BUILDING A TRUSTED and INTEROPERABLE HEALTH INFORMATION EXCHANGE ENVIRONMENT

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When this presidential election began, the war in Iraq was expected to be the defining issue. Over time, the economy has deteriorated, and has risen to the fore—but the economic issue the polls show has Americans most concerned is not jobs or inflation, but the tremendous cost of healthcare. Barack Obama, speaking about his own mother's death from cancer at the age of 53, has said that it is "morally wrong" for terminally ill people to have to worry about money. Hillary Clinton has called universal health care a "core Democratic principle". And John McCain finds it "simply disgraceful that 43 million Americans can not afford health care coverage".

A recent Wall Street Journal-NBC Survey found that almost 50 percent of the American public says the cost of health care is their number one economic concern. The rising cost of health care is the top personal pocketbook concern for both Democratic voters (45%) and Republicans (35%), well ahead of higher taxes or retirement security.

In 2007 the U.S. spent nearly $2.3 trillion on healthcare–16+ percent of GDP. This is roughly equivalent to the entire Chinese GDP. It is 4.3 times the amount spent on national defense.

Employers and consumers are struggling to cope with this health care cost crisis.
- More American families are bankrupted by health care costs than any other cause. One in four Americans say their family has had a problem paying for medical care during the past year, up 7 percentage points over the past nine years. Nearly 30 percent say someone in their family has delayed medical care in the past year for a medical condition was at least somewhat serious.
- Studies have shown that retiring elderly couples will need $200,000 - $300,000 in savings just to pay for the most basic medical coverage.
- Many American companies operate at a distinct competitive disadvantage because of the high cost of health coverage for their employees. Ford and GM pay nearly $1500 in health-care costs for each vehicle they produce, while BMW pays $450 per vehicle in Germany and Honda $150 per vehicle in Japan.

And we can expect in the near future a "tsunami of health care cost" sweeping down on us as 70 million aging baby boomers will start making new demands on our already creaking healthcare infrastructure. US spending on healthcare is expected to double to $4.3 trillion by 2017. This figure would represent nearly 20 percent of the US GDP. In addition, it is expected that the lifetime cost of providing disability payments and healthcare to Iraq and Afghan war veterans will likely cost U.S. taxpayers between $300 billion and $600 billion, depending on how long the war lasts.

Yet despite such high levels of spending, the quality of American healthcare lags behind in comparison with other developed countries.

- The United States is ranked #37 as a health system by the World Health Organization.
- Further, the Institute of Medicine has calculated that almost 100,000 Americans die every year from medical errors in hospitals. That's the equivalent of a Boeing 747 crashing every two or three days.
- The national costs of medical errors resulting in injury are estimated to be between $17-29 billion annually.
- HealthGrades' fifth annual Patient Safety in American Hospitals Study, which was just released, indicates that patient safety incidents cost the federal Medicare program $8.8 billion and resulted in 238,337 potentially preventable deaths during 2004 through 2006.

To be sure, there are elements of excellence in our health system, yet taken together, these figures cry for a transformation of health care in the US.

The Disruptive Power of Information Technology

So, what can we do? How can we improve the situation? Every presidential candidate has put forward ideas on how to address some of the problems identified. Obviously, there is no surprise that they differ in substance and priority. Yet, what they all agree upon is that the best hope for change lies in the disruptive power of information technology to create productivity gains and to improve patient outcomes by connecting the fragmented parts of the healthcare system. Hillary Clinton has said she will invest $3 billion a year in health IT grants to develop a paperless health care system. Barak Obama says he will invest $10 billion a year over the next five years for health IT systems.

Health information and information technology (Health IT) has barely begun to bring the productivity gains to healthcare that it has brought to so many other sectors. Health IT has the potential for dramatic improvements in efficiencies and cost savings, while at the same time improving the quality of care and reducing medical errors. Computerized physician order entry and electronic medical records linked in a national network based on interoperable data standards can help bring real coordination to a fragmented healthcare system. Duplicative tests can be reduced. Patients can also have easier access to their important health information, allowing them to be active participants in their own care.

We are not just eliminating paper, but creating a new and stronger doctor-patient relationship, focused on better quality healthcare and greater efficiency.

We know, today, that technology can improve efficiency, quality and safety. And, importantly, that it can do so in a cost-effective manner that justifies the investments necessary to deploy technology in healthcare. Rand has, for instance, measured that if most hospitals and doctors' offices adopted health IT, the potential efficiency savings for both inpatient and outpatient care could average over $77 billion per year. The largest savings

would come from reduced hospital stays (a result of increased safety and better scheduling and coordination), reduced nurses' administrative time, and more efficient drug utilization. Further, if all hospitals had a health IT system including Computerized Physician Order Entry, around 200,000 adverse drug events could be eliminated each year, at an annual savings of about $1 billion. And health IT would help with prevention by scanning patient records for risk factors and by recommending appropriate preventive services, such as vaccinations and screenings.

A comparative study released this month in the New England Journal of Medicine looked at the options for slowing the growth of health care costs. Health IT was seen as having the greatest potential for cost savings. In particular, the authors felt the greatest cost-reducing effect of health IT "will result from improved co-ordination among health care providers and from decision support that improves clinicians' use of tests and treatments. Such decision support has the potential to decrease variation among physicians in the use of health care services, thereby reducing both baseline costs and trends."

Yet, this potential is largely unrealized to date.

Health IT is lagging behind and what can we do about it?

Why has healthcare been so slow to adopt IT? And, most importantly, what can we do about it?

There are two main reasons why the healthcare sector has not embraced IT as dramatically as it could have. Neither of these is technical.

The first of these is financial--every dollar saved comes from someone's bottom line, often from the health system providing the cost savings through best of breed use of IT. Healthcare providers (and drug companies, and insurers) lack the financial incentives to change the way they operate. We therefore need to establish new business models that reward innovation and creative uses of technology.

One possible way to save money is to make greater use of the Internet. A number of robust health web sites exist on the Internet already, like Web MD and PatientsLikeMe. Some of these are linked into providers of care. Recently, both Microsoft and Google have announced their intention to enter the healthcare business by creating platforms that would allow patients to access personal health records and other resources. These companies are also looking at ways to make greater use of search and data storage solutions in the healthcare business. To really be successful, these businesses have to find ways to enhance consumer loyalty and impact on their health care choices, and to enable doctors and other providers of care to reduce costs and enhance their efficiency and quality of care.

Ultimately, transformation is unlikely to occur unless we change the way we reward and pay for health care. For example, our current fee-for-service payment system pays hospitals and doctors for each hospitalization, office visit, procedure, test, and surgery performed, but they cannot get paid more for providing the quality of care that avoids procedures.

To be sure, setting up new financial incentives requires, in Schumpeter's famous phrase,

"creative destruction." We will need new and innovative approaches beyond the fee-for-service model, such as pay for value and health outcomes, as well as rewarding information liquidity and sharing. But only with such innovations can we hope to use technology to its full potential.

The second problem (which is related to the first) has been the challenge of developing trusted uses of health information. This requires commitments to transparent privacy and security policies, the technology to back them up, and a legal and policy framework. If we are to transform healthcare, then we need the right policies--policies that prevent abuse and protect patient privacy. And such a policy framework must be developed in sync with the technology; not determined by certain technical design features afterwards.

American patients and consumers are currently excited about the potential of technology to change their healthcare. According to a recent survey, seventy percent of Americans would be more likely to vote for a presidential candidate who supports the creation of a nationwide health information network. Yet at the same time, patients remain concerned about potential privacy violations. According to a 2005 poll conducted by the California Health Care Foundation , 67% of Americans are concerned about the privacy of their personal medical records. Likewise, a 2006 survey by Harris/Westin found that 42% of Americans feel that "privacy risks outweigh expected benefits" from health IT.

In 2004, in an attempt to address the shortcomings in standards setting and in data security and privacy, the Markle Foundation in conjunction with a wide range of healthcare leaders, issued a Roadmap document entitled "Achieving Electronic Connectivity in Healthcare: A Preliminary Roadmap from the Nation's Public and Private-Sector Healthcare Leaders." In that document, we recommended a common framework, and we outlined a set of actions that could be taken to create a decentralized and standards-based information network. In another report, we have described the key features of this network.

First, any health information network must be architected around a **core set of principles** that protect privacy and enhance trust. Importantly, these principles should be realized through the employment of both technology and policy.

These principles are based on fair information practices. Including a commitment to "openness,"; specifying the purposes of any data collection; collecting only what is necessary for that purpose; adhering to the uses agreed to by the individual; allowing individuals to know and have a say in who and how their information is used; maintaining the integrity of the data;, audit; oversight; and remedies in the event of breach or misuse. Every health information initiative, public or private, should be expected to disclose how it addresses each of these principles.

Second, rather than searching for a unified or centralized network, any health information network should be decentralized, and empowered at the edges. It should be a "network of networks" where participants, grouped together through proximity, trust or patient care needs, can exchange appropriate data with their authorized users. The data resides with the creator to the extent possible rather than maintaining centralized databases of medical and patient information. We need to create better links between existing data and networks, so that they can "communicate" with each other. Such an approach also has the benefit of

being possible to build ground up, in an incremental manner. It avoids a "rip and replace" or "big bang" undertaking that would be far harder—and more expensive—to implement.

Policies and technologies that build patient trust--that protect privacy, that ensure the security of data, that encourage and empower patients to participate in their own treatment--are among the most important components of the framework. A health information network will not succeed if patients, perhaps frightened by a recent rash of media stories on data leakage, are unwilling to share their data.

Conclusion
There is a growing consensus on the clear benefits of IT in healthcare. The interesting thing for me is the extent to which this consensus cuts across government, business, and a variety of non-profit consumer and other public interest groups. Each of these sectors seems today to recognize the urgency of the problem, and the almost desperate need for reform. Health IT is not the silver bullet - just like managed care wasn't the silver bullet a decade or more ago - but there is no way to address our crying needs for improvement in health care quality and cost effectiveness without it.

The presidential election offers a genuine moment of opportunity. The leading candidates all appear to recognize the importance of transforming healthcare. I hope we will be able to turn words into action, and to seize this moment of opportunity.