

## Maintaining Personal Health Records on the Internet

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Increased mobility of patients, managed care organizations' changes in preferred providers, and use of a plethora of specialists result in an often-inaccessible, fragmented medical record of little use to the patient or physician. Also, emergency room physicians could benefit from access to the medical records of unconscious patients they have never seen. At present, they may have to rely on a low-tech bracelet to advise them of a patient's allergic reaction to a class of drugs.<sup>1</sup>

An ideal medical record would be Internet-based, but only available to physicians upon consent of the patient or in a *bona fide* emergency. The record could be electronically segregated into sections allowing various health care providers and others access on a "need to know" basis. Especially sensitive information such as HIV status and mental health information could be off limits to a pharmacist, who might only need to know the basics of a patient's health status together with a record of all current prescriptions for the patient. The patient should have full "read-only" access to the official record, and only licensed health care providers should be able to enter information in the record, to ensure the accuracy of the record. The record could however contain a patient section allowing the patient to enter self-recorded weight and blood pressure, frequency and severity of headaches, and other similar information. Such information could even be entered electronically via biometrics devices.

Although such comprehensive on-line medical records are not widely available, a number of web sites offer storage and Internet access for a Personal Health Record (PHR). They typically promote such storage for a variety of reasons. In an emergency, an attending physician can have access to critical information such as drugs being taken, allergic reactions to drugs, conditions such as heart problems or diabetes, and other important medical information. Such information can arguably be available even when the patient is too ill to communicate the history to emergency staff. Storing children's immunization records makes them accessible even if a parent changes jobs, insurers or physicians. Advance directive storage available at some sites allows individuals to ensure that physicians and other family members know such individuals' wishes in the event of an accident or serious illness.

Most sites at present rely on patient input of medical information, and some health care providers may be reluctant to rely on the accuracy and completeness of such records. Such records are likely to be better than a short oral medical history, but less comprehensive than medical records created and maintained by medical professionals.

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<sup>1</sup> Portions of this article were originally published in Ronald L. Scott, *Should You Place Your Medical Records on the Internet* (posted Sept. 24, 1999), available at <http://www.law.uh.edu/healthlaw/perspectives/Internet/991124Should.html> and Ronald L. Scott, *Cybermedicine and Virtual Pharmacies*, 103 W. VA. L. REV. 407, 431-33 (2001).

Ideally, a PHR also could incorporate electronic medical records (EMRs) maintained by physicians. One working group defined PHRs as follows:

The . . . PHR is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies.<sup>2</sup>

PHRs are different from EMRs, which often contain “a health history, doctors’ notes and laboratory and radiology results and are generally owned by and limited to the information collected by one doctor or hospital.”<sup>3</sup> PHRs often contain only information provided by the patient, while EMRs “rarely contain information provided by the patient.”<sup>4</sup> A majority of people are interested in PHRs, but most interest has been shown by “the chronically ill, frequent users of health care and people caring for elderly parents . . .”<sup>5</sup>

What happens if the web site maintaining the PHR goes out of business? A purely commercial web site without a business relationship to a health care provider or insurer is unlikely to be subject to the federal privacy and security standards required by the Health Insurance Portability and Accountability Act (HIPAA) and may not be subject to *any* laws relating to the privacy and security of the records it maintains. Even if records are not misused, a patient could find it most inconvenient for her records to simply “disappear” when a web site shuts down. In a 1999 article,<sup>6</sup> I included the link to a commercial web site that offered to maintain medical records on the Internet. Clicking on that link today ([www.4healthylife.com](http://www.4healthylife.com)) will redirect the user to weight control advertisements. This is not an isolated incident. A 2001 study compared various sites offering storage of PHRs.<sup>7</sup> A Majority of these sites either no longer exist or have morphed from free to pay sites.

A recently launched service sponsored in part by the American Medical Association may be the best current alternative for many patients wishing to store PHRs on the web. The service (iHealthRecord) is offered by Medem and is available at [www.medem.com](http://www.medem.com). About 90,000 physicians utilize some of Medem’s services such as secure email and physician web sites.<sup>8</sup> The iHealthRecord service allows for storage of PHRs, and provides patients customized medical information related to any conditions

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<sup>2</sup> The Personal Health Working Group, *Connecting For Health*, Final Report 3 (July 1, 2003), available at [http://www.connectingforhealth.org/resources/final\\_phwg\\_report1.pdf](http://www.connectingforhealth.org/resources/final_phwg_report1.pdf).

<sup>3</sup> *Id.* at 4.

<sup>4</sup> *Id.*

<sup>5</sup> *Id.* at 5.

<sup>6</sup> *Should You Place Your Medical Records on the Internet*, *supra* note 1.

<sup>7</sup> See [http://www.informatics-review.com/thoughts/PHR\\_Site\\_Comparison.htm](http://www.informatics-review.com/thoughts/PHR_Site_Comparison.htm).

<sup>8</sup> See Sarah Rubenstein, *Medical Records Come to the Web*, WALL ST. J., May 15, 2005, available at <http://www.indystar.com/apps/pbcs.dll/article?AID=/20050515/BUSINESS/505150355>.

they may have.<sup>9</sup> A search of the Medem site allows users to determine whether their physicians subscribe to Medem. Hopefully, the service will eventually allow physicians to add their EMRs to the patient's PHR.

Regulatory, security, and privacy concerns present serious barriers to maintenance of Internet-based medical records, but if these concerns can be adequately addressed, the benefits to patients could be enormous.<sup>10</sup>

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<sup>9</sup> *Id.*

<sup>10</sup> See generally Barbara J. Williams, *Virtual Web Wave of the Future: Integration of Healthcare Systems on the Internet*, 76 N. D. L. REV. 365, 372-75 (2000).