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## **Broad Coalition Says Consumer Role Is Key to Improving Health and Health Care**

*Organizations Endorse Markle Foundation Collaboration to Increase Consumer Access to Personal Health Information and Protect Privacy*

*Information Technology for Health Care Reform Should Increase Consumer Participation*

NEW YORK, N.Y. — The future of health care should encourage expanded use of information tools to help consumers better manage their health, 56 diverse organizations said today as they embraced a framework for personal health information access and privacy.

"Consumers need to be full participants in modern health information tools and services to help them prevent illness, communicate better with clinicians, understand costs and treatment options, make better health decisions, and take better care of loved ones," the group said in a joint [statement](#).

"Health reform requires putting the power of information at the fingertips of 300 million consumers," said Zoë Baird, president of the Markle Foundation, which convened the group. "If we do this right, consumers will contribute to a health care system that rewards quality, slows an unsustainable spiral of costs, and protects the privacy of sensitive information."

The recently enacted American Recovery and Reinvestment Act establishes billions of dollars in incentives for clinicians and hospitals to use health information technology, including electronic health records (EHRs). The law also clarifies that individuals have the right to receive copies of personal health information from EHRs in electronic formats and authorize their information to be stored in a service of the individual's choosing.

"In the age of the Internet, there is vast potential for consumers to connect online to new services to make their lives easier and healthier," said Carol Diamond, MD, MPH, chair of Markle Connecting for Health, which convened the group. "Providing consumers with electronic access to their information should be one of the things that the health IT incentives stimulate, so that many services may flourish by using information according to the individual's needs and wishes."

Deven McGraw, director of the Health Privacy Project for the Center for Democracy and Technology, said: "Sound policies are key to public trust — without which we will not see the benefits of health IT investments. Consumers and clinicians will not participate if they fear information will not be protected."

The Markle Connecting for Health Collaborative's Common Framework for Networked Personal Health Information — a set of practices to improve consumer access to personal health information and protect privacy — has been endorsed by a broad group of organizations. The list expanded

today with the addition of Allscripts, American College of Cardiology, American College of Emergency Physicians, American College of Physicians, CareGroup Healthcare System, Carestream Health Inc., Computer Sciences Corp., DrFirst, GenesysMD, Health 2.0 Accelerator, Health Level Seven, IEEE-USA, Intel Corp., Keas Inc., McKesson/RelayHealth, MedCommons, Medical Group Management Association, National Coalition for Cancer Survivorship, National Committee for Quality Assurance, National Quality Forum, Northwest Health Foundation, PatientsLikeMe, Prematics, Verizon, Visiting Nurse Service of New York, and Wal-Mart.

The full list of endorsing organizations since it was released in June 2008 includes:

AARP • Aetna • Allscripts • American Academy of Family Physicians • American College of Cardiology • American College of Emergency Physicians • American College of Physicians • Association of Cancer Online Resources (ACOR.org) • America's Health Insurance Plans • BlueCross BlueShield Association • CareGroup Healthcare System • Carestream Health Inc. • Center for Democracy and Technology • Center on Medical Record Rights and Privacy • Cisco Systems Inc. • Computer Sciences Corp. • Consumers Union • Dossia • DrFirst • FollowMe • Google • Geisinger Health System • GenesysMD • Health 2.0 Accelerator • Health Care For All • Health Level Seven • InterComponentWare Inc. • IEEE-USA • Intel Corp. • Intuit Inc. • Keas Inc. • McKesson/RelayHealth • Metavante • MedicAlert Foundation International • MedCommons • Medical Group Management Association • Microsoft Corp. • National Breast Cancer Coalition • National Coalition for Cancer Survivorship • National Committee for Quality Assurance • National Partnership for Women and Families • National Quality Forum • NewYork-Presbyterian Hospital • Northwest Health Foundation • Pacific Business Group on Health • Palo Alto Medical Foundation • Partners Healthcare System • PatientsLikeMe • Prematics • Surescripts • U.S. Department of Veterans Affairs • Vanderbilt Center for Better Health • Verizon • Visiting Nurse Service of New York • Wal-Mart • WebMD

The framework — developed by the Markle-operated **Connecting for Health** public-private collaborative — includes four overviews and fourteen specific technology and policy approaches for consumers to access health services, to obtain and control copies of health information about them, to authorize the sharing of their information with others, and sound privacy and security practices.

"All too often today, vital information falls through the cracks when individuals move across care settings," said John Rother, AARP executive vice president for policy. "That's why government and private health care purchasers understand that consumer access to personal health information is one key component of health IT and health care reform, and that it can be realized only if we can also create trust on the part of consumers," he said. "We're gratified that such a wide range of organizations have embraced this approach."

To view the framework, go to <http://www.connectingforhealth.org/phti/index.html> or [www.markle.org](http://www.markle.org).

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[The Markle Foundation](http://www.markle.org) works to accelerate the use of technologies to address critical public needs, particularly in the areas of health care and national security. The Markle Foundation Health Program is committed to accelerating the ability of patients and consumers to use information technology to improve their health and health care, while protecting patient privacy. The Markle Foundation envisions a time in the near future when individuals will be able to gain access to their own health information through nationwide electronic health information exchange, personal health records, and other emerging technologies, making it possible for patients to participate more fully in their own health care.

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