CONNECTING FOR HEALTH...A PUBLIC-PRIVATE COLLABORATIVE CONVENED BY THE MARKLE FOUNDATION

"In God we trust; all others must bring data."
--W. Edwards Deming, physicist and quality improvement pioneer

There is a critical need to push health care into the information age. Our nation faces an aging population, a rising tide of consumerism, escalating health care costs, medical safety lapses, and the increased complexity that advances such as genetic discoveries will introduce into clinical data analysis and application. In the face of such challenges, however, health care is not taking full advantage of the information and communications technologies that have revolutionized other industries. Enabling timely and efficient access to information can improve both the quality and cost-effectiveness of care and strengthen the efforts of consumers, patients, and caregivers.

Connecting for Health, a Public-Private Collaborative ("the Collaborative"), an effort convened by the Markle Foundation, intends to address the challenges of mobilizing information to improve quality, conduct timely research, empower patients to become full participants in their care, and bolster the public health infrastructure. The purpose of the Collaborative is neither to report nor exhort. It is, simply, to catalyze specific actions on a national basis that will rapidly clear the way for an interconnected, electronic national health information infrastructure. The Collaborative plans to accomplish this by focusing on three key areas,

- Accelerating the rate of adoption of national clinical data standards throughout the nation's health care system in order to facilitate interoperability.

- Identifying practical strategies and solutions for developing an interconnected electronic infrastructure that will ensure the secure and private transmission of medical information and support the continuity of personal health information across plans and providers.

- Actively working to understand what consumers will need and expect from an interconnected health information system and identifying key steps for meeting their needs.

Together, we must begin to address America's health care system's shortcomings head-on and identify practical solutions. The technology exists. And the political will in both the public and private sectors is ripe for driving the change that is necessary to make our vision for improved health and health care a reality.

> "Science is the knowledge of consequences, and dependence of one fact upon another."
> --Thomas Hobbes, 17th century English philosopher

Despite the sophistication of the U.S. health care system, enormous barriers continue to stand in the way of our delivering the best health care to all Americans. Because of the highly fragmented nature of our health care system—where care is delivered by a variety of independent physicians and other providers working in a broad spectrum of inpatient and ambulatory settings-- medical information is often collected and reported in a piecemeal fashion. Consumers and patients interact with many plans and providers over a lifetime, making the continuity of their personal health information, vital to health outcomes, a continuing challenge.

While the advent of electronic information systems has brought us closer to connecting health care information from disparate sources, there is still a significant amount of work to do. The lack of clinical data standardization, even within a single institution, has resulted in incompatible systems that frequently cannot communicate with each other in an efficient manner.

As a result of the fragmented state of health information,

- Physicians and other clinicians are sometimes providing patient care without knowing what has been done previously and by whom, resulting both in wasteful duplication and in clinical decisions that do not take into account critical data related to patient health. In fact, studies show that paper hospital records are unavailable when needed approximately one-third of the time.

- Hospitals and physicians are often unable to obtain usable information that will help either in applying research breakthroughs to the needs of individual patients or in avoiding preventable medical mistakes.

- Public health agencies and providers are unable to exchange the information that is critical to identifying, tracking, and responding to health threats ranging from traditional epidemics to deliberate bioterror attacks.

- Health services researchers do not have ready access to the data required to develop improved processes of care that will lead, in turn, to improved health outcomes.

Patients who wish to collaborate with their doctors in managing their own health are given little information with which to work. Meanwhile, private and governmental payers, as well as individual workers, taxpayers, and consumers, continue to bear the financial burden of clinical inefficiency.

While many recognize the need for electronic systems to address these challenges, electronic medical records are currently used by fewer than five percent of all U.S. hospitals. Moreover, without standards for interoperability among systems, there will still be significant gaps in the information needed by both patients and clinicians. The time for change is now.

ORGANIZATION

> "Providers, those responsible for population health, and most importantly consumers, should have ready access to timely, relevant, reliable and secure health care information through an interconnected, electronic health information infrastructure to drive better health and health care."
> --Zoë Baird, President, the Markle Foundation, 2002.

The Markle Foundation, an independent national philanthropy with interests in both technology and health care, will serve as convener for the Collaborative and play an active role in its work. In addition to providing initial funding of $2 million, the Markle Foundation will reach out to other stakeholders in the health care community to engage them in this effort. These stakeholders include practicing clinicians; hospitals; employers and other third-party payers; federal and state government organizations; health care information technology organizations; academic and research institutions; national standards groups; manufacturers; community organizations; and consumers.

The Collaborative will not favor any one industry or any one stakeholder. To the extent possible, all stakeholder groups will be represented either through Steering Group or Working Group membership or through an advisory role extended to all Collaborative partners. Individual partners will participate in various capacities depending upon their expertise, interest, and explicit commitment to taking actions that will result in the achievement of the Collaborative's goals.

Three Working Groups will develop a series of action-oriented deliverables in the areas of data standardization, privacy and security, and personal health within nine months of their first meeting. The Working Groups will be organized as follows:

- The **Data Standards Working Group** will focus on:
  - √ Establishing consensus on a core set of data and communication standards, specifications and related components that meet the overlapping needs of patients, providers, and public health agencies;
  - √ Defining the key barriers to the widespread adoption of those standards, specifications, and related components;
  - √ Identifying and implementing strategies to accelerate adoption.

The group will be chaired by W. Edward Hammond, PhD, President of the American Medical Informatics Association (AMIA), Vice-Chair of the Technical Steering Committee of HL7, and Professor, Community and Family Medicine at Duke University.   J. Marc Overhage, MD, PhD, Associate Professor of Medicine, Indiana University School of Medicine and Investigator, Regenstrief Institute will serve as vice-chair for the Working Group.

- The **Privacy and Security Working Group** will focus on:
  - √ Gaining consensus on high-level policies and workable requirements for clinical data sharing that protect the privacy of individuals;
  - √ Translating those policies and requirements into architectural models, controls and methods for clinical data exchange that can be implemented today.

The group will be chaired by Thomas H. Murray, PhD, President and Chief Executive Officer of the Hastings Center.

- The **Personal Health Working Group** will focus on:
  - √ Working to understand roles and opportunities for consumers in an interconnected health system;
  - √ Creating a shared vision for the attributes of a longitudinal, patient-centric, electronic health record.

The group will be chaired by David Lansky, PhD, President of the Foundation for Accountability.

Finally:

- A ***Steering Group*** will be convened by the Markle Foundation and chaired by Carol Diamond, MD, MPH, Managing Director of the Foundation's Information Technologies for Better Health Program. Janet Marchibroda, Chief Executive Officer of the eHealth Initiative, will serve as the Group's executive staff director. Three respected executive vice chairs will complete the group:

  John R. Lumpkin, MD, MPH, director, Illinois Department of Public Health and Chair, National Committee on Vital and Health Statistics;

  Herbert Pardes, MD, president and CEO, NewYork-Presbyterian Hospital;

  Russell J. Ricci, MD, general manager, IBM Global Healthcare Industry.

  The group will focus on:
  - √ Articulating a vision for the Collaborative's work;
  - √ Providing strategic oversight of the three Working Groups;
  - √ Obtaining consensus on and driving action plans to realize the work developed by the Collaborative.

RATIONALE

"There is a real possibility that the information highway and reorganization of the health-care system can create an opportunity for the physician, in collaboration with other members of the health-care team, to provide an even more sensitive, caring and compassionate service to their patients and society."
--Kenneth I. Shine, MD, President, Institute of Medicine

The Connecting for Health Collaborative is part of the larger effort to build a national health information infrastructure, an idea first broached in an Institute of Medicine report on computer-based patient records in 1991. That vision has since been elaborated on by a variety of governmental and private groups. It was endorsed most recently in a November, 2001 report by the President's Information Technology Advisory Committee and the National Committee on Vital Health Statistics entitled *Information for Health: A Strategy for Building the National Health Information Infrastructure.*

Even more broadly, the Collaborative's goals fit within the context of a rising tide of consumerism that is in the midst of reshaping the health care system into a new, more patient-centered form.

The Collaborative actively seeks to leverage the work already done by others in this field and to draw upon "best practices" demonstrated by existing clinical data sharing projects. The Collaborative is also building upon the work of the eHealth Initiative Foundation's *Public-Private Sector Collaboration to Improve Public Health*. The Foundation has convened federal agencies such as the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), state and local public health organizations, national standards groups, providers, and health care information technology organizations to drive the exchange of standardized, electronic clinical information for public health purposes.

DISSEMINATION

The work of the Collaborative will be shared broadly through a number of print and electronic formats, including:

- Markle Foundation Connecting for Health Web site;
- Meetings and conferences (in-person and via phone or Web access);
- Publications (electronic and print);
- Briefings for key stakeholder groups, policymakers and the news media;
- Outreach to other groups.

IMPROVING LIFE IN THE INFORMATION AGE

"We are at our best when we give the doctor who resides within each patient a chance to go to work."--Dr. Albert Schweitzer.

In a July, 1999 open letter, Markle president Zoë Baird discussed the ways in which the digital revolution has begun transforming our economic, social, political and cultural life. "Although entrepreneurial energy will continue to drive change," she wrote, "…the time is now, while the industry is still evolving, to move with the speed of the industry itself to help ensure that it meets public needs."

In health care, that means ensuring that information systems give individual patients a way of capturing their own health data, relating that data to the broader world of medical knowledge and doing all of that in an interactive environment that is secure and private.

Connecting for Health…A Private-Public Collaborative meshes with the Markle Foundation's history as catalyst, pioneer, experimenter and builder of bridges between government, business and academia. The moment of opportunity to build societal needs into a national health information infrastructure is at hand.