with a spouse, although some indicated that spouses should not automatically be allowed to view records: “especially if there is discord/divorce/separation, there would be things they didn’t want their partner to know,” Helen said. People were less consistent in their desire to share records with their parents or children, although most participants wanted to view their children’s PHRs if they were responsible for their care. Determining when parental access ends, however, was more difficult: “I don’t know if your mother needs to know what’s going on with you at 14, necessarily,” said Sandy. “I would say as soon as the child could use the computer properly and is trained [their records should be private].”

Adding: Some participants liked giving family members the ability to add information to their PHRs. In these cases, family members were caregivers and were therefore trustworthy people that the individual could rely on to make helpful and necessary additions to the PHR. However, other participants were concerned about their privacy and felt that allowing caregivers to add records would give them access to other, more personal, parts of their records.

Pharmacists

Viewing: Many participants were keen to allow pharmacists to access their medication records for several reasons. Some thought that pharmacists might be better equipped to alert patients to medication interactions, for example, especially if they are seeing multiple doctors who prescribe various medications. Whether patients are filling and refilling prescriptions is something that a pharmacist can track that a doctor cannot. Finally, pharmacies could track spending on medications for flexible spending or tax purposes.

Some participants, however, did not think it was necessary for pharmacists to have any access to their PHR because their medication information was already held by their doctors: “I’m sure the doctor is going to have whatever is prescribed in their records, so I don’t really see the need to be able to download from the pharmacy,” as Samantha said.

Adding: Participants wanted pharmacists to have access only to medication information, not other information in the PHR. Some people wanted pharmacists to add prescription information, but did not want to allow them to view anything else in the PHR. Tim explained, “I don’t particularly want my pharmacist looking through my info, but if the system were designed so they could just enter stuff, that’s fine.”

Insurance Companies

Viewing: One of our strongest findings was that participants did not want to share their PHRs with insurance companies for any reason. They did not trust insurance companies with the data and did not see the utility in sharing records with them. As Deb said, “[My records are] not something I would care for the insurance company to have access to.” Matt discussed his fear that insurance companies would misuse his data, although he could not think of specific instances of how his data might be misused.

Adding: No one discussed insurance companies adding information to their PHRs, presumably because they did not want insurers to have any kind of access.

Discussion

The amount of contact that patients had with particular physicians corresponded with how much access they wanted to grant to them. People trusted their PCPs the most and wanted them to access nearly

everything in their PHR, except for personal information like diet, exercise, and private notes – often written about doctors themselves. Interestingly, the desire for these private notes was bi-directional: participants also wanted PCPs to have a way to make notations in their PHRs that were inaccessible to anyone but the physician. This blurs the line between EMRs and PHRs and is consistent with our participants' desire to have access to their EMR data from their PHR. However, they did not want specialists or other care providers to have write access to their PHRs except in cases where they established an ongoing relationship with those specialists.

Allowing specialists to view records was an example of “situational sharing,” granting an individual access for a limited period of time for a particular circumstance; people also wanted to enable situational sharing for emergency personnel. Developing methods to facilitate situational sharing will be a challenge for PHR systems designers, because it involves an additional layer of complexity – time – and often needs to be initiated when the patient is incapacitated, as in an emergency.

Although people rely on a large network of support when they are sick and may have caregivers that are not family members, like friends, neighbors, or co-workers, the participants in our study only talked about family members accessing their PHRs. Our sample may have affected these responses, since we talked to parents of young children and adults taking care of older parents and did not speak with anyone who was giving or receiving care from a friend. More research is needed to determine other populations that may be granted access in PHR systems; given the literature on social support and health, it is probable that some individuals would want to grant a trusted friend or friends access.¹² The system should also have a mechanism for people to give access to a trusted friend or family member when they are not present or able to do so, like in cases of brain damage or mental illness.

One special case our participants mentioned is that of minors with PHRs. Children may want to take control of their records before they are legal adults; under current HIPAA regulations, legal minors can deny access to their parents in specific situations, particularly when parental consent is not necessary for care.¹³ PHR systems designers will need to take this into account, paying particular attention to state and federal laws regarding the health records of minors.

Conclusion

In this exploratory study, we investigated potential PHR users' perspectives on who should have access to their health records. We interviewed 43 people who were likely, because of their personal health-related circumstances, to be early adopters of PHRs. They were asked about four groups that they might want to access their PHRs, aside from themselves: physicians, pharmacists, family members, and insurance companies. Participants were comfortable with their primary care physician accessing nearly everything in their PHR, but wanted a way to make private notes in their record that no one else could see. People also wanted a way to share records in particular situations, a phenomenon we labeled “situational sharing,” such as during emergencies or for specialty care. They wanted to allow pharmacists access only to medication records. Most people also wanted to allow a family member, often a spouse, access to their records. Participants also discussed the necessity to access records of people for whom they were caretakers, including children and elderly parents. None of our participants wanted to allow insurance companies to access their PHRs. The diversity in responses indicates that a tiered access system managed by the patient is necessary for PHRs.

This study has several implications for designing effective, usable PHR systems. The ideal PHR will support tiered access, allowing users to designate different levels of access to different individuals either by class or by name. For example, users may want to allow all staff in their primary care provider's office access to their record and also designate access to particular family members by name. Allowing tiered access is a multi-dimensional problem for designers of PHR systems. The record must be classified logically into manageable pieces, each with their own options for access; the type of people that may have access need to be enumerated; and the interface must present these complex options to users in an intuitive manner. Recent research indicated that a list with checkboxes might be the most effective way for people to manage access to their PHRs, but more work in this area is required.¹⁴ The system must also support situational sharing, allowing users to define an optional time frame for access in case of emergencies or other situations in which additional healthcare providers could access the PHR. Finally, a way for patients to take personal notes that cannot be viewed by anyone must be available. Researchers should implement these features into existing and new PHR systems in order to test their feasibility and usability.

Acknowledgments

This paper is based on interviews conducted by Catherine L. Blake, Kristina Spurgin, Sanghee Oh, Barbara M. Wildemuth, and Yan Zhang. Financial support for this research was provided by a grant from the National Cancer Institute (“Evidence Base for Personal Health Record Usability,” PI Gary Marchionini, 2006 Supplement to grant, “M.I.N.C. for Mammography Maintenance,” CA 105786, PI Barbara Rimer).

References

1. Whiddett R, Hunter I, Engelbrecht J, Handy J. Patients’ attitudes towards sharing their health information. *Int J Med Inform.* 2006 Jul;75(7):530–41.
2. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc.* 2006 Apr;13(2):121–6.
3. Pyper C, Amery J, Watson M, Crook C. Access to electronic health records in primary care—a survey of patients’ views. *Med. Sci. Monit.* 2004 Nov;10(11):SR17–22.
4. Wuerdeman L, Volk L, Pizziferri L, Tsurikova R, Harris C, Feygin R, et al. How accurate is the information that patients contribute to their electronic health record? *AMIA Annu Symp Proc.* 2005;2005:834–8.
5. Witry MJ, Doucette WR, Daly JM, Levy BT, Chrischilles EA. Family physician perceptions of personal health records. *Perspect Health Inf Manag.* 2010;7(Winter).
6. Hassol A, Walker JM, Kidder D, Rokita K, Young D, Pierdon S, et al. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. *J Am Med Inform Assoc.* 2004 Dec;11(6):505–13.
7. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. *J Am Med Inform Assoc.* 2008 Jan;15(1):1–7.
8. Sprague L. Personal health records: the people’s choice. *NHPF Issue Brief.* 2006;820:1–13.
9. Connecting for health: the personal health working group final report. Markle Foundation; 2003. Available from: http://www.connectingforhealth.org/resources/final_phwg_report1.pdf
10. AHIMA e-HIM Personal Health Record Work Group. Defining the personal health record. *J AHIMA.* 2005 Jun;76(6):24-25.
11. Strauss A, Corbin JM. *Basics of qualitative research: grounded theory procedures and techniques.* Sage Publications, Inc; 1990.
12. Cohen SE, Syme SL. *Social support and health.* Academic Press; 1985.
13. Health insurance portability and accountability act: personal representatives. 45 CFR §164.502(g). 2001.
14. Røstad L, Alsos OA. Patient-administered access control: a usability study. In: *International Conference on Availability, Reliability and Security.* Los Alamitos, CA, USA: IEEE Computer Society; 2009. p. 877–81.