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Getting Familiar with Patients' Personal Health Records Avoiding Potential Liability Landmines

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As much as we have heard about electronic medical records (EMR) in the news this year, so have we heard about personal health records (PHR). A lot of this has to do with the splashy entrances into this space by no less than Google and Microsoft. Both these information technology behemoths are betting a lot on the assumption that patients will want to create and maintain their own medical records in readily accessible, yet highly secure, confidential electronic environments.

This past June, Microsoft, Google and dozens of organizations promoting consumer adoption of electronic PHRs agreed for the first time on a comprehensive set of privacy protections. An 18-month effort by health insurers, Web portals, doctors, hospitals and nonprofit groups produced a framework that will spur growth in the use of PHRs. The negotiations were orchestrated by the Markle Foundation, a New York-based nonprofit group that focuses on uses for information technology (*Goldstein, A.; Microsoft; Google; Consumers Endorse Health Privacy Standards.* http://www.bloomberg.com/apps/news?pid=20670001&refer=home&sid=a38 Kq3O.d86k).

The federal government has also begun to recognize the value of PHRs. The Medicare Program recently started a year-long pilot project in South Carolina testing online PHRs as a way to enable beneficiaries to get more involved in their care and better manage their (often chronic) conditions. Patients control their records and decide who has access to them—from doctors to family members. Users need an ID and password. Physicians can add information to the PHR, but patients can remove it. Patients may add information not found on Medicare claims. This may include notes, advance directives, out-of-pocket expenses and prescription drug information.

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The records will be helpful to doctors when patients seek medical care out of state and can't remember what procedures they received, according to Gerald E. Harmon, M.D., Immediate Past President of the South Carolina Medical Association. Because the records are on the internet, physicians will be able to access a patient's medical data from multiple locations - Hansen, D., Medicare Launches Personal Health Records for South Carolina Residents. <u>http://www.ama-assn.org/amednews/2008/07/21/gvsd0721.htm</u>

The Health Information Management Systems Society (HIMSS) strongly supports the widespread adoption of electronic personal health records (ePHRs). HIMSS envisions ePHRs that are universally accessible and layperson comprehensible, and that may be used as a lifelong tool for managing relevant health information that is owned, managed and shared by the individual or his or her legal proxy(s) (*HIMSS Personal Health Records Definition and Position Statement*.

http://www.himss.org/content/files/PHRDefinition071707.pdf).

Despite the obvious benefits of PHRs, they could raise some liability issues which need to be addressed, avoided or otherwise managed. Some of

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these are discussed below.

Integrating the patient's EMR (or paper-based record) and the PHR

According to the *HIMSS Personal Health Records Definition and Position Statement* cited above, the current forms of ePHRs in the market involve three basic models:

- Software utilized by individuals to enter and maintain their personal health information
- Web sites that are maintained by third parties (like Google or Microsoft) which allow patients to enter and access their information
- Web sites that allow patients to view information from other applications such as an institutional EMR, or from an application that maintains the individual's health insurance claims data.

The last of these models is referred to as a *tethered/connected ePHR*. In an *un-tethered/disconnected ePHR* model, only the patient, or individuals that have been granted access by the patient, has/have the ability to enter personal health information (PHI) into the ePHR.

Currently, these models do not support *interoperability*, allowing patients to freely transfer their self-entered PHI from an un-tethered to a tethered PHR. Consequently, a patient (or his designated family member or legal proxy) could add (or, as pointed out above, even change or omit) information within the PHR without the physician's knowledge.

This could result in a potentially dangerous situation; especially if the patient failed to grant physician-access to the PHR, which could have shown that the patient was taking medications or had other treatments or medical problems which could make particular courses of action quite risky. This might not even be limited to those situations where the PHR contained information about medications or other treatments obtained from other physicians. It could also relate to nonprescription agents or even so-called nutritional aids or herbal treatments which could either nullify or dangerously potentiate the effects of certain prescribed medications and other treatments.

As a regular part of questioning a patient or family members, physicians (and other caregivers in the physician's office) should inquire whether each patient might have PHRs and if they could gain access to them (as a trusted personal physician). Whether a physician has EMRs, or paper-based records, it is important to ensure that all information in the patient's PHR is also in the EMR, and vice versa.

Determining the accuracy of information entered into a patient's PHR

Even after physicians gain access to their patients' PHRs, that may not be enough to avoid potentially dangerous situations. Either they (or a nurse manager) need to check the accuracy of information entered into each patient's PHR. Without interoperability to access electronically all of a patient's other medical encounters (including treatments provided), this may be the next best way of ensuring safe and effective care. In fact, if complete, a patient's PHR should include not only information from these other clinical encounters, but also that from self care.

Being able to review a patient's PHR provides a great opportunity to get a much broader (and ultimately more accurate) clinical picture. Whether the physician (or a nurse manager) does this, reviewing the patient's PHR prompts a dialogue with patients about all of their medical problems and

treatments which could be impacted by currently proposed therapy.

Patients having PHRs could be viewed as yet another "can of worms" that shouldn't be opened. However, those (still relatively few) patients which have gone to the trouble of creating and maintaining PHRs are patients who are the most proactive about keeping track of their health. It is this type of patient who will be setting the standard for the new type of partnership between physicians and their patients in the near future—a much more coequal arrangement.

Physicians and their staff need to engage these patients on this basis. Both their clinical results and overall satisfaction with their care will improve commensurately. It is these two factors which are most determinative of whether such a patient may ever consider legal redress for a less-than-optimal outcome. Treating patients as equals and working with them to ensure that their PHRs are complete and accurate will go a long way toward minimizing the chances of litigation.

Dealing with information overload

Many physicians may view the rise of patients' PHRs as yet one more example of information overload impeding their ability to maintain an effective medical practice.

> Like a recurring dream about having to take a test they didn't study for, some physicians view the idea of patients with electronic PHRs as their own personal nightmare. Visions of patients handing over a computer disk containing years of blood pressure readings taken every four hours along with random recollections of rashes and muscle strains that physicians are required to somehow make sense of and memorize are followed by thoughts of being sued because there was a kernel of important information missed in the deluge.

- Zaroukian, M., Getting personal: legal liability, patient data overload among issues making physicians uneasy over the emergence of personal health records. http://goliath.ecnext.com/coms2/gi 0199-6573898/Gettingpersonal-Legal-liability-patient.html#abstract.

In the near future, the amount and type of data which patients put into their PHRs may be beyond their physicians' immediate control. Every patient approaches their health and potential health problems differently. Some are like the diligent (although rather compulsive) student who notes everything the professor says in class and then also outlines each chapter. Then there is the student who (when he shows up for class and stays awake) only takes few, if any, notes during classes, who may or may not read (or even purchase) the books and yet somehow aces all his courses.

Patients are much the same way when it comes to documenting things about their health, their medical problems, their treatments and their responses to them over time. Like EMRs, many of the PHRs (whether from Google, Microsoft, different health insurers and other sources) provide templates (or checklists) to assist patients (and their families) in compiling complete and accurate PHRs.

Those PHRs that permit "rolled up" or summarized versions (complete with handy graphics and other illustrations) of patients' conditions and their



progress over time can be very helpful to physicians. Others, however, may permit a tremendous amount of non-standardized free text and other inputs from patients and their families, which can make them quite difficult to decipher and overwhelming in their detail.

Whether or not the medical standard of care in treating patients with PHRs is somehow higher cannot be concluded at this time. However, as PHRs become more prevalent, it is a safe bet that they will become a factor in cases in which they could have been accessed by physicians to have prevented an adverse event.

Consequently, like so much else in modern medical practice and risk management, to be forewarned is to be forearmed. Physicians need to be aware of PHRs and have someone in their offices access (assuming patient permission), review, and, ideally, summarize and present them in a comprehensible form to their physicians (without omitting vital information which could impact current treatment options and outcomes).

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