

Educating and Engaging Consumers in Health IT and Privacy

May 8, 2009

The health IT movement is fast and furious. Paper-based health records are quickly moving online where health information can be collected, stored, and shared electronically. Policymakers are aware of the movement - the federal government [just committed \\$19 billion in the economic recovery legislation](#) [1] for health IT efforts. Providers for the most part are also in the know - they've either already embraced the technology, or will likely do so in the near future. But how clued in are consumers about health IT? Do they know what an electronic health record (EHR) is, or how their health information is used or disclosed? Likewise, do consumers understand health privacy laws and their protections under the law in the event their health information is misused? These are important questions to consider as we move forward; educating and engaging consumers about health IT and privacy is integral to building trust and, ultimately, the success of health IT. The importance of educating and engaging consumers on health IT and privacy issues is underscored by a provision in the economic recovery legislation that requires the U.S. Department of Health and Human Services to create and maintain a multi-faceted national education initiative. The purpose of this initiative is to educate consumers about the uses of their health information, the effects of such uses, and their rights in the event information is misused. The initiative's programs must be offered in different languages, and provide consumers with information that is clear and understandable. Independent of the forthcoming HHS initiative, a number of consumer advocacy groups have jumped into this consumer education space. CDT applauds the efforts of two recently launched consumer websites created to educate and engage consumers on health IT and privacy issues. [Ehealth4ny](#) [2], part of the Consumer Education and Engagement for eHealth Project initiative of the Legal Action Center, was created to educate New Yorkers about the benefits of health IT and to engage them in their own health care. However, the site is not limited to information relevant to NY residents; it also includes information for a broader, national audience. The site provides an [extensive list of Resources](#) [3] that offers consumers everything from an educational brochure and instructive video about health IT, to more policy-driven materials that cover policy developments in both NY and nationally. The site also helps NY based consumers locate Regional Health Information Organizations (RHIOs) near them. [Robert Gellman and The World Privacy Forum](#) [4] have developed an online resource for consumers to help them understand the federal health privacy laws and rules, how they work, and how they protect consumers. [The Guide](#) [5] uses a user-friendly Frequently Asked Questions (FAQs) format and, in certain places, includes a "Rule of Thumb" sidebar that provides further explanation on more thorny issues. Both websites provide consumers with a valuable resource for accurate, easy to understand, important information about health IT and privacy. Educating and engaging consumers will go a long way in building consumer trust, which is critical to advancing health IT.

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Links:

[1] <http://fdsys.gpo.gov/fdsys/pkg/BILLS-111hr1ENR/pdf/BILLS-111hr1ENR.pdf>

[2] <http://www.ehealth4ny.org>

[3] <http://www.ehealth4ny.org/resources.html>

[4] <http://www.worldprivacyforum.org/hipaa/index.html>

[5] <http://www.worldprivacyforum.org/hipaa/guidecontents.html>