The Future of the Personal Health Record

If we allow ourselves to envision and dream of a better health care system, one that permits us to feel connected, supported, and in control of our own and our families destiny's, two words come to mind – information and planning. These two words in turn logically demand a place for information to reside and a structure or application that would allow an individual and family to plan ahead, monitor success, and catalogue learning's and adjustments – a "record" if you will. In turn, the "record" is a critical enabler of health system reform. Don Detmer, President of the American Medical Informatics Association, said it best in his 2006 Congressional testimony; "Significant improvements in healthcare safety and quality will not be achieved for Americans without robust, secure electronic health records within a national health information infrastructure."

In September 2006, an expert panel with leaders in the field from the US and the UK was convened by The American Medical Informatics Association, Kaiser-Permanente, The Robert Wood Johnson Foundation and the Agency for Health Care Research and Quality. The briefing materials provided in preparation for the meetings included landmark papers over the past decade. In a number of locations, the principles outlined by the Institute of Medicine in “Crossing The Quality Chasm”, were reviewed and endorsed. These include “providing safe, effective, patient-centered, timely, efficient and equitable health care.”

Much of the time devoted to this effort involved deliberations around whether we collectively were sufficiently ahead of the curve. Stated another way, were we planning for the present (which is already, in part, the past), or for the future (which may be just around the corner), or for the distant future (which, if converging trends were to reach a tipping point, might only be five to ten years away)? And could “The Record,” which organized information, allowed for structured home-based planning, and embraced health as the leading edge of development, the holistic pursuit of one’s full human potential, could that record actually be the “tipping point” for a truly preventive health care system?

To adequately address those questions, let’s stop for a moment here to look around. Aging is rapidly converting us from three to four and five generation families with exponential leaps in health management complexity. The health consumer movement has moved from emancipation to empowerment and now to engagement with leading edge consumers demanding fundamental health system reform including the re-centering of the health care system around the multigenerational family, its needs and priorities. And finally, information technology advances allow us to consider a vast array of new horizontal and vertical linkages, robust bi-directional data feeds and simultaneous virtual education, joint decision making and lifespan planning in a healthy coordinate manner directed jointly by the people and people caring for the people.

As these trends intersect with each other, they point us toward several issues that were yesterday’s possibilities, but are tomorrow’s near realities. All relate to the issue of “The Record”.

First, what is it? Dr. Paul Tang and colleagues defined leading edge thinking on “The Record” in a publication in 2006. Here’s what they said. “Personal health record systems are more than just static repositories for patient data; they combine data, knowledge and software tools, which help patients to become active participants in their own care. When Personal Health Records (PHR’s) are integrated with electronic record systems, they provide greater benefits than would stand alone systems for consumers.” This comment captures an evolution in thinking over the past decade. Original discussions of this topic focused on electronics medical records or EMR’s, and
aspired to create greater safety, accuracy and efficiency by converting the paper based systems for data gathering and charting of doctors, nurses and hospitals’ notes to electronic formats. But as leaders diligently worked to gather financial assets and political support for the conversion, the organizing foundations of health care, weakened by successive waves of health consumerism, globalization, societal aging, and Internet broad band penetration, began to shift under foot. In fact, by 2005 it had become quite clear that “The Record” properly resided with the patient from whom health data emerged, and that the segment of data that flowed through the hands of hospitals, doctors and nurses was only a part of “The Record”. Thus the concept of a Personal Health Record gradually subsumed the vision of an Electronic Medical Record, forcing leaders in the field to rethink their basic suppositions including focus of control, span of influence, and data sources. 

Just as leaders in the field are recovering from the first wave of change, a second wave is squarely at their backs. This wave involves one word in the term Personal Health Record and that is “health”. It is now clear that in a truly preventive system, health is not the health system, nor a collection of disintegrated, late-stage reactive interventions; nor is health our deeply siloed elite training institutions or formidable hospital complexes. Rather, health is a life fully lived – hopeful, productive, fulfilling, rewarding and manageable. The determinants of such a life begin before birth, embedded in the healthful behaviors of ones’ future parents, and extend beyond death to ones’ survivors and their needs for bereavement support and recovery.

Considering this broader view of health, what would be the scope of “The Record” and what might reside on it? The Lifespan Planning Record (LPR) for a single individual born today must extend out at least 100 years. An effective approach would need to consider economic, social, educational, and spiritual goals and milestones as well as medical and scientific objectives. Born today, the newborn child’s plan would already be inhabited with a great deal of data. The records of parents, grandparents and siblings would be represented. Required future diagnostic and preventive therapeutic measures would be flagged on the timeline. And the most useful and accessible intelligence databases would be seamlessly interwoven for easy use by the people caring for each other and this new global citizen. That is just today. For each successive tomorrow this “living record” would flexibly grow as knowledge grew and adjust to assist informed decision making, preventive behavior and full and complete human development.

Where will the knowledge come from? On the health and science side, it will emerge from three electronic databases: the Clinical Research Database, the Continuing Professional Development (CPD) database, and the Continuing Consumer Education (CCE) database. These databases will desegregate and converge to allow discovery to become practice, and practice to assure early diagnosis and treatment plan adherence without translation delays. But beyond this, the sources of information and contributors to the “health space” will exponentially expand. West Coast Health? Add Google, Intel and Microsoft to Stanford. East Coast Health? Add Time-Warner, GE and Citicorp to Harvard.

The bottom line is that just as the Electronic Medical Record (EMR) has been subsumed by the Personal Health Record (PHR), the Personal Health Record is now being subsumed by the Lifespan Planning Record (LPR). This means that the LPR is tomorrow’s “killer application” and the EMR and PHR are, as we speak, rapidly becoming “chips” within it.

For Health Politics, I’m Mike Magee.

References
2. Testimony of Don E. Detmer, MD, MA, President and Chief Executive Officer, American Medical Informatics Association. “Getting to a ‘Smarter’ Health Information System: Legislative Proposals to Promote the Adoption of Electronic Health Records (EHRs), Before the Committee on Energy and Commerce, Subcommittee on Health. March 16, 2006.