

A Different Way of Thinking About Health Information....

Patient Generated Data

August 13, 2012

Joy Pritts, JD
Chief Privacy Officer
Office of the National Coordinator for Health
Information Technology (ONC)
US Department of Health and Human Services

Putting the **I** in Health**IT**
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Putting Patients at the Center of Care



- Patient as Partner
- Engaged patients demonstrate better health outcomes
- Patients increasingly expect engagement via IT, as in many other aspects of their lives

HHS Patient-Centered Initiatives



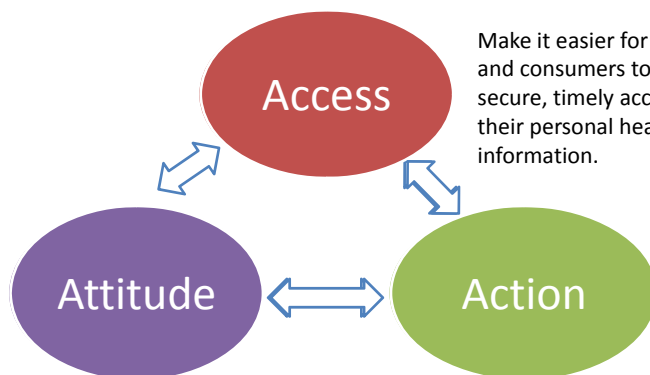
- **Text4Health**
- **CLIA Program and HIPAA Privacy Rule; Patients' Access to Test Reports**
 - NPRM published September 14, 2011
 - Joint CMS, CDC, and OCR NPRM
 - Would expand the rights of patients to directly access their lab results reports
 - Designed to empower patients to be informed partners with their healthcare providers
- **Meaningful Use**

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ONC's Consumer Engagement Strategy: The Three A's



Make it easier for patients and consumers to get secure, timely access to their personal health information.

Support a shift in attitudes about the traditional role of patients and providers and the role technology can play in empowering patients to be more engaged partners in care.

Catalyze the development of tools and services that help consumers (and their providers) take action with their health information.

ONC Patient Centered Data Initiatives



- **Patient Generated Data Whitepaper (RTI)**
 - April 2012
 - Technical, operational, legal, cultural/educational issues
- **HIT Policy Committee Hearing on Patient Generated Data**
 - June 8, 2012
- **Study on patient access, review and feedback (identifying errors and omissions in medical records)**
 - NORC at Geisinger
 - Anticipated date of release 1st Qtr 2013

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mHealth Privacy/Security



- **Patient generated data issues**
 - Legal protections
 - HIPAA?
 - White House initiative on internet privacy
 - Consumer awareness, attitudes, expectations?
- **mHealth Privacy and Security Consumer Attitudes Research:**
 - ONC is conducting focus group research to identify and explore the attitudes and preferences of consumers
 - Explore potential safeguards

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For more information ...



- Overview of other HHS mHealth activities:
<http://www.hhs.gov/open/initiatives/mhealth/index.html>
- CLIA NPRM: <https://www.federalregister.gov/articles/2011/09/14/2011-23525/cli-program-and-hipaa-privacy-rule-patients-access-to-test-reports>
- Medicare and Medicaid Electronic Health Record Incentive Program (Meaningful Use) Stage 2: <http://www.gpo.gov/fdsys/pkg/FR-2012-03-07/pdf/2012-4443.pdf>
- Federal mHealth Collaborative: <http://www.hrsa.gov/healthit/mhealth.html>
- Patient & Families Perspective Privacy & Security Information:
<http://www.healthit.gov/patients-families/protecting-your-privacy-security>
- Consumer Data Privacy in a Networked World: A Framework For Protecting Privacy and Promoting Innovation in the Global Digital Economy (Administration White Paper): <http://www.whitehouse.gov/sites/default/files/privacy-final.pdf>

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