Testimony of

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Overview

My name is Daniel Weitzner. Thank you to the co-chairs and the committee staff for inviting me to testify on Personal Health Records. I am Director of the MIT Decentralized Information Group, Principal Research Scientist at the MIT Computer Science and Artificial Intelligence Laboratory, and Technology and Society Policy Director at the World Wide Web Consortium. The testimony I offer today is reflects my views alone.

Understanding the possible evolution of Personal Health Records requires a perspective on the challenges and pressures that the overall Health Information Technology environment is likely to experience in the coming years, and on how the future of HIT is likely to be different from its past. The potential of HIT to improve quality, lower cost, and realize of other healthcare goals[1] has been recognized for decades, even if there have been debates about the degree of cost savings and the scope of quality benefits. The first phase of comprehensive Federal efforts as articulated by then-President Bush's goal of 100% EMR software deployment by 2014 was a strategy based on software deployment in doctor's offices and construction of nation-wide health information exchange networks. That approach lead to important advances in the development of technical standards and certification processes, but failed to yield substantial process toward a widely-deployed HIT environment that has the potential to actually contribute to care quality and cost savings.

With the new Administration and the passage of the HITECH Act as part of the American Recovery and Reinvestment Act of 2009 (ARRA), we see a substantially different approach to achieving the same broad goals. The HIT strategy as reflected in the Recovery Act and recent statements[2] by the incoming National Coordinator for Health Information Technology, Dr. David Blumenthal, is explicitly driven by health quality, not technology deployment. The HITECT provisions of the Recovery Act create incentives for HIT deployment that require HIT satisfy not only technical requirements but also *meaningful use* requirements. Meaningful use requirements are meant to assure that the HIT deployed will contribute to improved health quality. This shift from a technology-driven strategy to one directly targeted toward health policy goals will have a major impact on the HIT environment going forward.

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[1] Institute of Medicine, Crossing the Quality Chasm: A New Health System for the Twenty-first Century (Washington: National Academy Press, 2001).
[2] Blumenthal, D. 2009. Stimulating the Adoption of Health Information Technology. The New England Journal of Medicine 0: NEJMp0901592. http://content.nejm.org/cgi/content/full/NEJMp0901592.

As the Subcommittee considers privacy and security issues in the evolution of HIT, three dynamics deserve special attention:

1. <u>Emphasis on local experimentation to generate a diversity of HIT best practices:</u> The Recovery Act funds a set of Regional Health Information Technology Extension Centers (RHITECs) in order to encourage the development and dissemination of HIT best practices, showing the way to sustainable models for meaningful use of HIT.
2. <u>Technology and business model innovation based on open standards:</u> Following the model of the Internet and the World Wide Web, technical and business-model innovation to create useful and deployable HIT will be based on a platform of open standards, clear health policy requirements, and flexibility for innovation.
3. <u>Meaningful Use and Health Care Payment Reform:</u> HIT will only develop to meet health care goals if the overall health care environment is reformed to reward the results that health IT seeks to enable. Health care providers need better information-based tools to provide quality care, but will only be encourage to use these tools at large scale with the right financial incentives in place.[3]

I.   Local Successes in a Diversity of National Experiments

While Electronic Medical Record deployment has been slow[4] and evidence of real health care benefits from EMR use are limited,[5] there are successes worthy of emulation. Concentrated local effort to deploy EMRs across regions of various sizes -- including New York City (NYC PCIP),[6] Eastern Massachusetts (MAeHC), Indiana, and Tennessee -- are all models which the HITECH Act will build on. The salient features of many of these existing projects include:

- Priority attention to information needs of primary care providers;
- System design focused on health care outcomes, as opposed to abstract data interchange or reporting features;
- Dedicated effort toward practice transformation;
- Administrative effort devoted to local information exchange between labs, hospitals, public health entities and primary care providers;

The success of HITECH depends on replicating these models and developing new approaches appropriate to the many diverse environments across the country in which HIT must succeed. The mechanism adopted in the Act through which to pursue this goal is the Regional Health Information Technology Extension Center (RHITEC). Through this funding authority, the ONC can support the creation of a variety of locally-oriented HIT deployment models that will help pave the way toward full deployment of meaningfully-useful health information technology.

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[3] Park T., Basch P, A Historic Opportunity: Wedding Health Information Technology to Care Delivery Innovation and Provider Payment Reform, Center for American Progress (May 2009) http://www.americanprogress.org/issues/2009/05/pdf/health_it.pdf.

[4] For example, DesRoches CM, Campbell EG, Rao SR, Donelan K, Ferris TG, Jha A, Kaushal R, Levy DE, Rosenbaum S, Shields AE, Blumenthal D. Electronic health records in ambulatory care--a national survey of physicians. *N Engl J Med.* 2008 Jul 3;359(1):50-60.

[5] Chaudhry B, Wang J, Wu S, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Ann Intern Med.* 2006;144(10):742-752.

[6] Mostashari, F., M. Tripathi, et al. (2009). "A Tale Of Two Large Community Electronic Health Record Extension Projects." Health Affairs 28(2): 345-356.

II.   HIT progress through innovation based on open standards, not centrally-controlled design

The state-of-the-art infrastructure for information sharing in the 21st century is the Internet and the World Wide Web. Successful information exchange in all sectors of the US economy is based on the Internet and the World Wide Web, utilizing open standards, common definitions and identifiers, and shared best practices regarding privacy and security.[7] Information exchange occurs seamlessly, without the need to aggregate all data from a given region or state into specially-built networks. Information exchange architectures that rely on aggregating all data in central location only to share it back out to those who need are often chronically out-of-step with the changing needs of users. Healthcare should follow the successful examples of other sectors, and utilize simple decentralized, web-based services as the technical platform for information sharing.

Two characteristics make decentralized web-based information exchange flexible and sustainable:

1. *Independently-operated information services:* institutions that are the authoritative source of the data (i.e., state licensing agencies maintaining an authoritative list of health care providers, CMS providing the National Provider Identifier index, etc.) can make data available in standard formats such that the information is usable by any HIT application. There is no need to combine all of these services in a single, cumbersome network.
2. *Standards-based techniques for integrating data from multiple sources:* HIT software vendors can easily design their systems to exchange and integrate data from the variety of web-based information services that come to make up the health information exchange ecosystem. State-of-the-art commercially available software in industries such as finance and manufacturing take advantage of these techniques. The health care environment should do so as well.

The flexibility offered by a web-services approach to HIE is critical as overall health care environment evolves. It may appear more efficient to combine all of these services together into a single large system. Centralized networks are difficult to govern, expensive to maintain, and chronically out-of-step with the needs of its diverse users. Rather, simple web-based services can be the technical platform for information sharing, *provided* all of the parties to the exchange have the proper incentives and motivations to share.

This more decentralized approach to health information sharing is the more likely path to success, but it does pose challenges for privacy protection and security best practices. Centralized data stores are vulnerable to attack and less robust against failure, but are also easier to monitor for regulatory compliance. Nevertheless, we are likely to see more diverse, decentralized information flow in the future so privacy and security strategies will have to adapt to this more complex environment.

III.   Meaningful Use and Health Care Payment Reform

The clear goal of the HITECH Act is to fund EHRs that can meet soon-to-be-defined meaningful use standards, assuring that use of these systems will contribute to health care goals. In the near term, the Medicare and Medicaid incentive funding mechanism in the Act will encourage the market toward development of EHRs that can actually contribute to health quality. But in the long run we must recognize

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[7] See, for example, Standards Within the Context of the Health IT Initiatives: IT Thought Leaders Panel Carol Diamond's statement before the National Committee on Vital and Health Statistics (NCVHS), Subcommittee on Standards (24 February 2009) and Achieving the Health IT Objectives of the American Recovery and Reinvestment Act: A Framework for 'Meaningful Use' and 'Certified or Qualified' EHR, Markle Foundation (May 2009). http://www.markle.org/downloadable_assets/20090430_meaningful_use.pdf

that disappointing results from HIT are caused by a *policy failure*, not flawed technical design. Physicians and the larger health care system will not utilize health information for quality and cost reduction purposes unless and until they see economic incentive to do so. Today, reducing unnecessary care and increase quality (leading to healthier patients) often *costs* providers money. This absence of a business case for health and quality improvement, providers have generally not demanded that health IT vendors produce products that support health quality improvement. Instead, today's EHRs are designed to help providers with coding for billing purposes and documenting care for malpractice purposes. These limitation are not driven by the technical difficulty. Adding solid clinical decision support with patient registry and reminder functionality is relatively straightforward, and could be done by most vendors in a short period of time. Rather, it is the lack of provider demand for these capabilities, which is in turn driven by the absence of a true business case for health and quality improvement.[8]

IV. Conclusions

If we accept this as a likely trajectory for the evolution:

- A diversity of approaches around the country
- A variety of application styles based on light weight open data interchange standards
- HIT usage driven by meaningful use requirements and a reformed payment system that reward better quality and lower costs

then what can we expect efforts in efforts to address privacy and security issues associated with PHRs and other health information technologies?

First, a diversity of approaches (technical and business practices) suggests that proposed privacy and security policy solutions will have to be articulated in functional, not technical terms. Second, local/regional extension centers are ideal environments in which to develop privacy and security best practices. Privacy and security experts can involve themselves in the design and operation of these local experiments in order to assure that current best practices are taken into consideration and adapted along with evolving HIT applications. Third, the more decentralized system of health information flow that is likely to result will pose a novel set of regulatory and administrative challenges. This committee is ideally suited to monitor these developments and develop flexible approaches to privacy assurance. Finally, requirements to show health care outcomes for both meaningful use standards and eventual payment reform and system redesign will require extensive collection and analysis of sensitive, personal health information. Privacy and security considerations, therefore, remain central to the success of health care innovation and policy reform.

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[8] Park & Basch, *id.*