PREPARED STATEMENT BY CAROL D. DIAMOND, MD, MPH
MANAGING DIRECTOR, MARKLE FOUNDATION
CHAIR, CONNECTING FOR HEALTH

Committee on Government Reform
U.S. House of Representatives

Engaging Americans in their Health and their Health Care through Health IT

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Chairman Davis and distinguished members of the Committee on Government Reform, thank you for inviting me to meet with you today.

Attention Has Intensified

In the last few years, public and private sector awareness of the need for information technology in health care has intensified dramatically. Prominent government activities include the President's call for the creation of electronic health records for all Americans, numerous legislative bills, implementation of many agency pilots and programs, the activities of the Office of the National Coordinator for Health Information Technology, and, most recently, the establishment by Secretary Leavitt of the AHIC. These efforts represent a broad commitment to bring about change.

But all this is merely prelude. We continue to lack an information infrastructure that supports safe, efficient, evidence-based medical care. Even the best-trained, best-equipped, and best-intentioned American health professional cannot provide high quality care in an information vacuum. No research study or pilot program better highlights this point than the reality of Hurricane Katrina. As you know, hundreds of thousands of residents of areas hit by the hurricane were displaced from their homes and most are still living in shelters or temporary housing across the United States. Neither the evacuees nor their current health care providers have access to their paper medical records, many of which were destroyed by the hurricane. A survey by the Kaiser Family Foundation and the Washington Post estimated that 40 percent of evacuees were taking prescription medications before the storm hit, and many more need new or additional medications now. Many of their medical records can never be recovered and have literally been washed away by the total devastation of their usual sources of care. Piecing their medical histories together and figuring out what medications they were on is a daunting task for those providing their care now.

From the earliest experiences of the first responders providing medical care to the heart-wrenching stories that continue to emerge about the consequences of such a massive disruption in health care for these evacuees there was a clear message about what was needed—the ability to know at a minimum what prescription medications and therapeutic regimens these evacuees were on before the disaster hit. Without access to their prescriptions and recent medication history, thousands of Americans with daily health care needs ranging from cancer to managing serious chronic conditions have been suddenly exposed to grave risks. Katrina underscores the critical need for real-time access to the most-up-to-date summary of medical history information at the point-of-care, regardless of where individuals are being treated.

In response to the storm, ONCHIT, the Markle Foundation, and 150 other public and private organizations worked closely in an intense crash effort to establish an online service for authorized health professionals to gain electronic access to prescription medication records for evacuees (www.katrinahealth.org). The medication history information from a variety of government and commercial sources has been indexed and made accessible through a single Internet portal. Sources include electronic databases from commercial pharmacies, government health insurance programs such as Medicaid and the Veteran's Health Administration, private insurers, and pharmacy benefits managers in the states affected by the storm. As a result of this effort, today most evacuees can approach any retail pharmacist or licensed physician in America and, with proper credentials, gain access to vital information about their recent medication history.

This was a marvelous collaborative effort – but it should not require weeks of 24/7 heroics by hundreds of good-hearted Americans responding to a tragedy to move a simple string of bytes across a wire into a health professional's hands. In truth, the technologies to move health information between facilities or communities are relatively well understood – and operate today within many complex enterprises. Instead, KatrinaHealth.org came into being because of a good-faith commitment to overcome established business, legal, and policy obstacles to information sharing. If there is any lesson in this that can be instructive going forward, it is that a narrow focus on the technical aspects of creating an electronic health information environment will not produce a sustainable, effective network. The policies that govern information access, acceptable uses, consent, privacy and security must be crafted in parallel with the deployment of technology if we are to have a trusted and effective health information environment. And the technology choices, themselves, must incorporate the policy objectives.

Today, if I were to need emergency care here in Washington, no information about me would be available to my providers, and my care would depend on my memory and good guesses by my doctors – just as over a million Katrina victims found themselves without their health information at a critical time. We must move quickly to create an information environment that can move a patient's critical health information where it's needed, when it's needed – while protecting the privacy and security of that information and providing the patient with the ability to access and control it.

About Connecting For Health

Many of us involved in the response to Katrina have been working together over the last few years as part of a broad collaboration focused on using information technology to provide the American people with electronic access to their medical records. Our history of collaboration and problem solving toward this goal enabled us to move quickly to meet the emergency needs caused by the hurricane.

For the last three 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 health care into the information age - to improve the quality of health care, reduce medical errors, lower costs and empower patients.

Today, Connecting for Health is a truly unique public-private sector initiative, consisting of over 100 stakeholders representing providers, patients, payers, accreditors, government agencies, researchers and health care information systems manufacturers and vendors (see the appendix for the list of current Steering Group members).

Connecting for Health has been actively participating in shaping the national drive toward interoperable health. In our 2004 Roadmap document, "Achieving Electronic Connectivity in Healthcare: A Preliminary Roadmap from the Nation's Public and Private-Sector Healthcare Leaders," we recommended a consensus set of immediate actions to be taken by all health care stakeholders to create a decentralized and standards-based information network of networks that is effective for health care and patients.

Based on the principles laid out in the Roadmap, Connecting for Health is now operating a novel prototype of an electronic national health information exchange based on common, open standards. This effort is the first step in enabling patients and authorized physicians in all 50 states and DC to share health information on a completely voluntary basis in a secure and private manner. The prototype, which includes the exchange of information both within and among local communities, is now being conducted in California, Indiana, and Massachusetts.

To be specific, the model of information exchange Connecting for Health envisions– based on a "Common Framework" of open, consensus-driven and non-proprietary standards, uniform policies that protect privacy, assure security, and support existing trust relationships, and a common technical approach to linking personal health information – can be the springboard to a generation of innovation and improvement in health care and in personal health. Clinical models, self-care and decision-support tools, application and communications software, and even redesigned care practices will emerge within this new environment. Research and innovative approaches to prevention and treatment can be strengthened and the results integrated more rapidly into health care and health-related decision making. The delivery of high quality care can become more likely, less expensive, and timelier – bringing the right skills and knowledge to the right person at the right time. We can put patients and families at the very center of the health care system, supported and surrounded by an information environment that they can use –

or allow others to use – to make decisions, monitor health, provide feedback, and support strategic analytic functions that produce measurable improvements in health.

The Connecting for Health Model

The basic idea underlying the Roadmap and now the prototype is that information exchange can take place among existing health care institutions over the Internet if all participants adhere to a small set of shared rules—a "Common Framework" of technical components, standardized methodologies, and explicit policies for information use and governance. We believe that general adoption of this small set of critical tools can permit rapid attainment of an interoperable information environment that supports modern health care practice.

The many Connecting for Health collaborators identified several features of the future health information environment. These provide the basis for the prototype information exchanges we are now operating. With contemporary technology – and to help protect patients' privacy – we do not advocate a system that requires taking personal health information out of the hands of those who collect it: doctors, patients, hospitals, pharmacies and others. There are many effective information networks already working in health care today – tying together large health systems like the Veterans Health Administration or Kaiser Permanente, community-wide networks such as the New England Health Exchange Network, and large business networks such as the prescription benefits management and laboratory companies. We can leverage the investment and sophistication of these existing networks, and tie them together in a distributed, federated "network of networks". By adopting common data standards, and common rules for handling the information and assuring patient privacy, any authorized party should be able to access and share appropriate information with another authorized party.

The key to this approach is the articulation of nationally uniform policies and technical standards – so that every entity that wishes to share information across the network knows the rules and can choose to conform to them. Every network participant – and every patient – needs to be confident that health information will be handled in a secure, reliable and trustworthy way. Patients must be afforded a means of controlling who accesses their personal health information and how it is used. And, as the Internet has taught us, we do not need to have a central administrator issuing permissions or charging a toll for every information exchange if the network has been properly designed.

Connecting for Health believes that there needs to be a single national entity to promulgate both the policy and technical standards that provide structure to our health information environment. The AHIC recently defined by Secretary Leavitt may be the first institutional attempt to provide these functions, and we intend to work closely with the AHIC and the contractors and partners that will be engaged. Our work highlights the importance of several elements of these national standards and policy bodies. They must represent the public interest – both through their governance and participatory processes - and not only the interests of any particular professional or stakeholder sector. They must maintain transparency and accountability to the public. Above all, the work of defining policies and public priorities must be closely linked to the selection and implementation of the enabling technologies.

These design characteristics have been endorsed by a broad-cross section of public interest and private sector stakeholders, and are now being implemented in our prototype. We believe that they form the basis of a distinctively American solution to the challenges of 21st century health care. It is particularly important to note that this approach creates an information architecture that provides maximum protection to the privacy of personal health information while accommodating innovation in the management of information and, indeed, in the configuring of health care services.

Engaging Patients in the Process

The will to overcome the technical, financial, and other barriers to information exchange, and the ultimate success of efforts to promote widespread adoption of HIT and electronic health records will depend on the confidence and willingness of consumers to accept and use the technology.

Policymakers must take into account that the public has serious concerns about health information technology. Seventy percent of Americans believe that a system of electronic health records would result in exposure of private health information, and 69 percent worry that such a system would result in more sharing of personal health information without their knowledge, according to a recent Harris survey. The same survey found that almost half of Americans believe that the privacy risks outweigh any other benefits that health information technology has to offer.

Given the concerns expressed by the public, the federal government needs to establish a meaningful process to address the issues and priorities of consumers as it moves forward with AHIC and other activities spear-headed by ONCHIT to advance widespread adoption of HIT. We are working now with a network of over thirty national consumer groups who are aware of the importance of information technology in health care and want to help shape this agenda for the benefit of their constituents. These groups are ready to serve on appropriate boards and commissions, but the need to address consumer concerns goes beyond nominal participation in advisory bodies.

We must remember that Americans regard their personal health information as "sacred," and all of us share a public trust to treat their information with suitable care and not merely as a business commodity. Patients and consumers must be given the ability to control whether and how their information is used, and both technology and policy solutions must make every effort to assure the secure handling of patient information. As we design our health information environment – including the first projects prioritized by the AHIC and other federal investments, we must include the patient and family as essential users of the information network. We hear much talk about "patient-centered" and "consumer-driven" health care, but these objectives will not be reached if we fail to design our information network with the individual as the most important user.

Engaging Americans in their own Care

Personal Health Records (PHRs) can and should play an important role in helping bridge an information gap that exists too often today between people and the health professionals who serve them. Such PHRs would enable people to manage their health information and health care transactions electronically. By facilitating a host of health management activities, PHRs have the potential not only to improve personal and family health but also to support major national health objectives.

There is good reason to believe that general use of PHRs – leveraging an interoperable health IT environment - could improve health and trigger a restructuring of our health care system (see the Connecting for Health report "Connecting Americans to their Healthcare" at www.connectingforhealth.org). In early research studies, PHRs have been found to help people:

- Understand the health issues and decisions they face.
- Improve engagement with physician recommendations and disease management plans.
- Assume a greater responsibility for their care.
- Monitor important data about themselves on a regular basis.
- Verify the accuracy of the information in their medical records.
- Avoid bureaucracy in tracking down their information.
- Facilitate communication with family members and friends about health issues.
- Improve communication with physicians.
- Share in the decision making process with their provider.
- Require less physician time is spent tracking down medication information.
- Flag interactions, contraindications, side effects and allergies.
- Reduce the number and the associated costs of unnecessary and duplicative tests.
- Increase the efficiency of making and responding to requests for information from various providers.
- Improve the outcomes of care, and reduce the associated health care costs, for people with chronic conditions.
- Save professional, administrative and patient time.

But most of these gains cannot be achieved if personal health records remain isolated from the mainstream of medical care. The value of electronic health records will only be maximized when we have a health information environment that allows information to move freely from one professional component to another – and for it to move both to and from the patient.

Several federal agencies have begun to include PHRs in their programs and plans. This expanding federal activity is generating questions about how government can best support and serve the public interest as PHRs evolve. Awareness is growing within and beyond government of the need for a more strategic and coordinated federal approach in this area. In addition, many governmental agencies have espoused the principles of patient-centered care, greater consumer control and empowerment, improved chronic care management and fuller translation of knowledge into practice with respect to both public health and health care. If PHRs are a means toward these important policy goals, as many believe, then government can be expected to help nurture their development in its own programs and in the country as a whole.

These dual goals – an interoperable environment and widespread distribution of personal health records that connect to that environment – will only be achieved by collaboration between the public and private sectors, and with federal leadership.

Congress and the Administration have begun to take the critical first steps. The creation of a single national entity to set standards and policies, development of personal health records by government agencies, funding of small demonstration projects – these are all worthwhile. But the images of Hurricane Katrina victims should remind us that we need to act quickly and creatively. Key elements of infrastructure must be created immediately, so that every bit of health information that is now stored in digital form can be made available to those who need it when authorized by the patient.

Conclusion

As the government continues to evaluate and coordinate national efforts, Connecting for Health will be ready to help in any appropriate way. We represent the widest diversity of our great health care system – patients, professionals, payers, researchers, technologists, regulators – and we want to see our national system fulfill its potential to help every American achieve the best possible health with the available resources. Our approach is above all pragmatic; it is based not on any particular ideology or economic interest, but on our shared sense of what practical actions will bring results. We can work together to achieve the national vision of an interconnected heath system by 2014. 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

Peter A. Andersen, MD, Senior Program Manager, Lockheed Martin Information Technology
William Braithwaite, MD, Senior Vice President and Chief Medical Officer, eHealth Initiative, Co-Chair Policy Sub Committee
Claire Broome, MD, Sr. Advisor to Director for Integrated Health Information Systems, Centers for Disease Control and Prevention
Gary Christopherson, Deputy Director, Quality Improvement Group Office of Clinical Standards and Quality, Centers For Medicare and Medicaid Services
Carolyn Clancy, MD, Director, Agency for Healthcare Research and Quality
Janet Corrigan, PhD, President and CEO, National Committee for Quality Health Care
Mike Cummins, Chief Information Officer, VHA Inc.
Francois de Brantes, Program Leader, Health Care Initiatives, GE Corporate Headquarters
Mary Jo Deering, PhD, Director for Informatics Dissemination, National Cancer Institute/National Institutes of Health, USDHHS
Don Detmer, MD, FACMI. President, AMIA
Carol Diamond, MD, MPH, Managing Director of the Health Program, Markle Foundation
David Epstein, Director, Solution Development - Public Sector, IBM
Colin Evans, Director Policy & Standards, Digital Health Group, Intel Corporation
Mark Frisse, M.D., MBA, MSc, Accenture Professor and Director, Tennessee Volunteer eHealth Initiative, Vanderbilt Center for Better Health, Co-Chair Policy Sub Committee
Daniel T. Garrett, Vice President and Managing Partner, Computer Sciences Corporation
Peter Geerlofs, MD, Chief Medical Officer, Allscripts Healthcare Solutions
John Glaser, PhD, Chief Information Officer, Partners HealthCare System
John Halamka, MD, Chief Information Officer, CareGroup Healthcare System
W. Edward Hammond, PhD, Professor, Community and Family Medicine Duke University
Linda Harris, Ph.D., Senior Health Communication Scientist, National Cancer Institute
Douglas Henley, MD, Executive Vice President, American Academy of Family

Physicians
Joseph Heyman, MD, Secretary, 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
Charles Jaffe, MD, PhD, Senior Global Strategist, Digital Health Group, Intel Corporation
William F. Jessee, MD, President and CEO, MGMA
Michael L. Kappel, Sr Vice-President, Government Strategy and Relations, McKesson Provider Technologies
Brian Keaton, MD, FACEP, Attending Physician/ EM Informatics Director and Board Member, ACEP Summa Health System
Linda Kloss, RHIA, CAE, Executive Vice President and CEO, AHIMA
Allan Korn, MD, FACP, SVP eClinical Affairs Blue Cross Blue Shield Association
David Lansky, PhD, Senior Director, Markle Foundation
Gail Latimer, MSN, RN, Vice President, Chief Nursing Officer, Siemens Corporation
Mark Leavitt, MD, PhD, FHIMSS, Medical Director / Director of Ambulatory Care HIMSS - The Source for Healthcare Information
Gary Levine, Senior Director, Business Planning & Development, Medco Health Solutions
Jack Lewin, MD, President, California Medical Association
Stephen Lieber, CAE, President, HIMSS
John R. Lumpkin, Senior Vice President Director, Health Care Group, Robert Wood Johnson Foundation
Patricia MacTaggart, Director, EDS Executive State and Local Government
Janet M. Marchibroda, Executive Director, eHealth Inititiative
Howard Messing, President, Meditech
Arnold Milstein, MD, MPH, Medical Director, Pacific Business Group on Health, The Leapfrog Group
Margaret O'Kane, President, National Committee for Quality Assurance
Dennis O'Leary, MD, President, Joint Commission on Accreditation of Healthcare Organizations
J. Marc Overhage, MD, President and Chief Executive Officer, Indiana Health Information Exchange; Associate Professor of Medicine, Indinana University, School of Medicine Regenstrief Institute for Healthcare
Herbert Pardes, MD, Chief Executive Officer, New York-Presbyterian Hospitals, University Hospitals of Columbia and Cornell
Alison Rein, Assistant Director of Food and Health Policy, National Consumers League
Russell J. Ricci, MD, Chief Medical and Strategic Officer, HealthSTAR Communications
Craig Richardson, Vice President, Health Care Connectivity and Alliances, Johnson and Johnson Health Care Systems, Inc
Wes Rishel, Board Chair, Health Level Seven, Gartner
William Rollow, MD, Deputy Director, Quality Improvement Group Office of Clinical Standards and Quality Centers for Medicare and Medicaid Services
David Schulke, Executive Vice President, The American Health Quality Association

Steve Shihadeh, General Manager of the Healthcare Industry Solutions Group, Microsoft
Clay Shirky, Adjunct Professor, New York University
Steve Sleigh, PhD, Director, Strategic Resources, International Association of Machine and Aerospace Workers
Michael Solomon, VP Strategic Planning & Initiatives, IDX Systems Corporation
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
Robin Thomashauer, Executive Director, Council for Affordable Quality Healthcare
John Tooker, MD, MBA, FACP, Executive Vice President American College of Physicians
Micky Tripathi, Chief Executive Officer, Massachusetts eHealth Collaborative
Charlene Underwood, Director/Government & Industry Affairs, Siemens Corporation
Robert Wah, MD, Captain, MC, USN Director, Information Management, Department of Defense
Scott Wallace, President/Chief Executive Officer, The National Alliance for Health Information Technology
Andrew Wiesenthal, MD, Associate Executive Director, The Permanente Federation
Robert B. Williams, MD, MIS Director, Healthcare Consulting Deloitte
Chelle Woolley, Communications Officer, RxHub
William Yasnoff, MD, PhD, Managing Partner, NHII Advisors