

Thinking Out Loud... Reaping What We Sow

*“Man is the architect of his own destiny.
I designed mine and I have lived it.”*

—Albina Cruces Vasquez, 101 years old, *Teacher of the Century*¹

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A nagging thought plagues me lately regarding unintended consequences, the *what if* after all these years of working to leverage technology on behalf of patient care the vision comes true, but the reality that surrounds it shrouds the benefits. What if the destiny we thought we were designing was one that supported the tyranny of information instead of the confidential and private transfer of information for the good of the patient community?

One would think that a momentous event stirred this kind of thought. None did. It was only the late delivery of our newspaper on a Sunday morning that brought it to the fore. Picture this: My husband and I, just up from our sleep, were ready to slide into our morning routine—reading the newspaper and enjoying a leisurely cup of coffee while we debated what we read. The only thing missing this time was our newspaper. As small as a missing newspaper early in the morning might seem, it was at the time a sorely missed luxury, and for me the origin of a thought that had been pushed into the backwaters of my mind since 1996 when a col-

league and I attended the international *TEPR* (Toward an Electronic Patient Record) Conference. In a minute you will learn what happened at this conference.

Back to the missing newspaper... The only recourse was to take my cup of coffee, go online, and read about the world's happenings in electronic format. The home page where I landed listed the day's news in chronological order, enumerating each day by the hour. Integrated within each event were links to outside sources such as the newspaper of the country related to the news event. These linkages peeled away geographical and intellectual barriers.

I roamed the e-Health in Developing Countries Conference 2004, and then moved to the Health and Human Services news release in which Secretary Thompson announced two things: first, the appointment of David Brailer, MD, as the National Health Information Technology Coordinator, and second, several new accomplishments in international standards development. The next site on my itinerary was the Medical Informatics Weblog, which considered the European

Commission's e-Health action plan.

My curiosity was alive and well, running freely over these Web pages as would my appetite over a menu at a favorite restaurant after a two-day fast. The style of each page's content fed my curiosity and sustained my enthusiasm at peak pitch even more than before because it allowed me to speed-read with ease, so that almost two hours slid by unnoticed... bringing us full round to the 1996 *TEPR* Conference.

For Better, or For Worse?

One of the reasons for attending the *TEPR* eight years ago was to learn more about how and why the medical informatics movement began in The Netherlands, where it first took root. My intention was to attend a session that two of the Dutch leaders were scheduled to conduct, and there to discuss these questions with them. Waiting for everyone to leave after this session, I introduced myself to them and relayed my purpose. They listened with full attention and openly discussed their views, more than adequately answering my many questions. We wanted to continue our discussion and agreed that we would have

lunch together. It was here that I met their friends from Germany.

Over lunch we discussed the impact a computerized patient record would have on society, both for the better and for the worse... the better being improved patient care, and the worse, private records unintentionally accessible to the public. The *worse* scenario, the scenario in which patients lose their privacy in the quest for improved care, at a minimum suggests that we use prudence as we deploy a technology that could outstrip our ability to control its tentacles. Their German friends suggested that only medical data cards, on which personal medical data are stored, would suffice because this is the only medium over which the patient has complete control.

Why are we concerned about the privacy of patient information when countries are beginning to take the necessary steps to protect it? Let's take the case of the U.S.A. Here, the 1996 Health Insurance Portability and Accountability Act (HIPAA) provides the guidelines to protect an individual's personal health information and requires healthcare providers to adhere to its provisions. Nevertheless, unless we close a loophole in the Fair and Accurate Credit Transaction of 2003 (still open for public comment as of this article's writing), banks may not be subject to the privacy guidelines of HIPAA. This is because banks are not a claims clearinghouse, only a deliverer of insurance payments, and are therefore not subject to the provisions of the HIPAA guidelines despite the fact that they may have access to personal medical information when they process the ex-

planation of medical payments to providers.² This is one example of one statute at an unintended cross-purpose with another statute. While this example is country-specific, its applicability is probably generic and hence an area of concern.

Vigilance

As a result, the question about the privacy of patient health information morphs into one about whether we can be vigilant enough as a global society to monitor what is so very easy to do, that is, transfer electronic information seamlessly across state and national boundaries (as I did when I roamed the corridors of the Internet when there was no newspaper on a Sunday morning). The difference is that others may read information about *us* when we wish to keep that information to ourselves.

Is the prudent risk worth the advantage? I believe it is, as long as we adopt the position that prudent risk requires active oversight. For those who use information in the normal course of business, information assumes the dual role of a right and a responsibility—the right to use it and the responsibility to be accountable for its use. Therefore, when my company states that it is our intention to continue to weave advanced technology into the TIME™ Clinical and Financial System, we also mean that we intend to continue to unobtrusively embed within its workflow processes the right security and privacy protections as new technology becomes available. To do otherwise would militate against our long-held conviction that “The practice of medicine is the practice of information.”

Think!

The saga of patient privacy is still being written by good people who are similar to Albina Cruces Vasquez, mentioned in this article's dedication. Born in March 1903, Albina survived the 1917–1920 Mexican Revolution and eventually wrote a chapter in the annals of education. She took up teaching when she was just 15 years old. With only her will to direct her actions, she founded a school in an old seed house in 1947, later building a new schoolhouse the same year by soliciting donations in the market, asking students to bring in a brick each day. Three years later, the President of Mexico personally inaugurated the school she had built. Asked about her core beliefs, she said, “I never scold them. I never hit them. I always ask them to *think*,” adding that, “Children respond when you talk to them, when you keep your promises, and when you respect them as human beings.”

Were we to change only a few words of Albina's quote, we will have addressed the responsible use of information in our new century, namely, “People respond to the responsible use of information especially when it is theirs, when you keep your promises, and when you respect their rights as human beings.” Let's think about the destiny we build today and ensure that it is the one we wish to live tomorrow.

References

1. “Teacher of the Century,” *Richmond Times Dispatch*, April 10, 2004, p A4.
2. “Proposal Clarifies Lenders' Use of Medical Data,” by Sara Schaefer Munoz. *Wall Street Journal*, April 29, 2004, p D2. **D&T**