

Rethinking the Role of Consent in Protecting Health Information Privacy

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Washington - The Center for Democracy & Technology today released a major policy paper intended to move the health privacy debate from its outdated focus on patient consent to a comprehensive framework that will provide more effective privacy protection.

CDT's paper argues that personal health information should easily flow for treatment, payment, and certain core administrative tasks without requiring patient consent, but that stricter limits need to be placed on marketing and other secondary uses. Rather than relying on consent to control all uses of health information, CDT says, consent should be used in a more focused way, required, for example, for access and disclosure of information in the new Personal Health Records being established on the Internet, or for uses and disclosures of information for marketing purposes.

"Requiring consent for all data sharing in health care will only overwhelm patients, leading them to give blanket consent and providing very weak protection," said Deven McGraw, director of the Health Privacy Project at CDT.

CDT is advocating for the inclusion of privacy protections in the President's economic stimulus bill, which contains at least \$20 billion for a national health information technology network.

"To build public trust in health information technology, we need a comprehensive policy framework that sets clear enforceable rules for who can access health information and for what purposes," said Leslie Harris, CDT's president and CEO. "A meaningful role for consumer choice should be part of this framework, too," Harris said. "This paper explains how patient consent can be strengthened within such a framework, but there is more to privacy than consent."

In addition to consent properly focused, the comprehensive privacy framework would include other privacy principles, such as the right of patient access, implementation of technologies that ensure user authentication and provide audit trails for all disclosures, and strong oversight and accountability procedures.

"If we get away from viewing consent as the be all and end all of privacy, and use this stimulus funding to establish a more comprehensive framework of protections, we can break the privacy log-jam that has been impeding adoption of health information technology," McGraw said.

On Tuesday, Jan. 27, Deven McGraw will testify before the Senate Judiciary Committee in support of the privacy provisions in the health technology section of the economic stimulus bill.

CDT's paper can be found online here:

www.cdt.org/healthprivacy/200910126Consent.pdf [1]

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