

PHR Debates: The Personal Record Gets Political, but There Is Danger in Rushing Legislation

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by Dan Rode, MBA, FHFMA

Personal health records (PHRs) are a mainstay of several federal and state legislative efforts, and they factor heavily in some federal regulatory discussions. However, many questions remain about how to proceed. Is the healthcare industry ready for laws and regulations governing PHRs?

While groups including AHIMA have promoted particular PHR characteristics for several years, the industry has yet to agree upon a single model. Meanwhile, more products and services seem to appear each day. Similarly, there is no agreement to date on how PHRs fit into the healthcare process.

However, the political process often does not wait for clarity before passing legislation or promulgating regulations. It is important that the HIM profession work with policy makers to ensure that any proposed laws and regulations truly empower consumers and promote the appropriate flow of clinical information in both electronic health records (EHRs) and health information exchange (HIE).

The Babel of PHRs

There are now more than half a dozen commonly recognized PHR models in use or in development:

- Provider-based “tethered” models, which offer a combination of provider and consumer-entered data, along with functions such as appointment scheduling and record requests
- Health plan models, similarly tethered, which offer claims and secondhand provider data, along with consumer-entered data
- Provider or health plan portals, offering a view of certain provider or plan information
- Employer-based models that offer benefit information and allow consumer-submitted data
- Employer-sponsored models such as Dossia
- Internet models such as those announced by Microsoft and Google
- Health record banks that offer a centralized data bank controlled by the individual
- Consumer-held PHRs in a variety of desktop, flash drive, and other configurations

In many aspects these models overlap. But they differ in several respects:

- The level of consumer control
- The amount of personal information that the consumer can enter and the value of such information
- The amount of EHR data that should be carried by the PHR or accessible electronically by the consumer
- The use of claims data, which is considered limited by the claim requirements and the ICD-9-CM classification codes themselves
- The ability to determine the source of information as well as the credibility and integrity of the data
- The potential for discrimination if personally entered health and family history data are misused by the PHR vendor or operator

An additional discussion is whether a PHR carrying health information from every consumer’s provider and plan could become the vehicle for HIE, rather than HIE entities themselves. Many of these concerns will be resolved over time as the products and the health information environment mature.

The good news is that health providers and plans, employers, policy makers, and the market are sold on the value of PHRs. The bad news is that confusion largely surrounds the nuances of the different models, their impact on the exchange of health

information, and the confidentiality, privacy, and security concerns. Even the term has caused confusion. In this article a PHR is a record controlled by the individual.

Legislation and Reality

Interoperability becomes a key issue if PHRs are to provide or receive health information from a variety of entities. While some policy makers have attempted to legislate this type of exchange, the progress toward actual standards that permit appropriate exchange is only now under way.

The standard development organization Health Level Seven is currently balloting standards that will allow the electronic exchange of data between a PHR and the EHR system functional model standard. Only when data can be standardized will there be true interoperability and usefulness; otherwise the process is essentially one step up from paper and fax.

Standards for data shared between the EHR and the PHR are necessary for a variety of functional reasons. When I approached my primary care practice with my PHR flash drive, for instance, I was kindly told that the office could not upload or download information electronically. Realities like this—the limitations of existing systems, or the lack of any electronic system at all—pose barriers to policy makers who consider mandating PHR use.

Various state governments and Congress have proposed legislation that would require some consumer segments use PHRs by a certain date, but legislation cannot create communication where necessary interoperable technology does not exist.

Reconciling PHRs and EHRs

Often there is confusion surrounding the differences between PHRs and EHRs. In some instances, suggestions have arisen that PHRs might replace EHRs completely. That is unlikely, because healthcare providers require their own record systems for legal, population health, and business purposes beyond the primary use for patient care and treatment.

Could there be a day when a PHR might capture all data obtained electronically from an individual's various providers? Yes, this is possible. Will the PHR then become "the" health record? Probably not, if the record is meant to be accessed and used unilaterally, without hesitation, by another healthcare provider. Providers will want to know the data's origin and whether the integrity of the information has been maintained.

Data integrity becomes a fundamental issue in the integration of PHR information with other health records. It is important to know the origin and subsequent reliability of the data.

It has been suggested by some, including policy makers, that a PHR or record bank should become the sole record. Today's slow progress in developing and implementing standard electronic health records suggests that if PHRs were to ever completely replace the provider record, it will be a long time from now.

Ensuring Privacy and Security

Privacy and security are also important PHR elements, especially for any model where information is maintained by a custodian or an operator, such as an Internet provider or a health record bank. Most PHRs offered by providers or health plans today are tethered to the custodian's HIPAA-covered records.

If the provider or plan is a covered entity under HIPAA and if the PHR contains data solely from the provider or plan record system, then the PHR is covered under HIPAA. But does the rule apply to data entered by the patient? Do HIPAA's treatment, payment, and operations requirements apply? Many within the industry say no and call for additional privacy notification and agreements between the provider or plan and the individual.

A variety of PHR vendors are not covered by HIPAA. The American Health Information Community work group on confidentiality, privacy, and security has suggested that, at a minimum, PHR vendors or operators be required to meet appropriate HIPAA standards. None of these suggestions has been entertained at the federal level to date.

Some argue that HIPAA is inadequate when it comes to PHRs. Internet providers note that they are covered by Federal Trade Commission rules that would apply if the provider did not abide by its posted privacy notice. However, the Federal Trade

Commission rules do not dictate what must be covered in a PHR privacy notice.

Meanwhile, some state legislators are considering addressing these privacy concerns through state laws and regulations. If they are not careful, existing conflicts and confusion between federal and state requirements could increase.

Furthermore, states that move too fast could enact laws or regulations that do not fit all PHR models. While some PHR vendors have tried to have their specific model be the subject of approved state efforts, many in the industry are calling for caution until standards are in place. Earlier this year the American Health Information Community recommended that the Certification Commission for Healthcare Information Technology consider security standards for any PHR product that it might certify. CCHIT does not currently certify PHRs.

Call to PHR Action

HIM professionals need to get involved to ensure that any legislation or regulations in their state be done with complete knowledge of the current state of PHRs and how the PHR will interact with the EHR.

PHRs are a positive tool to improve the health of individual consumers and, over time, the health of the entire community. The industry must work in concert to ensure that individuals have PHRs that capture data correctly, maintain data reliability, and interact with other systems when needed.

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