The Personal Health Data Revolution, Connected Health, and Cancer

March 26, 2015 • San Francisco, CA
Hyatt Regency San Francisco
#cHealth4Cancer

In this workshop, second in a series on connected health and cancer, the President's Cancer Panel and leaders in various sectors will examine the role of personal health data as a driver of change in how individuals manage health and institutions conduct research. As more data are generated by health-tracking apps and devices, individuals and researchers are ready to use these data to the fullest potential. In many cases, user-generated data are being merged with other information sources to understand patterns in risk factors and population health. This exciting new era brings many opportunities for population health, health care, and research, but also challenges. Questions for exploration at this workshop include the following:

- How do we generate knowledge from personal health data and then translate knowledge into health behavior change and improved health outcomes?
- How can and do individuals use their own data for self-change? How do we leverage the collective input of *Patient-Powered Networks* for population change?
- What is needed to optimize the flow of data? What standards are needed?
- Who owns data generated by these applications?
- What changes in informed consent are needed to reflect changes in the ways people contribute data for research, in online recruitment strategies for clinical trials, and in online communication among clinical trial participants?
- What safeguards are needed to ensure both privacy and security?
- What is required to move from a small number of elite institutions using multiple levels of data to inform prevention and care to a larger number of institutions implementing data-informed prevention and care?
- How can challenges with current electronic health records be addressed to maximize benefits for patients? How should standards be developed and implemented?

This workshop is co-chaired by two national leaders in connected health. **David K. Ahern, PhD,** is Director, Program in Behavioral Informatics and eHealth, Brigham and Women's Hospital and Special Advisor, Division of Cancer Control and Population Sciences, National Cancer Institute. **Bradford W. Hesse, PhD,** is Chief, Health Communication and Informatics Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

Presentations and moderated discussions among participants will inform the Panel's recommendations in a formal report to the President of the United States after the conclusion of series workshops.

Visit pcp.cancer.gov or follow the Panel on Twitter at @PresCancerPanel for more information. Join us by live-tweeting during the workshop using #cHealth4Cancer (connected health for cancer). Meetings of the President's Cancer Panel are open to the public.