

# CONNECTING FOR HEALTH<sup>SM</sup>

MARKLE FOUNDATION

*A Public-Private Collaborative*

March 6, 2006

To Secretary Leavitt and the Members of the AHIC:

We, the members of the Personal Health Technology Council, commend your leadership in promoting Guiding Principles that emphasize consumer empowerment and the protection of personal health information. We believe that these principles should inform the AHIC discussion and the process of developing policies for the emerging person-centered, networked health information environment. We recognize that a clear and pragmatic approach that reflects fresh thinking and a deliberate, participatory process will be necessary.

The HIT agenda will be slowed and put at risk unless the AHIC establishes **a public process to develop and disseminate policies** to guide the work of Federal agencies and contractors, and provide voluntary guidance to health information exchange efforts in the private sector.

The policy process must provide for periodic review and revision, a mechanism for evaluating exceptions, and a means to ensure accountability to the principles and policies. To be successful, these review and oversight mechanisms must be broadly participatory and inclusive.

In light of the immediate deployment of various prototype and demonstration projects, time is of the essence to ensure that policy development and technology deployment are undertaken in tandem and earn the trust and support of the American public.

## **Consumer Empowerment Working Group Guiding Principles**

Individuals should be guaranteed the right to access their own health information.

Individuals should be able to access their personally identifiable health information conveniently and affordably.

Individuals should know how their personally identifiable health information may be used and who has access to it.

Individuals should have control over whether and how their personally identifiable health information is shared.

Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information.

The governance and administration of electronic health information networks should be transparent and publicly accountable.

## PERSONAL HEALTH TECHNOLOGY COUNCIL

The Markle Foundation's Personal Health Technology Council endorses the above letter and principles.

Endorsement by the Council, whose members are listed below, does not imply endorsement by the organizations of the Council members.

<b>Lead</b>	Rex Cowdry, MD Executive Director Maryland Health Care Commission	Ed Fotsch, MD Chief Executive Officer Medem
David Lansky, PhD Director, Health Program Markle Foundation	Nancy Davenport-Ennis CEO National Patient Advocate Foundation	Peter Frishauf Board of Directors Healthcare Marketing & Communications Council, Inc.
<b>Members</b>	Richard Dick Chief Executive Officer You Take Control	Gilles Frydman President ACOR
Tim Andrews Principal Transform Partners	Eric Dishman General Manager, Consumer Health Platform Intel Corporation Digital Health Group	Janlori Goldman Director Health Privacy Project
Wendy Angst General Manager CapMed, A Division of Bio- Imaging Technologies, Inc.	Stephen Downs Senior Program Officer Robert Wood Johnson Foundation	Ken Goodman, PhD Director, Bioethics Program University of Miami
Rodney Armstead, MD, FACP Chief Executive Officer Care 1st Health Plan Arizona	Joyce Dubow Associate Director AARP Public Policy Institute	Jonathan Hare CEO Resilient
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Carmella Bocchino, RN, MBA Vice President, Medical Affairs American Association of Health Plans	Stefanie Fenton E2E Healthcare Category Management Intuit	Kathleen Mahan Vice President, Product Management SureScripts
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### Participating Federal Agencies:

- Agency for Healthcare Research and Quality
- Centers for Medicare & Medicaid Services
- Department of Veteran's Affairs
- National Cancer Institute
- Office of Disease Prevention and Health Promotion

Note: Federal employees collaborate on the Council but make no endorsement.