



Patients' Perspectives on Personal Health Records: An Assessment of Needs and Concerns

by

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Purpose

- To identify current concerns with health records
- To identify needs for PHRs from the patient's perspective

Participants

- Parents of young children
- Adults with chronic illnesses
- Adults caring for elderly parents
- Older adults

Rationale for selection:

- Most likely to adopt PHRs

Methods

- 43 semi-structured interviews, each 30-45 minutes
- Open coding and analysis with Nvivo, v.7

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Findings

Status of existing health records

- Health records of some kind (primarily financial) are kept
- Little confidence in ability to find and use records
- Sharing records across health providers resulted in repetition of tests and procedures

Ideal PHR

- Data: lab test results, medications, appointments and their outcomes, providers' notes, and personal notes
- Uses: prior to a visit to the doctor, to monitor trends in their health indicators over time, and when needed for emergency care

Ongoing maintenance

- Comfortable with their health care provider accessing/updating, but very wary of anyone having access who is not directly involved in their care
- Not universally comfortable with any external entity holding their records
- Uncomfortable with responsibility of holding records themselves

"If I had to go now to get it, it would take me, like, two days to figure out where stuff is. I know I wouldn't have thrown stuff away, but.... I got divorced two times and have five kids. I don't know, maybe I did throw a lot of it away."

"[My] financial records offered me a record of who was treated, for what, when."

"Something has to be done about this whole issue in the next 10 years because our whole health system is changing. More people are going to be aging at the same time than ever before, and this issue is of particular concern to the aging. Their care tends to fall through the cracks, and they get to where they can't keep track of these things for themselves any more."

"I do recall one time, needing my immunization record and not being able to find it, for myself, to know which immunizations I'd had and when. When I did find it, I wasn't sure if it had been updated correctly. I wasn't sure that everything was on there."

"There have been times when I wanted to look back. Like, I had an exposure to a bat a couple of years ago when I was pregnant for the first time. And they wanted to know if I ever had a rabies shot, and there was no way for me to find that info. I couldn't find it. I'd been to so many doctors and called so many doctors and couldn't figure out if I'd had it, so I had to get the whole series of rabies shots again. And then, a year later, I found a little vaccination card I'd tucked away in a box somewhere, and I had indeed had the rabies shots. I wouldn't have had to go through all of that."

"It would be nice to be able to access that - some tests and outcomes - cholesterol, weight, ekg, from last year - would be great and helpful."

"The list of medications and doses. Maybe the prescription numbers, it would be easy to call up. That would be perfect for a database. Which doctor prescribed it, the doctor's phone number and contact information. My pharmacy, its contact information."

"Well, I don't know. As long 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."

"Before you go to the doctor for a planned visit - not an emergency - [you would] review your notes. So you have a ball-park sense, too, for your doctor. Partly, the need for that is, sometimes you get your doctor, sometimes you get a physician's assistant, sometimes you get the stand-in doctor because your doctor ended up calling in sick today. And you want to be able to give them a coherent quick up-date too."

"If I had a question I wanted to answer, [I would use it]. Like if I was trying to figure out how many migraines I've had over the past couple of months compared to last year."

"I think it would be fine. I think [the doctor's office has] the capacity and organizational systems. Software systems exist that could [handle] those records for an individual patient."

"[My health records are] really none of their business. It's between me and my doctor, not me and my insurance company... I don't think that's the appropriate place. They are a business and a doctor is a separate entity. I wouldn't feel comfortable with that."

"But you know, I personally don't think it would take more than a couple of hours per month to keep up the type of information I put into it. To me the bigger challenge would be how much time would physicians be willing to put into that to keep it up."

"I have had a hard drive crash once. I think I would back it up a lot so that I didn't lose [my records]. Otherwise, I would be very comfortable with it."

"I don't think I'd want [my home computer] to be the only place [my records] were stored because computers can break."