

P R E S I D E N T ' S C A N C E R P A N E L

NATIONAL CANCER PROGRAM

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The Personal Health Data Revolution, Connected Health, and Cancer March 26, 2015

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The President's Cancer Panel held the second workshop in its series on connected health and cancer on March 26, 2015, in San Francisco, California. The workshop, entitled *The Personal Health Data Revolution, Connected Health, and Cancer*, brought together leaders in academia, technology, government, advocacy, and health care. Selected invitees delivered brief presentations, and participants discussed the current personal health data landscape and ways in which personal health data could be utilized for individual health management, health care, public health, and research.

Personal health data are being captured via an expanding and increasingly diverse set of devices, apps, services, and systems, ranging from wearable devices to social media and electronic health records. In addition to recording traditional medical data, these tools facilitate collection of information on social and environmental factors that has the potential to improve health and quality of life.

Workshop participants noted that enhanced access to and meaningful integration of personal health data could improve both quality of cancer care and quality of life for patients and enhance cancer control and prevention for individuals at risk of cancer. Moreover, they noted the role of connected health in facilitating both formal and informal communication on many levels. However, barriers to access and integration exist. Policies and practices often make it difficult for patients to access their own medical data and hamper data sharing among institutions and providers. Interoperable platforms needed to facilitate data integration, as well as common standards for personal health data, also are lacking. Importantly, data must be presented in meaningful ways to inform decision making by individuals and health care providers. When used optimally, integrated data systems should enhance patient engagement and patient-provider communication.

Participants discussed opportunities for research created by large-scale data integration. In addition to interoperable platforms and open-access policies, development of effective informed consent and deidentification processes would help researchers effectively utilize the wide range of personal health data being generated. New metrics and methods able to accommodate large, integrated data sets would complement traditional research methods. Several participants emphasized that research should be participatory and patient-centered, with patients involved in hypothesis generation, study design, and analysis.

Participants advocated for broad stakeholder involvement in efforts to achieve a connected health system, which will require action beyond the health care system. Findings and recommendations from the series will be presented in the Panel's 2014–2015 Report to the President of the United States.