

Alliance for Health Reform Briefing
A Different Way of Thinking About Health Information
August 13, 2012

The Alliance for Health Reform held a briefing on technology and patient-generated health information titled “A Different Way of Thinking About Health Information.” Panelists featured were Stephen Downs, chief technology and information officer of RWJF, Stephen Rothemich, MD, associate professor of family medicine at Virginia Commonwealth University, Deven McGraw, Director of the Health Privacy Project at the Center for Democracy and Technology, and Joy Pritts, Chief Privacy Officer of the Office of the National Coordinator for Health Information Technology (ONC). Panelists discussed innovative Project HealthDesign apps for smartphone-based patient-generated health data, presented findings from smartphone app field testing, identified legal and policy issues faced by Project HealthDesign grantees, and emphasized patient centered data initiatives.

Stephen Downs presented an overview of the national Project HealthDesign program. The program seeks to address whether access to granular patient generated health data can make a difference in care. Downs classified this data as observations of daily living (ODLs), which include mood, sleep, diet, medication adherence, etc. Project HealthDesign has helped study participants identify, capture, store and review ODL data and provide feedback to patients after the data is analyzed and interpreted. There are 5 current Project HealthDesign teams addressing asthma, Crohn’s Disease, cognitive decline, high-risk infants and obesity. Downs believes these programs will be effective because of the direct feedback patients receive from providers.

Stephen Rothemich, MD, discussed BreathEasy, a smartphone PHR for asthma patients. ODL data is entered through the app and viewed by clinicians through the BreathEasy Clinician Dashboard. A user centered design process was used in app development and followed by a 6 month field testing period. Dr. Rothemich stated the impact of BreathEasy was educational for patient participants, who found the app easy to use and enjoyed collecting ODLs, and understood their asthma control and triggers better. The impact of BreathEasy was not overwhelming for clinicians and provided clinically useful information.

Deven McGraw addressed legal and policy issues faced by Project HealthDesign grantees. McGraw identified 3 policy concerns: security of mobile devices, professional liability concerns and privacy and data access concerns. While all these concerns pose challenges for grantees, McGraw emphasized that these concerns can be met.

Joy Pritts talked about patient generated data. Pritts emphasized the importance of placing patients at the center of care, to ensure engagement and better health outcomes. She identified HHS patient-centered initiatives, including Text4Health, the CLIA program and HIPAA privacy rule, and Meaningful Use. ONC’s consumer engagement strategy is the 3 A’s: Access, Attitude and Action, which strives to make access to personal health information easier while supporting a shift in attitude about the roles of patients and providers in care, to catalyze the development of tools and services that help consumers take action with the health information. Pritts highlighted ONC’s mHealth privacy and security research on consumer attitudes, which seeks to identify consumer attitudes and preferences and explore potential safeguards.

Following panelist presentations, the audience was given the opportunity for questions. Audience members asked about many topics surrounding technology and patient-generated health information, including clinician workflow, reimbursement, utilization, FDA regulation of apps, data aggregation and new models of care coordination and the ability to assist clinicians as these initiatives scale in size and numbers of participants.

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