

The Story on Security: Stay Tuned for Details...

Jeffrey C. Bauer, PhD

Security of health-related information brings to mind the first news report of an everyday event such as another automobile accident or telecom bankruptcy. The announcer intones a provocative headline enticing us to tune in later for the full story, but the teaser tells us all we care to know. We can guess the rest of the story; it is more of the same. For example, “New HIPAA regulations announced in Washington” would not generate enough uncertainty or excitement to make us rush home for the five o’clock news.

But every so often, a story does not turn out as expected. As much as we might think we could write the script for the next report on health data security, events are likely to evolve in some unexpected directions. Security in general and HIPAA in particular are ongoing stories positioned for strange twists.

One variable in the future evolution of these stories is different meanings of security. To IT professionals, security means activities like backing up data and being prepared for disasters, preventing records from falling into unauthorized hands, encrypting information so that it is unreadable to individuals who do not have need or approval to view it, and verifying the identity of anyone who attempts to enter the network. The news in the trade press is largely generated by technological changes — new hardware and software that help a provider stay one step ahead of the hackers while improving the efficiency and safety of operations.

Consumers, politicians, and news reporters focus on a different dimension of security. They want their health information to flow where it needs to go, speeding care and simplifying payment. They just don’t

want anyone outside the system to get data from their medical records. Stories in the popular media tend to be anecdotes of unfortunate individuals who lost a job or could not get insurance or a loan due to a leak of information. News about teenagers breaking into providers’ data banks also draws attention.

Unexpected developments in future news about the security of health information will result from convergence of two factors that are not yet widely publicized: the growing anachronisms of HIPAA and the emerging expectations of consumers. As Paul Harvey would say, we need to understand “the rest of the story.” IT professionals could figure prominently in development of the big picture.

The full story begins with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a bad law passed with good intentions. Ironically, HIPAA might have a desirable impact in much the same way that an incompetent doctor could help a patient by accidentally prescribing the right medicine. Like a physician who has not kept up with the latest medical knowledge, HIPAA is based on an outdated (i.e., mid-1990s) concept of information technology — one that implicitly mistrusted the electronic transfer of data because computer networks were in their infancy.

Data exchange today is built on platforms that were unimaginable to politicians and bureaucrats in 1996. Consequently, the evolution of HIPAA is shaped by conflict between the technologically obsolete letter of the law and the subsequently established reality of secure network computing. HIPAA applies the rules of the paper trail to the information superhighway, diverting IT resources from the excit-

ing challenge of solving problems with new technologies to the mundane task of complying with an archaic law.

The situation will change, most likely for the better, when health system leaders finally mobilize political power to repeal HIPAA — an unfunded mandate — because they have compelling evidence that the law causes more problems than it solves. Depending on the evolution of enforcement policy, steep fines and jail time for some unwitting health system executives may also accelerate a revolt. Watch for the story sometime between 2005 and 2007.

Consumers might cause this news item to appear sooner rather than later. HIPAA was based on a political belief that Americans were uniformly opposed to any identifiable release of their health information. The law was passed with little or no consideration of its negative impact on medical research (a process becoming dependent on network computing), disease management, patient-practitioner communications, prompt payment incentives, and other important activities of health care. HIPAA’s restrictions on the transmission of patient-identifiable data have started to cause problems in all these areas.

However, genetic screening is the force most likely to rally the public against HIPAA. Genomics was expected to revolutionize treatment of disease, but following recent news about serious problems associated with therapeutic manipulation of genetic material, its more immediate promise now lies in diagnostics. DNA microarrays and new applications of MRI, CT, and PET will soon be able to identify an individual’s susceptibility to many serious conditions. This emerging field of medicine already has a name,

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predictive molecular pathology. Consumers who learn they are susceptible to a specific disease will want to be identified, for example, by pharmaceutical companies that are researching or marketing responsive drugs. HIPAA will be a Catch-22 (the senseless bureaucratic impediment to workable solutions, for readers too young to know Joseph Heller's remarkable novel by the same name).

We will learn over the next few years that data cannot be kept private with certainty. Much information about each of us will be publicly accessible, directly or indirectly, in spite of our best efforts to keep it secret. Ironically, the post-September 11 push for national security will be a major cause of problems with data security. We will soon recognize the futility of trying to hide our medical information in

order to protect our insurability, our employment, and our credit worthiness. Congress will decide by the end of this decade that anti-discrimination laws are the only way to prevent abuses of health data — further exposing the long-term irrelevance of HIPAA.

This futuristic outlook probably disturbs many IT professionals who are working hard to implement HIPAA. If HIPAA is doomed, why bother? The answers are straightforward. First, HIPAA is the law for at least the next few years, and few of us have the time for civil disobedience and its consequences. Second, most HIPAA implementation strategies are the right thing to do, even if done for the wrong reasons. Third, visionary IT leaders are in the best position to educate other health professionals

and the public about the superior benefits of 21st century information technology, a point lost in the rush to comply with the law. HIPAA is so 20th century.

A little activism could go a long way. Imagine this future headline: "Information technology experts are taking over the revolution to create higher-quality, less expensive health care. Stay tuned for details at five." Why not make that 2005? It looks possible in my crystal ball.

About the Author

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