

NHPF Forum Session
Meeting Announcement



**Toward a National Health
Information Infrastructure: Local,
National, and Global Opportunities**

A DISCUSSION FEATURING:

Don Detmer, MD, MA
*Professor Emeritus and Professor
of Medical Education*
Department of Health
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University of Virginia
Senior Associate
Judge Institute of Management,
University of Cambridge

Carolyn M. Clancy, MD
Director
Agency for Healthcare Research
and Quality (AHRQ)

**Friday,
May 21, 2004**

11:45 am — *Lunch*

12:15–2:00 pm — *Discussion*

**Reserve Officers Association
of the United States**

One Constitution Avenue, NE
Congressional Hall of Honor —
Fifth Floor
*(Across from the Dirksen Senate
Office Building)*

To register:

Please call Marcia Howard at
202/872-1392 as soon as
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THE GEORGE
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Toward a National Health Information Infrastructure: Local, National, and Global Opportunities

In April 2004, President Bush and Sen. Hillary Clinton (D-NY) both made public calls for bringing the health care industry into the 21st century in terms of information technology (IT). They were not the first to recommend the development of a national health information infrastructure (NHII) as a feature of health care in the United States. It was a prominent recommendation in the Institute of Medicine's influential 2001 report, *Crossing the Quality Chasm*. Observing, at that point, that IT had "barely touched patient care," the *Chasm* report pointed to improvements in patient safety, self-management, and compliance; deployment of evidence-based medicine; and communication between and among clinicians and patients that could come through electronic channels. (This followed a decade-earlier IOM recommendation that a standard computerized patient record be developed and adopted.) Also in 2001, the National Committee on Vital and Health Statistics (NCVHS), a public committee whose mission is to advise the secretary of health and human services on health information policy, issued *Information for Health*, a report citing "a timely opportunity and an urgent need to build a 21st-century health support system."¹

Delay, redundancy, and error are laid to the charge of paper records and insufficient communication. Optimistic views of future health

SESSION OVERVIEW

This meeting will assess the progress of the United States in developing an infrastructure to permit health information to be exchanged electronically across organizational and political borders. Experts in the field will describe how information technology (IT) can support individual, clinician, research, and public health interests. They will discuss the challenges that remain, notably definition of standards, incentives for IT adoption and use, and protection of privacy. Speakers will give examples of IT advances in other countries and review initiatives currently underway in this country, especially at the federal government level.

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care feature EHRs—along with instant access to clinical imaging, telemedicine, drug interaction alerts, and similar capabilities—which are already technologically possible. EHRs can be a vehicle not only to increase clinical efficiency but also to empower consumers with the information to take greater control of their own health.

At various levels, efforts are underway to wield IT to improve health care quality. Some health plans, integrated delivery systems, and even physician groups operate with an EHR and accompanying communication and decision-support tools. Standards-setting bodies are gaining acceptance of data and transaction standards and forging stakeholder coalitions to take progress to the next level. Grants from the government and private funders are becoming available for IT investment. For example, the Agency for Healthcare Research and Quality (AHRQ) is making available approximately \$30 million in grants to develop a research base on the value of IT implementation, along with additional funding for standards development and for demonstrations in five states or regions that will support inter-organization exchange of health data on a local level. The sum of these activities has yet to reach critical mass, and whether the separately orbiting local and national initiatives can coalesce into a national infrastructure remains to be seen.

The observation has been made that many of the basic components of the NHII already exist and are operating in their own spheres; what they lack are interconnections. Interconnection is an international as well as a domestic issue, as other countries, notably Canada, Australia, and England/Wales, have already invested in national health information infrastructures and are making decisions about the standards that will define them. The United States is playing catch-up.

Principles

Information for Health, the NCVHS report mentioned above, outlined a strategy for building an American NHII. In introducing it, NCVHS members voiced their belief that implementation of the NHII would have “dramatic impact on the effectiveness, efficiency, and overall quality of health and health care in the United States.” Serious problems such as public health emergencies, medical errors, and disparities in access and treatment, they said, could be addressed in a more timely and comprehensible fashion.

Information for Health posits an infrastructure with three “dimensions,” corresponding to the applications of an NHII that would meet the needs of consumers, health care providers, and public health officials.

- The personal health dimension would provide support for individuals (and families) in managing their own wellness and healthcare decision making, with better access to their own health

records, reliable information about their disease or condition, and sources of help such as a nurse call center or a medication reminder system. Recent research in Europe has shown that the informed patient is more confident and less costly.² Because reimbursement policies play a huge role in patient decisions (“Is this covered?”), insurers would ideally be included in the loop as well, so that they could support the infrastructure and—again, ideally—serve as a patient’s ally.

■ Physicians and other health professionals would have access to more complete and accurate patient data, along with clinical guidelines, electronic prescribing capability, and other support services. Though some physicians currently have such access within their medical group or integrated delivery system, the NHII would enable appropriate care delivery across care settings.

■ Public health officials could more easily document the health of the population and study influences on it, identify and track health threats, implement and monitor health education campaigns, and conduct research. (Indeed, research may be seen as cutting across the dimensions.)

Moving Forward

As things stand, health information is stored in manifold locations in multiple media, from a patient’s allergy alert bracelet to a physician’s paper file to a population health database. It is not difficult to perceive the benefit of moving toward common points of access and a shared architecture. However, there are equally recognizable impediments to doing so, beginning with cost. Noted health informatics expert Don Detmer speaks of the need to convert impediments to enablers, including:

■ **Incentives** — Most reimbursement mechanisms are based on volume of services performed regardless of quality or outcomes. Investment in technology to promote quality may lead to fewer unnecessary tests, office visits, and mistakes that later must be fixed—all of which are good for the patient but represent lost revenue to a physician or hospital. Unless higher quality can be measured and tied to higher reimbursement, investing money in IT in order to lose money in reimbursements is likely to remain a difficult sell to providers.

■ **Standards** — Critical to the establishment of an NHII is the development of standards for data definition and transmissions; such standards “enable parts to fit together, assure consistency over time, and facilitate communication.”³ A variety of standards-setting bodies exist, and many public-private initiatives are under way to achieve consensus on the various standards sets that must underlie a national infrastructure. For example, the Health Insurance

Portability and Accountability Act (HIPAA) of 1996 established administrative transaction standards for the exchange of health care data. In March 2003, the Departments of Health and Human Services (DHHS), Defense, and Veterans Affairs announced a set of uniform standards for the electronic exchange of clinical health information to be adopted across the federal government as part of the Consolidated Health Informatics Initiative.

■ **Privacy** — HIPAA also contains provisions pertaining to the security and confidentiality of health care data, including a variety of personal identifiers, but has not resolved longstanding debate in this area about what degree of protection is sufficient (or too much). For example, federal policymakers remain reluctant to pursue the unique personal health identifier (akin to a Social Security number for health), whereas millions of Europeans are now using a “smart card” technology based on unique personal identifiers for authentication.

■ **Leadership** — The NCVHS report spoke bluntly to this issue, saying that “the most important missing ingredient, which could accelerate and coordinate progress on the NHII, is leadership, specifically, Federal leadership.” President Bush has recently responded to the committee’s call for the establishment of a new NHII office within DHHS, whose director would report directly to the secretary and whose charge would be to oversee and coordinate a broad range of health information policy, research, and program activities in both the public and private sectors.

Rep. Nancy Johnson (R-CT) has introduced The National Health Information Infrastructure Act (H.R. 2915). The Senate HELP Committee is in discussions aimed at crafting a bipartisan proposal to enable the development of an NHII. Short of these, but moving in the same direction, are provisions in the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003 that, among other things, build monitoring technologies into demonstration program specifications, authorize the secretary to make grants to physicians for building the IT component of electronic prescribing, and establish a Commission on Systematic Interoperability.

Other Countries’ Progress

Whereas the United States is struggling with questions of communication, collaboration, and cost, other countries have forged farther ahead with their own infrastructures. Since 1997, the government of Canada has supported the expansion of information and communications technologies in health care. The Canadian Health Infostructure initiative was based on the strategic goals of empowering consumers, strengthening and integrating health care services, creating the information resources for accountability and feedback, and improving

privacy protections. Coordination and direction is provided by an independent corporation, Canada Health Infoway, established by the government in 2000; among its priorities is the creation of a country-wide interlinked EHR system.

England's National Health Service announced late last year that it was embarking on one of the largest IT projects ever—an estimated \$17 billion wiring of every hospital, clinic, and physician's office in the country. The project will include an EHR system containing the full health record of each citizen and an administrative system that provides for electronic scheduling, referral, and prescribing. The National Institute for Clinical Excellence (NICE), already an established part of the National Health System for England and Wales, will continue to offer guidance on current "best practice" in health technologies and clinical management to patients, health professionals, and the public.

In this forum session, **Don Detmer, MD**, will draw on his varied and multinational experience to talk about what an NHII could and should be, the challenges involved in moving forward, and what the United States can learn from other countries. Detmer, long considered a visionary on the subject, is a leader in academic medicine and a pioneer of the computerized patient record concept. **Carolyn Clancy, MA**, director of AHRQ and co-chair of the Department of Health and Human Services' Council on the Application of Health Information Technology (CAHIT), will describe initiatives the federal government has undertaken and public-private partnerships that have convened around health care technology. AHRQ is home to research centers specializing in areas such as quality improvement, outcomes and effectiveness of care, and clinical practice and technology assessment. It is also a major source of funding and technical assistance for health services research.

KEY QUESTIONS

- How can a common infrastructure and interoperability be achieved in the complex, multiparty American health care system, as opposed to a single-payer national system, as found in Britain and Canada?
- Who are the key stakeholders, and what are the needs that must be satisfied in order for them to be fully supportive of NHII development? How can differing goals and incentives be aligned? Are there outright opponents to a development effort?
- What steps might the federal government take to exercise leadership as a purchaser and/or regulator in the establishment of an NHII? To what extent are such steps already under way?
- What lessons from other countries' experience can be applied in the United States? What will it take for the United States to catch up? What are the potential consequences of delay?

- What can policymakers do to address the barriers that remain to interoperability and widespread access to electronic information without compromising privacy? How do we balance privacy with the need for access to data for care and research purposes?
- Should we envisage a role for licensing and accrediting bodies in assessing the capabilities of clinicians and institutions to collect, use, and transmit health information?

SPEAKERS

Don E. Detmer, MD, MA, is professor emeritus and professor of medical education in the Department of Health Evaluation Sciences at the University of Virginia and Senior Associate of the Judge Institute of Management, University of Cambridge. From 1999 to 2003, he was the Dennis Gillings professor of health management and director of Cambridge University Health, the policy center at the Judge Institute (Cambridge's business school). Detmer is immediate past chair of the Board on Health Care Services of the Institute of Medicine and of the National Committee on Vital and Health Statistics and has also chaired the Board of Regents at the National Library of Medicine. He is currently vice-chair of the China Medical Board of New York, Inc.; a trustee of the Nuffield Trust of London; research director of the J&J Centre for Advancing Health Information; and chair of the International Committee of the American Medical Informatics Association.

Carolyn M. Clancy, MD, is director of Agency for Healthcare Research and Quality (AHRQ). Prior to this appointment, she served as acting director for nearly a year and, before that, as director of AHRQ's Center for Outcomes and Effectiveness Research. She holds an academic appointment at the George Washington University School of Medicine and serves as senior associate editor of *Health Services Research*. Clancy is a general internist and health services researcher, and a graduate of Boston College and the University of Massachusetts Medical School.

ENDNOTES

1. National Committee on Vital and Health Statistics, *Information for Health: A Strategy for Building the National Health Information Infrastructure*, November 15, 2001; available at <http://ncvhs.hhs.gov/nhiilayo.pdf>.
2. D. E. Detmer, P. D. Singleton, A. MacLeod, S. Wait, M. Taylor, and J. Ridgwell, "The Informed Patient: Study Report," Judge Institute of Management, University of Cambridge, March 2003; available at <http://www.jims.cam.ac.uk/research/health/tip/pdf/crstudy.pdf>.
3. Don E. Detmer, "Building the National Health Information Infrastructure for Personal Health, Health Care Services, Public Health, and Research," *BMC Medical Informatics and Decision Making*, 3:1, January 6, 2003; available at <http://www.biomedcentral.com/1472-6947/3/1>.