

## The Promise and Progress of Health Information Technology in America

I was asked to talk today about what it was like to serve on the federal Commission for Systemic Interoperability (CSI) and also provide some perspective on HIT, how it feels right now in the market, and a perspective on progress and barriers. Your timing couldn't be better. Yesterday, October 25th was the one-year anniversary of the release of our report, *Ending the Document Game*.

So where are we in HIT?

Technology consulting firm Gartner would call what has happened in the last couple of years "the hype cycle" and they use it to describe the course of new technology triggers. And it is fairly predictable.

There is a technology trigger, in this instance the internet...enthusiasm builds for a big idea/transformation visions emerge, then a flurry of publicized activity, story after story in the press, expert predictions, new publications dedicated to the area, and a frenzy of conferences all with notable speakers. The onslaught of activity builds to a peak of inflated expectations and wonderment about what can happen, how it will be applied. A leader emerges, a visionary, who carries the word to one and all. He/she is the keynote at every important conference. A religion is borne.

And then reality strikes. Gartner calls it the trough of disillusionment. There are visible technology and implementation failures both in terms of execution as well as cost. No one makes money. The press coverage shifts, conferences diminish, and some publications cease to exist. The leader retreats, frequently becomes reflective or sometimes disenfranchised.

Some people push on despite the disillusionment. Focused experimentation and solid hard work frequently done on differing fronts by multiple organizations lead to how to apply the technology, risks and benefits are recognized, and ultimately that leads to off the shelf methods and tools.

Finally the real world benefits are accepted. Second and third generation models emerge. How well it goes depends on the size of the market and the magnitude of the benefits.

So does that describe the path of health IT over the last few years? Parts of it sound very familiar although the later chapter is yet to be written.

But before I go any further let me go back to the beginning. My life and lessons as a member of the Commission on Systemic Interoperability.

The CSI was established into statute as part of the Medicare Modernization Act of 2003. The enabling legislation was passed before ONCHIT was established, before David Brailer was even hired. The Internet had emerged as that technology trigger and a few important senators, including Frist and Clinton, saw the potential and a need to establish a road map for Health IT. The legislation charged the Commission with developing that roadmap and a report had to be delivered to the Congress no later than October 25, 2005. A full two years was envisioned as the timeframe for the work to be done.

You learn some things when you enter into the political arena and one lesson is the interesting interplay between the legislative and executive branches, some might suggest a power struggle, but regardless negotiations take place over appointments, process, and of course ultimate authority to act. Happens at the state level, no difference at the federal level.

The net result of the jockeying was our Commission wasn't named until very late 2004, a full year after the act was passed. By that time ONCHIT was established, David Brailer was hired, ARQH was rolling out grants to RHIOs, and we were clearly headed to the peak of that hype cycle. Expectations for our group were high but it also felt like we were in front of a freight train going at full speed.

Scott Wallace, our Chairman acted quickly, our first meeting was January 9<sup>th</sup> of 2005, less than a month after we were officially named --but already 13 months after the bill was passed.

His expediency was met with the full force of the federal government. Details were important so we set about filling out mounds of paper including conflict of Interest statements during our Christmas Holiday. Officially we were employees of the National Institute of Health so all their conflict of interest standards applied to the members of the commission. This just happened to be during the time they had come under public scrutiny for failure to apply them to scientific investigators.

My recollection is everyone named to the Commission had a material conflict so a waiver was required for each and every one of us to serve. It was our first moment of solidarity as a Commission...we showed up for that first meeting early that morning, were told of our conflicts, and no one was willing to give up their day jobs (and pay) for this assignment lasting nine months and paying \$250 per meeting.

It's important to have someone who understands how to get things done. Thanks to Don Lindstrom, our NIH sponsor, the waivers were delivered that afternoon and we were able to convene our first session. The good news was we had bonded as a group, something that would serve us well in the coming months.

Our next wake up call was that we really had less than a year to do what was envisioned as two years of work. We would need to allow six weeks of publication time required by the Government printing office. We now only had nine months to and I quote “develop a comprehensive strategy including priorities and timelines for adoption and implementation of a privacy protected system of electronic personal health information developed around consumers to facilitate wellness and safe delivery optimal healthcare.”

You also had a group of people, we numbered 11, coming at this from very different perspectives, representing medicine, insurance, technology, government, and the private sector. We were fortunate. High quality people, many members had focused on health IT as a career and a cause, but what we quickly learned is that just having worked in the area didn't necessarily result in a similar point of view.

Ivan Seidenberg, the CEO of Verizon, was the sole healthcare outsider and clearly from a different world although he was quick to point out that he paid over \$3 billion per year in employee health care cost. He also understood the technology implications and necessary business models. He was a good reality check for the group.

So, surrounded by Ivan, several health system leaders, noted academics, physicians, and some of our countries leading informatics experts, it didn't take me long to figure out I was clearly the weak link in the group although asked to wear a number of hats.

I was the lone representative from the health insurance world and quickly recognized any quick vote on who should pay wouldn't go my way. I also happened to be a nurse so I was asked to cover that waterfront, my parents were both disabled for many years so consumers fell into my bucket, and our health plan is a significant participant in largest state Medicaid managed care program so state Medicaid programs were on my radar as well.

I also described myself as a CHIN survivor, Community Health Information Networks that were launched in the mid 1990's that failed on a spectacular scale across the country. I was an active player on that front and threw my fair share of capital down that black hole. So I had my business hat on looking for how to make this thing work both technically but also financially.

Perhaps the single most important decision we made as a Commission was to focus our report on Consumers. The move to look at health IT from a consumer benefit perspective was a fairly hard turn from the national discussion. Indeed the four goals that were laid out by Dr Brailer were almost totally clinician focused. They included Informed clinical practice, Interconnect clinicians, personalize care, and improve population health.

We agreed that these were important components, but the Commission believed that many of the barriers, including privacy concerns, could only be overcome if consumers were convinced the benefits outweighed the cost and risks related to privacy for consumers. We also concluded that regardless of who paid, ultimately consumers would have to pay either in the form of fees, provider payments, premiums, or taxes. They had to want to buy and pay for this to move forward.

Consequently much of our report was directed at outlining both in print as well as video how consumers would benefit in real tangible ways. We also decided that our recommendations would be consensus... that is no dissention letters at the end from any one member.

Our recommendations were in three categories:

1. Adoption
2. Interoperability
3. Connectivity

Adoption recommendations focused on incentives, including pay for performance and grants targeted at rural and safety net populations, removal of regulatory barriers such as Stark prohibitions, reporting on adoption gaps, and initiatives to address workforce needs. We also recommended a public awareness campaign targeted at consumers and other constituencies to educate them on the many benefits of electronic systems as well as risks associated with the current paper based record keeping.

The interoperability recommendations included product certification, data standards, and patient drug records. Many of these standards have made significant strides although the progress was driven in some part due to Katrina, which drove home the lack of information about people in a time of disaster.

The connectivity recommendations included the development of a national standard for patient authentication and identity, federal privacy, and the creation of a nationwide health information network. We also called for consumer protections and criminal sanctions for privacy violations by any individual or entity.

So it has been a year since those recommendations were made. Where are we? Did the work matter?

Well there are two health IT bills that address a number of the recommendations, one from the senate and one from the house, and there is a need to reconcile them. I will leave to your judgment the potential for bipartisan legislation to occur on any subject right now.

The good news is that HHS has moved forward and acted on many of the recommendations.

- Some rules were issued to clarify the safe harbors for providers. Some want more clarity, the House Bill throws the gates wide open and doesn't even require interoperability.
- AHIC was formed and is charged with monitoring the gaps in adoption, pushing standards, providing leadership.
  - AHIC has adopted recommendations for federal agencies to sponsor pilot programs consistent with the reports recommendations. They have also established "consumer empowerment working solution" and sought public input. They are charged with the consumer education/public outreach messaging.
  - AHIC has also made a medication list/history one of the two main target areas for development. (other one is electronic registration/history)
- Most encouraging is the HHS contract CCHIT the and certification of products based on established criteria. They started with Ambulatory products, working on inpatient and then network components. This is important step and will encourage physicians and hospitals to move forward with purchases.
- HHS also awarded a contract for standards development to HITSP. The NGA/HISPC (health information security and privacy collaboration) is working to implement a process to address variations in business policies and state laws regarding privacy and security.
- The FDA has also engaged. They have committed to enforce RFID standards and push further for standardization of product identifiers for both suppliers and pharmaceuticals and a general streamlining of the healthcare supply chain.

Some real progress and movement by HHS and AHIC with the jury out on congress.

So I'm encouraged but also cognizant of how much needs to happen. And that brings me back to Gartner's hype cycle. I worry that we find ourselves maybe entering that trough of disillusionment.

RHIOs, as originally envisioned have failed to establish successful business models and an alternative model has yet to emerge. Models that place the cost on private employers fail to recognize that considerable benefit comes from managing chronic care, far more prevalent in public populations like Medicare and Medicaid.

Adoption by clinicians is slow. The reality that certified products and Stark exemptions, while helpful, don't address the issues surrounding disrupted office processes, lowered productivity, and won't overcome a payment system that rewards volume and encourages investment in technology that generates payments like MRIs hits hard and impedes significant progress.

I also see struggles around that "shared vision" we thought existed. While the public message was "transforming healthcare" we see that some thought health IT was about technology and the potential to see the next Dot.com investment opportunity. Some thought it was "new money" for the healthcare system. Others thought it was about quality, but maybe not about transparency, especially if that involved consumers or payment changes.

More recently some have commented in the press about Dr. Brailer's resignation and that his successor has an "I" in front of his title that stands for interim. Dr. Brailer was recently quoted saying "the private sector must push, the will and capacity to do so has left the federal government". That's a major statement from him. And I suspect it's true. The war in Iraq, the difficulties associated with Katrina, climbing federal deficits, and tough political races don't make fertile soil for bipartisan efforts to prevail.

But there are signs of pushing on too. People are starting to think about this differently.

Brailer went on to say persuading docs is no longer the focus..."that game is over." There is even more movement to underscore that shift...Brailer's four stated priorities recently were now cost and affordability, transparency, consumerism, and IT interoperability.

These are echoed by Secretary Leavitt. He refers to the four cornerstones...

1. Adopt quality standards
2. Adopt price transparency
3. promote an interoperable health system
4. and use incentives to promote quality

Basically he is calling on empowering consumers through information, transparency, accessibility of that information, and providing rewards for acting on the information to make better choices, enabling consumers.

Focused experimentation is also emerging especially at the State level and I believe that is where the real action will occur. We are having discussion at Tennessee's E-Health Council and that is occurring in many states across the country. We are working hard to figure out what can work.

We're working through the issues on a local level and figuring out what we need to do to move forward in Tennessee, in the absence of federal guidelines. The mission is doubly challenging, because we're also being careful to create a system of interoperability that could easily adapt to federal preemptions down the pike.

Tennessee is a unique state when it comes to the issues surrounding interoperable health records. For one thing, we're a state with eight borders, so that creates complexities in terms of data tracking across many state lines. We also are a state with several RHIOs already underway, each with its own vision and plan. We also have Shared Health, a company my health plan started just two years ago, initially as a solution to the problems we were having in Tennessee with the TennCare Medicaid program and to support chronic care coordination. It is a unique partnership between private and public sectors. All these efforts must be reconciled to move forward successfully.

Shared Health, our initiative, has a signature product called the clinical health record, or CHR that currently has about 40% of clinicians in our state registered as users. The CHR is unique from the traditional EHR, because it offers a much more panoramic view, with information on patient demographics, medical diagnoses and procedures, medications, allergies, and vital signs and immunizations.

Really, what the CHR does is give any Shared Health-registered doctor—anywhere—all of this information at the point of care.

Just a few weeks ago we announced that, not only was it the largest public-private health information exchange in the nation, with nearly 2 million enrollees, a third of our states population, but that it also set a precedent by making TennCare the first Medicaid program in the country to convert all beneficiaries to an electronic health record application, albeit a simple first step. We were also awarded a demonstration project for Medicare to demonstrate we can populate the Personal Health Record from the Medicare data base.

And we've learned a few things along the way.

- For one thing, we have learned that there is a need for critical mass. The wider the net, the more useful the information that systems like Community Connection link together becomes. Critical mass also drives adoption, and, as you know, this stuff doesn't work if providers don't use it.
- Another lesson has been that public-private partnerships can get this done. Shared Health's first customer was the TennCare Bureau, and the critical mass we see in the CHR would not have been possible without the state's willingness to share information, and its commitment to finding innovative solutions for providing health care to the Medicaid population.

- From BlueCross' perspective, we also have learned that making structural changes to the health care delivery system requires a good deal of risk-taking. We've had to take a non-proprietary approach to sharing information that frankly, most insurers don't want to share. And we had to be willing to launch an initiative that raises questions for the broader HIT community for which all the answers do not yet exist.
- Finally all the efforts, from Shared Health to RHIOs, to hundreds of other efforts on the HIT front, all of these must have a joint vision and must work together on behalf of patients and consumers.

Finally, I want to say that my commitment to furthering HIT deployment and adoption isn't just a by-product of my job. It wasn't driven by IOM reports, Commission appointments, and it certainly doesn't represent any effort to give health plans more control over the system.

Rather, my commitment is personal. It was personal when I became the family historian and caretaker for disabled aging parents. It became personal when I saw firsthand the dangers inherent in an unconnected health care world. My parents became the pawns in a complex system where Medicare reimbursement drove bizarre behavior with outcomes that no one could clearly see and a world without real accountability. And despite 30 years in health care that includes nursing, hospital administration, and now health plans...despite access to my physician husband...despite a brother, an attorney who specializes in disability rights...despite a sister-in-law who runs a home health agency...despite knowledge and resources, we couldn't make it better for the people we loved most. And if that hasn't happened to you yet, chances are high that it will.

This was not about bad people. It was good people trying to work miracles in many instances but who were limited by an infrastructure that was frustrating and defeating even on its best day.

We have the opportunity to change that, to make it better for our communities, for those frontline health care workers, for your family, for you.

That's why I'm here today, and that's what ultimately needs to come from the national dialogue that we're having now.

Thanks for inviting me to be here with you today, and I'm happy to take questions.

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