

**PREPARED STATEMENT BY CAROLD DIAMOND, MD, MPH
MANAGING DIRECTOR, MARKLE FOUNDATION;
CHAIR, CONNECTING FOR HEALTH**

Committee on Energy and Commerce
Subcommittee on Health
U.S. House of Representatives

**Health Information Technology:
Improving Quality and Value of Patient Care**

July 22, 2004

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Chairman Bilirakis, Congressman Brown and distinguished members of the Subcommittee on Health, thank you for inviting me to meet with you today.

For the last two years, I have had the privilege of chairing Connecting for Health (see www.connectingforhealth.org), an initiative established and operated by the Markle Foundation, with additional funding and support from the Robert Wood Johnson Foundation. Connecting for Health is committed to accelerating actions on a national basis to tackle the barriers that prevent us from bringing healthcare into the information age to improve the quality of healthcare, reduce medical errors, lower costs and empower patients.

Connecting for Health is based on the belief that the development of an interconnected health information infrastructure will depend upon close cooperation between the public and private sectors in a way that maximizes the benefits of their complementary expertise and experience. Today, Connecting for Health is a truly unique *public-private sector initiative*, consisting of over 100 broad-based stakeholders representing providers, patients, payers, accreditors, government agencies, researchers and healthcare information systems manufacturers and vendors (see the appendix for the list of current Steering and Working Group members). I am delighted to have this opportunity to inform this Committee on progress made within the context of Connecting for Health and on what we believe the conditions to be to accelerate the adoption and use of Information Technology to improve the quality of health care in the United States.

Momentum is growing ...

Last year, this Committee showed true leadership by introducing groundbreaking and innovative Health Information Technology initiatives in the Medicare Modernization Act including a process to create standards for electronic prescribing that physicians and pharmacists can use; the development of a safe harbor in the Stark and Anti-Kickback Acts that would allow hospitals to disseminate technology to physicians; the authorization of various grants to accelerate e-prescribing; the development of a chronic

care improvement program that will test disease management strategies and the call for the use of monitoring technologies to exchange clinical information (among other things).

In addition to the work in this Committee, other notable recent developments include: the President's call for the creation of electronic health records for all Americans in ten years; the establishment by the Department of Health and Human Services of the National Health Information Technology Coordinator and the appointment of Dr. David Brailer to the position; the release announced by Dr. Brailer of the report on the nation's first strategic framework to develop electronic health records; the various legislative bills proposed and introduced by Senator Ted Kennedy, Senator Hilary Rodham Clinton and Representative Nancy Johnson, Senator Judd Gregg, among others; and the creation of a "21st Century Healthcare Caucus" within the House of Representatives focused on IT and Healthcare (of which some members of this Committee are part of), all showing a bipartisan recognition of the importance of addressing these issues promptly. Furthermore, the Defense Department and the Veterans Administration have been building and implementing very sophisticated health IT systems. HHS agencies, including the CDC, CMS, AHRQ, the Health Resources and Services Administration and others are conducting demonstration projects, grant programs and other developmental activities.

This momentum is a result of the growing understanding and evidence, produced by various studies, groups and pilot projects, that smart investments in health care information technology can rein in costs, eliminate waste and improve patient safety and health care quality

However, while progress has been made, we have not yet accomplished all that we need to. It is important to keep in mind the real and constant difficulties patients face in today's uncoordinated, paper-based system. Every one of us is touched by the U.S. health system – from before birth until death. During our lives, we experience both predictable and unpredictable needs for health care assistance. Every time we encounter the healthcare system, information about our background, medical history, health status, and insurance are immediately required. And every medical encounter produces its own trail of documentation.

The stakes are high...

There are hundreds of millions of doctor office visits alone every year in the United States. A complex patchwork of healthcare practitioners and payers process information for each one of those visits. The records are either on paper or in separate computer systems that typically have limited, if any, ability to exchange data electronically (except for purposes of reimbursement). In all those files of paper and streams of data, no one has a bigger stake in the information from a particular clinical encounter than the patient who needed it. And, in nearly all circumstances, no one in the system can know more about the patient's life than that patient. Health professionals have no way of accessing all of the important information about our health, and we have no way of compiling and managing the information about ourselves.

In our fragmented and pluralistic delivery system, the electronic personal health record is an essential tool for integrating the delivery of health care and putting each patient at the center of their care. It can support the shift from episodic and acute care toward continuous healing relationships with physicians and healthcare professionals. It represents a transition from a patient record that is physician-centered, retrospective and incomplete to one that is patient-centered, prospective, interactive and complete.

Throughout the course of our work a number of individuals have agreed to share their stories with us, and in our attempt to bring the private and public sectors together we have explored the deficiencies of our paper-based healthcare system through these real-life stories (a selection of testimonies is available at our website, www.connectingforhealth.org). For instance, a Michigan father and his young daughter, who has a rare and complicated leukemia, told us about the pile of files he has to carry every time he joins his daughter to see a specialist, fearing that she would not get the best care without every clinician understanding the complexities of her disease or knowing what worked best for her in the past. His story is supplemented by the stories of other patients who went out of their way to have access to their medical information, and use it to receive the best possible care for themselves and their families. These stories remind us how patients and their families struggle to overcome preventable information gaps in healthcare each and every day. They have made us even more determined to break open the logjam blocking the flow of vital healthcare information, which is required to improve healthcare quality, safety, and efficiency.

Connecting for Health's Preliminary Roadmap

Since its creation, Connecting for Health has demonstrated that blending together the knowledge and experience of the public and private sectors can provide a highly effective formula for progress. Early in its inception, Connecting for Health led the national debate on electronic clinical data standards. The group drove consensus on the adoption of an initial set of standards, developed case studies on privacy and security, and helped define the electronic personal health record.

While we do not offer a prescription for which innovations in care will be most effective in improving healthcare quality or reducing medical error, we do know that most of them cannot be realized without the rapid, accurate, and secure exchange of personal health information among authorized users. And we believe that the greatest improvements in healthcare – leading to the most profound opportunities for better health – will occur when each American can access, control, and make use of their own health information in partnership with their care team.

Just last week, Connecting for Health released its second report: a *Preliminary Roadmap for Achieving Electronic Connectivity in Healthcare* (available at http://www.connectingforhealth.org/resources/cfh_roadmap_final_0714.pdf). The report aims to facilitate broad agreement on a set of immediate actions that can be taken by all healthcare stakeholders over the next several years in order to efficiently create a decentralized and standards-based network that is effective for healthcare and patients.

Our report is meant to build a realistic path forward and we do not call for whole-scale revision to the current system. Such an approach would be dangerously disruptive and prohibitively expensive. Instead we have brought a diverse group of stakeholders together to offer an incremental path forward that builds on two important concepts.

First, we accept, with appreciation, the good work already done in developing specific electronic health record (EHR) and personal health record (PHR) applications. Medication management tools are offered by pharmacies and pharmacy benefit managers; chronic disease tools are optimized for congestive heart failure or diabetes sufferers; secure e-mail and results reporting systems are being integrated with both hospital and ambulatory EHRs. Connecting for Health does not say that one approach is right and another wrong, but that the national infrastructure must support and accommodate connectivity among all of these – and that they must all conform to a small set of common principles, including use of an agreed upon set of standards. This goal manifests in our recommendation for creating a technical framework that is required to take our fragmented healthcare system and make investments that can lead to a more integrated, high quality patient care experience.

Second, the model we envision allows individuals and their authorized health professionals to construct the health record appropriate to their needs exactly when and how it is needed. The most innovative aspect the Preliminary Roadmap is the recommendations on how to develop a national health infrastructure through the creation of a “network of networks,” based on open standards, which can be created without a central database of health records or a National Health ID--both long-time barriers that have prevented bringing the benefits of information technology to the field of healthcare.

In order to be accepted by patients and providers, the network must safeguard the privacy of health information. Among the important implications of our proposed system for a network of networks, is that personal health information would continue to reside where it does now, primarily with hospitals and healthcare providers. According to the patient’s preferences, relevant health data could be assembled from numerous sources at the point of care, enabling decision making to be informed by past treatment successes and failures and medication history. Both the patient and the clinician could have direct access to this vital information.

The secure and confidential treatment of patient information is a fundamental design criterion of the health information infrastructure we endorse. We recommend the inclusion of architectural, technical, and policy safeguards within the “Common Framework,” to safeguard the privacy and security of patient data while at the same time permitting the rapid and accurate exchange of information among authorized users. Proposed steps for safeguarding privacy and security are embedded in the fabric of all of the Preliminary Roadmap recommendation areas.

Information about an individual’s health is usually stored in many different places by a variety of healthcare providers. According to the system we propose, information would be accessible only to authorized users and aggregated at the individual

patient level when and where it is needed. This would preclude the need to create large central stores of information.

Regardless, a set of standards and secure networks would allow information such as lab results, x-rays and medical history as well as clinical guidelines, drug labeling and current research findings to move where it is needed, immediately and securely. Regardless of where a beneficiary is receiving care, health information exchange networks would allow for information about medication history and potentially serious drug interactions to be available in real-time, along with out of pocket costs and therapeutic alternatives, before the physician transmits a prescription to a pharmacy.

Key Recommendations

The key recommendations fall into three broad categories:

- **Creating a Technical Framework for Connectivity:** A non-proprietary "network of networks" built on the Internet is essential to support the rapid acceleration of electronic connectivity that will enable the flow of information to support patient care. Such a network should be based on a "Common Framework." Only by conforming to a "Common Framework" can we ensure that data exchange pilots, personal health records, and regional systems will be able to interoperate across and with other regional systems. The network should be decentralized, based on interoperable standards, define standards for secure Internet transport, safeguard patient privacy and be built incrementally, without the use of a unique National Health ID or a centralized database of records.
- **Addressing Financial Barriers:** The current system does not provide incentives for the investment in high-quality healthcare achieved through interoperable information systems, and therefore incentives need to be redirected. Financial and other incentives and related processes must be designed to promote improvements in healthcare quality through the adoption of clinical applications and information exchange based on standards.
- **Engaging the American Public:** The public must be informed with a consistent set of messages to be used by government, healthcare, and consumer leaders to promote how patients can improve their own health and healthcare through the benefits of electronic connectivity and to encourage patients and consumers to access their own health information.

1. Creating a Technical Framework for Connectivity

In order to provide a majority of their benefits, clinical applications must interconnect with other clinical systems. The potential to avoid medical errors and drug interactions, to deliver real-time prompts and reminders at the point of care and directly to the patient or caregiver, and to improve the ability to conduct clinical research depend

on a highly connected network of regional healthcare communities that exchange data between effectively used clinical systems such as personal health records.

Unless there is purposeful attention paid to infrastructure requirements at the local, regional and national level, it is unlikely that piecemeal technology adoption will result in the connected infrastructure necessary to realize the quality of care and economic efficiency gains promised by IT. The network requires a high degree of connectivity that arises from trust, safeguards for privacy and security and a strategy that minimizes risks of patient data misuse. With that said, the approach must be voluntary and built on the premise of patient control and authorization.

In order to accelerate electronic connectivity, a non-proprietary “*network of networks*” built on the Internet that is based on standards and a decentralized and federated architecture should be developed, building upon local and regional networks. In addition, our proposed network is designed to be flexible to accommodate the various electronic health record (EHR) and personal health record (PHR) models that are already being developed. And in order to support the creation of the network where national standards are implemented locally and regionally, we have determined that a “*Common Framework*” is needed.

This “*Common Framework*” is comprised of standards, policies and methodologies that can be replicated quickly to ensure connectivity, reliable authentication; it would also include a minimum suite of standards that work together to support information exchange. We recommend that the common framework be tested and evaluated through a “*reference implementation or pilot project*” within the next 12 months. Because our incremental approach is designed to leverage existing infrastructure, it dictates that secure connectivity be built on the Internet and its communication protocols.

2. Addressing Financial Barriers

Among the most often cited barriers to the adoption of information technology in healthcare are misaligned financial incentives. Because of the way the payment system is structured, for many providers, especially in the small practice primary care setting, the acquisition or use of IT results in a net financial loss. Ambulatory care practices are on the front line for the treatment of patients in the United States today, specifically the chronically ill, yet have the lowest adoption rates of healthcare IT. One of the main reasons physicians and hospitals are not adopting clinical information technology at a rapid rate is due to the poor financial case. Despite these financial barriers, however, the promise of EHRs and other clinical information technology remain formidable. As several studies have shown, EHRs can advance the quality and efficiency of care, resulting in reduced medical errors, reduced utilization, and improved ability to manage chronic disease, the improved longevity and health status, among other potential benefits.

This gap between the potential of clinical information technology and the willingness to adopt these technologies raises the question of whether the market appropriately supports technology purchasers in society's efforts to realize value.

We recommend that incentives for IT—including applications, electronic connectivity and information exchange—include the requirement of use of standards and *interoperability*, since the majority of the benefits of IT accrue only when systems can talk to each other. Failure to encourage interoperability could lead to the growth of technologically sophisticated islands or silos of information, which would decrease the potential value of the investment in IT dramatically.

Our recommendations include the results of our insights regarding the level of incentives that would require “tilt” or cause significant change in the number of small and ambulatory private practices that begin to adopt electronic health records as a result.

3. Engaging the American Public

Our own research found that most members of the public do not fully understand the problem we are trying to solve. Many are unaware, except for a general perception that costs are high, of the inadequacy of our healthcare system, and the high volume of medical errors. In addition, the majority of Americans assume that their doctors use information technology far more than is actually the case. In fact, according to our own survey, more than half believe their own doctors are far more “wired” than is actually the case. Given these gaps in knowledge, it is not surprising that most people have not thought about how better use of technology within the system might improve healthcare quality.

Our research further shows that most patients or consumers have not fully conceived how they could benefit from *their own* access to and control of personal health information. This is in part because patients are in general used to being somewhat peripheral players in the traditional pattern of care. Many assume that their care is primarily the responsibility of the professionals. However, our research indicates that the vast majority of patients, when presented with a description of services that would enable them to participate more fully and conveniently in self-care, such as the ability to view test results or e-mail doctors directly, show a significant level of interest. We believe that it is essential to increase public awareness of the avoidable problems with healthcare delivery and of the potential of technology, and therefore recommend a large public education effort towards that end.

In order to support implementation of its recommendations, Connecting for Health will release a final version of the Roadmap and detailed reports by individual Working Groups that contributed to it by September. The final Roadmap will provide additional detailed recommendations for action and commitments from Connecting for Health's Steering Group members, and I would be delighted to share these with the members of this Committee in due course.

Finally: Robert Frost famously finished his poem, “The Road Not Taken,” by writing that he chose the road “less traveled by,/And that has made all the difference.” We believe that the Connecting for Health Collaborative is, in its own way, also on a journey. We invite all stakeholders in healthcare to examine the choices presented in this *Preliminary Roadmap* and then join with us, on behalf of those whose lives and health are at stake, in finding those paths that will make the greatest positive difference.

The steps forward described in the Connecting for Health Preliminary Roadmap will permit such innovations in care and patient engagement to occur. We believe that they will allow clinicians, entrepreneurs, and families to develop new and better ways to deliver services, to monitor health, and to manage care. They will also enhance the quality of research and public health. A system that provides an abundance of complete, reliable information to the point of care – and to the home – can reduce waste, error, and frustration while improving diagnostic accuracy, the quality of communications, and even the ability of family members to care for each other.

Thank you. I will be pleased to try to answer any questions members may wish to ask.

Appendix : Connecting for Health, Steering Group Participants

Steering Group Leaders

Carol Diamond, MD, MPH, Managing Director, Health, Markle Foundation
Daniel Garrett, Vice President and Managing Director of Computer Sciences Corporation's Global Health Solutions Practice
John R. Lumpkin, MD, MPH, Senior Vice President, Robert Wood Johnson Foundation and Chair, National Committee on Vital and Health Statistics
Janet M. Marchibroda, Executive Officer of the eHealth Initiative and the Foundation for eHealth Initiative
Herbert Pardes, MD, President and CEO, New York-Presbyterian Hospital

Steering Group Members

James Bradley, Chief Executive Officer, RxHub
Claire Broome, MD, Sr. Advisor, Integrated Health Information Systems, Centers for Disease Control and Prevention
Gwendolyn A. Brown, Director, Healthcare Policy, EDS, Global Government Affairs
Nancy Brown, Senior Vice President of Strategic Planning, McKesson Corporation
Garry Carneal, President and Chief Executive Officer, URAC
Gary Christopherson, Senior Advisor to the Under Secretary, Veterans Health Administration, Department of Veterans Affairs
Carolyn Clancy, MD, Director, Agency for Healthcare Research and Quality
Nathaniel Clarke, MD, Medical Director, American Diabetes Association
Richard A. Correll, President, College of Healthcare Information Management Executives
Janet Corrigan, PhD, Division Director, Institute of Medicine
Molly J. Coye, MD, MPH, Chief Executive Officer and Founder, Health Technology Center
Kelly Cronin, Executive Director, Council on the Application of Health Information Technology, Department of Health and Human Services
Mike Cummins, Chief Information Officer, VHA Inc.
Francois de Brantes, Program Leader, Healthcare Initiatives, General Electric Corporation
Mary Jo Deering, PhD, Special Expert for Informatics Dissemination and Coordination, U. S. Department of Health and Human Services
Carol Diamond, MD, MPH, Managing Director, Health, Markle Foundation
Robert Dickler, Sr. VP Division of Healthcare Affairs, Association of American Medical Colleges
Craig Fuller, Chief Executive Officer, National Association Of Chain Drug Stores
Daniel Garrett, Vice President, Managing Partner, Global Healthcare Leader, Computer Sciences Corporation
Peter Geerlofs, MD, Chief Medical Officer, Allscripts Healthcare Solutions
John Glaser, PhD, Vice President and Chief Information Officer, Partners Healthcare System, Chair, Working Group on Financial, Organizational and Legal Sustainability
Paul Gorup, Vice President and Co-Founder, Cerner Corporation
John Halamka, MD, Chief Information Officer, CareGroup Healthcare System; Chief Information Officer, Harvard Medical School
W. Edward Hammond, PhD, Professor, Community and Family Medicine Duke University
Linda Harris, PhD, Senior Health Communication Scientist, National Cancer Institute
C. Martin Harris, MD, Chief Information Officer, Cleveland Clinic
Douglas Henley, MD, Executive Vice President, American Academy of Family Physicians
Joseph Heyman, MD, Trustee, American Medical Association, American Medical Association
Yin Ho, MD, Director eBusiness, Pfizer, Inc
Kevin Hutchinson, Chief Executive Officer, SureScripts
Michael Jackman, Chief Technology Officer Health Imaging Group, Eastman Kodak Company
William F. Jessee, MD, President and Chief Executive Officer Medical Group Management Association

Brian Keaton, MD, FACEP, Attending Physician/EM Informatics Director and Summa Health System, Board Member, American College of Emergency Physicians
 Kenneth W. Kizer, MD, MPH, President and Chief Executive Officer, National Quality Forum
 Linda Kloss, Executive Vice President and Chief Executive Officer American Health Information Management Association
 David Lansky, PhD, President, Foundation for Accountability; Chair, Working Group on Policies for Electronic Information Sharing Between Doctors and Patients
 Mark Leavitt, MD, PhD, FHIMSS, Medical Director and Director of Ambulatory Care, Health Care Information and Management Systems Society
 Randy Levin, MD, Associate Director for Electronic Submissions Food and Drug Administration
 Jack Lewin, MD, President, California Medical Association
 Stephen Lieber, President, Healthcare Information and Management Systems Society
 Donald Lindberg, MD, Director, National Library of Medicine
 John R. Lumpkin, MD, MPH, Sr. Vice President, Director, Healthcare Group, Robert Wood Johnson Foundation and Chair, National Committee Vital and Health Statistics
 Janet M. Marchibroda, Executive Director, Foundation for eHealth Initiative; Chief Executive Officer, eHealth Initiative
 Clement McDonald, MD, Director of Regenstrief Institute; Distinguished Professor of Medicine, Indiana University School of Medicine
 Arnold Milstein, MD, MPH, Medical Director, Pacific Business Group on Health, The Leapfrog Group
 Thomas Murray, PhD, President, The Hastings Center
 Margaret O'Kane, President, National Committee for Quality Assurance
 Dennis S. O'Leary, MD, President, Joint Commission on Accreditation of Healthcare Organizations
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 Herbert Pardes, MD, Chief Executive Officer, New York-Presbyterian Hospitals, University Hospitals of Columbia and Cornell
 James Reardon, Chief Information Officer, Tricare Management Activity, Department of Defense
 Russell J. Ricci, MD, Chief Medical and Strategy Officer, HealthSTAR Communications
 Craig Richardson, Vice President Health Care Connectivity and Alliances, Johnson & Johnson Pharmaceutical Services
 Wes Rishel, Vice President, Gartner Research
 William Rollow, MD, Deputy Director, Quality Improvement Group Office of Clinical Standards and Quality Centers for Medicare and Medicaid Services
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 Ellen Stovall, President, National Coalition for Cancer Survivorship
 Thomas Sullivan, MD, Past President, Massachusetts Medical Society, Women's Health Center Cardiology
 Paul Tang, MD, Chief Medical Information Officer, Palo Alto Medical Foundation
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