Piecing together the PHR

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by Kevin Heubusch

What health information is most useful to consumers? That's a question only consumers can answer, one by one.

The personal health record, or PHR, might lack a common definition, a common data set, a common format, and a short list of sponsors. But it has one thing in abundance, and that's potential.

PHRs have the potential to promote patient-centered care by providing consumers with information and tools to better manage their health and healthcare. They have the potential to deliver a wide variety of personal and general health information through a wide variety of technologies. Perhaps the best indication of their potential is the many opinions on what they are and how they should work.

But for PHRs to have a future, the healthcare industry must learn what consumers want from them-the different types of information that different types of consumers find useful. If PHRs are with us in five or 10 years, they will be flexible tools that offer consumers a range of data and resources that can be used according to need and interest.

Enter Claims Data

The PHR of the future is richly populated with a wealth of data. In the present, the selection is a little more of a grab bag. As envisioned, consumers are a major supplier of their personal information, and they can request their clinical records from their providers. Some physician practices and hospitals offer views into clinical information they hold in electronic systems. The newcomer to the PHR is claims-based data held by payers.

Claims data weren't in the picture when PHRs were first envisioned. But with payers and employers now interested in PHRs, claims-based data could move front and center. If current interest holds, claims-based data could become prevalent in many PHRs.

Not everyone is comfortable with that, because claims-based data aren't created for consumer or provider use. Offering them in PHRs, intended to manage health and healthcare, will take some explaining.

Consumers who receive claims-based data will require explanation of both what the data represent and what they don't, says Michelle Kornfeld, RHIT, a senior business analyst and charge auditor at Sisters of Mercy Health System in St. Louis. Claims data are generated to describe the resources used to treat the patient, she says. They do not necessarily describe the patient's condition.

For example, a claim with a diagnosis code representing a heart attack is submitted to describe the resources used by the hospital to rule out or confirm a heart attack. It does not mean the patient had a heart attack. PHR providers must explain this clearly, Kornfeld notes.

In addition, claims data may describe the same encounter differently depending on the setting, Kornfeld says, because different coding conventions apply to inpatient, outpatient, and professional services. Admission to an inpatient facility for chest pains might result in a claim for treating myocardial infarction. The same visit to an emergency department might result in a claim for treating chest pains.

There is another reason for the unease. Properly coded, claims data are quality data. But the complexity of coding for reimbursement, the variety of settings in which it is done, and the long journey that coded data would travel from provider to payer to consumer offer opportunities for incorrect or misleading information to end up in PHRs.

Short on Details, but Abundant

Claims generally can offer three types of data: services provided and dates, lab tests ordered, and prescriptions filled. They might record an emergency room visit or a prescription filled for blood thinners. However, given their purpose, that's usually as detailed as they get.

If you picture the current explanation of benefits (EOBs) that many payers provide, the information on care received is often very general, says Colleen Goethals, MS, RHIA, an HIM consultant with Midwest Medical Record Association in Schaumburg, IL. "When I get my EOB, it just says 'lab test,'" she notes. It does not provide the results, and it may not specify the test. In fact, x-rays are described as lab tests on Goethal's EOBs, she says.

For a payer's purposes, grouping lab tests and x-rays under diagnostic testing makes sense. For consumers and their providers, the benefit will come from knowing which test was a colonoscopy and which was a chest x-ray. The PHR could offer that additional detail, though the results wouldn't be available.

Prescription information is equally slight on detail. Claims data may list prescriptions that were filled under a drug plan, explains Paul Tang, MD, vice president and chief medical information officer of the Palo Alto Medical Foundation and chairman of the American Medical Informatics Association. "But you won't have access to when the drug is stopped, when the dose is changed, or what the instructions are. You basically only have the fact that this drug was dispensed."

It's basic information, admittedly, but that ability to compile a simple medication history is one of the most immediate, useful benefits that PHRs are offering this year.

Many Pieces to Complete the Picture

Discussions about the types of data that should go into PHRs revolve around expected use, notes Jeff Miller, vice president of health and life sciences at Hewlett-Packard. "Individuals have different expectations over what they want to accomplish, and therefore certain pieces of data are more relevant to them," he says. In the big picture, the PHR is about "getting the right information put together in a way that can be coupled with the right tools" to benefit consumers and the healthcare system.

"Ultimately when we think about PHRs, it's including multiple sources of data," Miller says. "It might include claims data, it might include clinical data as reported by clinicians from an [electronic] or other type of record. It might include self-reported data, where someone is doing home health monitoring and they're reporting that data either manually, or maybe the home health monitoring solution actually automatically updates the PHR with information."

Home monitoring and self-reported data offer some of the most interesting potential for PHRs. PHRs and related technologies allow us to revisit how and where we collect data, Miller notes. "There's a rich source of data right in our own home and our personal lives that for many patients will provide greater insight into their health conditions and their ability to manage those health conditions."

In the case of a hypertensive patient, Miller says, "What would be very useful for a clinician is to not just know that this patient was diagnosed as hypertensive-that maybe they were on a calcium channel blocker-but that their blood pressure and weight had seen the following changes over the past three months. That last piece of data, more likely than not, would be self-reported."

Jon White, MD, is director of the health IT portfolio at the Agency for Healthcare Research and Quality, which funds research on PHRs. He sees an opportunity for patients to use PHRs to communicate their health priorities and worries. "That's not health data as we might generally conceive of it, but it could be very helpful in their care," he says. That is a discussion that doctors often have with a patient, but it does not always result in full communication.

The more flexible the PHR in this regard, the more helpful. Goethals, an HIM professional, created a PHR that reads like a history and physical. "It was a new doctor, and I wanted a complete history of things I felt he really needed to know," she says. "He looked at it and said, 'This is awesome. It answers all my questions.'"

PHR as Conversation Starter?

The limited information that claims data offer is more health history than many patients currently bring to their doctor visits, say supporters, and it's enough to get a conversation started between patient and provider. Basic claims data also can serve as a reminder of dates of services and a foundation for a more comprehensive record.

"I think claims data as a building block is great," says Goethals. "But there is so much information that will never be included. I think that if you realize that, and realize your claims data is only going to be a small percentage of what your true full PHR should be, it's a good start. It'll complement the PHR, but it should not be a substitute for the PHR."

That's a point Goethals hopes employers and payers offering claims-based PHRs make clear to consumers. She hopes they educate users on other pieces of data necessary to complete their health picture.

As a physician, White says he welcomes any information that can shed light on his patient's health. A simple list of prescriptions from claims data tied to a pharmacy benefits manager is a start, he says. "Something as simple as someone walking in with their medicine bottles is helpful for me… Whatever fragments of information I can assemble from anyplace, sure, that's going to be useful." He is quick to add, "Now, it becomes progressively more useful the richer the information…"

Tang sees a "modest benefit" in PHRs that serve as conversation starters. Like many, he is looking for something more out of PHRs. "It might be a stimulant, but it's not the right moment. It's not a teachable moment," he says-a moment when a physician helps a patient make the connection between his or her health information and better health behavior.

"PHRs can be very transformative, a powerful tool in changing behavior," Tang says. This can be through something as simple as test results displayed on a graph. "When people see the results of their behavior-whether it's eating better, exercising, or even taking a pill regularly-then they are more likely to do that behavior," he says. These are moments when patients are most likely to seek information-to click on a link to learn more about improving their blood sugar, for example-and when a physician's advice is more likely to stick.

Data You Can Use

You can talk about consumer-driven care with payers, and you can talk about it with doctors, White says, but only consumers can make it work.

"We talk a lot about value-driven healthcare," he says. "The principle is totally fine. But it assumes an educated consumer." PHR sponsors must be ready to provide support and education in tandem with health data and technology.

The first step in making clinical data meaningful to consumers is to translate it, Tang says. Goethals, too, is an advocate of plain language. Everyone in the hospital may talk in terms of myocardial infarctions and MIs, she says, but consumers talk about heart attacks.

Tang's practice has programmed patient-friendly names for common diagnoses into its PHR. Physician and patient have different views into the same problem list, and each sees it described in language appropriate to them. Common terms such as LDL, or low cholesterol diet, link to definitions in plain language and to selected Web sites that offer additional information.

The same effort will be required in offering useful claims-based data. "I'm a doctor," White comments, "and I have a really hard time understanding a lot of the stuff that comes from my insurance company…"

Claims data will have to be "in English and in layman's terms," agrees Goethals. "You would have to have almost a new group of experts who understand how to decipher claims into meaningful data" for consumers, she says.

In addition, claims-based data will require an explanation of what they do-and do not-represent. Kornfeld suggests a disclaimer: “These are the recent diagnoses that were submitted to your insurance company. Please discuss with your physician. You may or may not have these conditions.”

The missing piece right now is the patient advocate, Kornfeld says. HIM professionals can work with consumers to understand the types of data in their records. For clinical data, she says, they should direct patients to their clinicians, as they have always done.

Different Consumers, Different Needs

For Tang, the PHR’s ultimate goal is providing consumers with “access to all the information about their health and healthcare. That doesn’t say whether it’s going to be in one database or distributed,” he says. What matters is that consumers have their information when they need it.

Figuring out what information that is and how consumers are most likely to use it is key, and not enough work has been done to date, says White. It’s useless to “create a really complete personal health record that no patient ever looks at,” he says.

Part of the work will be learning about the different needs of different users. “We tend to think of the consumer in the singular sense, and I think we need to understand that there are certain segments of the consumer population that have both a different need and a different background in terms of their capability to use information,” Miller says.

For example, people with chronic conditions are more likely to be familiar with raw clinical information such as hemoglobin levels, and they will be better able to relate that information to the state of their health. Providing that same information to other consumers may be more confusing than helpful, at least initially, Miller notes. It is important that the tools and data match individual consumer needs.

Tang’s practice offers patients access to a range of their data, from the administrative and insurance information on file to test results. The practice’s current PHR software cannot display progress notes, but Tang says that in annual surveys to date, patients have not expressed much interest in seeing them.

Otherwise, the practice filters information only as required by California law, which forbids sharing information on HIV, drug abuse, hepatitis, or any tissue samples. In the case of tissue samples, Tang points out, this covers results for common procedures such as pap smears and skin biopsies.

White believes that PHRs should offer the maximum amount of information and let patients decide what is useful. “It’s all information about me,” he says, “why wouldn’t I want to see it?” At the very least, he says, it’s a chance to review provider or payer records and check for errors.

“I think for a long time we’ve really thought of personal health records as mini-electronic health records and that they would contain the same kind of information presented in the same kind of way,” White says. But that may not be what consumers find most helpful. “What keeps me up at night as a doctor worrying about my patients is very different from the things that keep me up at night as a patient worrying about my health,” he says.

“So I think the market needs to consider how people think about their health, and what worries them about their health, and what kinds of things are going to have a benefit to patients in the long-term,” White continues. “And then present that information in ways that they find useful. Is that on a computer screen, on a cell phone, a mailing to their home? I don’t know.

“The big first step is to have people comfortable with having their health information available to them electronically,” White says. “And then things will take off from there. Once people understand the power of that, they’ll want to use it in ways that we don’t know or understand now.”

Living in Interesting Times

In near term, we’ll see simpler health management approaches, helping us better understand and manage our individual health conditions in a very broad sense, predicts Miller. Aetna, for example, is reviewing information in members’ PHRs to identify wellness care that may be missing, such as vaccinations. It's a first step in helping those who are actively involved in managing their health do a better job.

Near-term benefits are important, because the more sophisticated uses of PHRs-such as advanced transfer of data between patient and provider-are farther off in the future, waiting on greater consumer awareness, provider adoption of electronic records, and standards for capturing, securing, sharing, and employing electronic health data.

PHRs-in the sense of consumer access to their digital personal health information-will change next year and each year after that. The term itself could be left behind as technology and use evolve, especially as focus shifts from "record" to access. As the fortune cookie says, White sums up, "May you live in interesting times."

Meanwhile, he is optimistic. "I have faith in the system, that eventually we're going to come out with good tools and good sources of information and good ways of doing this." As part of that process, he says, much will come and go. "I think useful things will rise to the top, and other stuff will blow away in the wind."

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