A Consumer Perspective on Healthcare Privacy

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Wanted: Digital Ralph
“Privacy is an inherent human right, and a requirement for maintaining the human condition with dignity and respect.”

--Bruce Schneier

“The Eternal Value of Privacy”

http://www.wired.com/politics/security/commentary/securitymatters/2006/05/70886
Jeremy Bentham’s Panopticon
HIPAA... PRIVACY RULE or DISCLOSURE RULE?
Final Privacy Rule--2002

“The consent provisions…are replaced with a new provision…that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, healthcare operations.”

--67 Federal Register 53211
“Without a clearly defined approach that establishes milestones for integrating its efforts and fully addresses key privacy principles and these challenges, it is likely that HHS’s goal to safeguard personal health information as part of its national strategy for health IT will not be met.”
Health information privacy is the right to control the acquisition, uses, or disclosures of identifiable health data.

Informational privacy is a core value of American society.
Trust in professional ethics and established health privacy and confidentiality rules encourages individuals to share information they would not want publicly known.

Retain HIPAA’s “minimum necessary” standard for information access, based on the role and status of the requester.
The NHIN should incorporate Fair Information Practices regarding collection, use, notice and access to information.

HHS should support legislative or regulatory measures to eliminate or reduce the potential harmful discriminatory effects of personal health information disclosure.
Engage the public in the design, functioning, and oversight of the NHIN by appointing meaningful numbers of consumers to all national, regional, and local boards governing the NHIN.

65% of those surveyed would not disclose information to their provider because they worried it would go into computerized records.
75% of Americans are concerned about the loss of medical privacy due to the use of an electronic health and information system.
2005 Harris Survey: “How the Public Sees Health Records and an EMR Program”

- 70% concerned or very concerned about medical information leaks due to weak security
- 69% believed more information would be shared without their knowledge
- 65% wouldn’t disclose information because of worries about computerized records
- 62% believe existing privacy rules would be curtailed in the name of efficiency
- Respondents evenly split on whether benefits outweigh the risks (48%) or risks outweigh the benefits (47%)
Latest HHS/NHIN RFP seeks technology to:

- Provide consumers with capabilities to help manage the flow of their information
- Allow consumers to identify and manage locations for storage of their PHRs
- Manage consumer-controlled providers of care and access permission information
Latest HHS/NHIN RFP seeks technology to:

- Manage consumer choices to not participate in network services
- Give consumers access to audit logging and disclosure information for PHR and HIE data
- Route consumer requests for data corrections
WWRD?
Top 10 Privacy Practices

10

Provide meaningful penalties and enforcement mechanisms for privacy violations detected by patients, advocates, and government regulators, including a private right of action.
Top 10 Privacy Practices

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Preserve stronger privacy protections in state laws. In other words, no federal pre-emption of state laws.
Top 10 Privacy Practices

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Patients should be notified promptly of suspected or actual security breaches, without splitting hairs about whether or not there is a risk to an individual from a disclosure—as is the case with the California breach notification law (CA Civil Code §1798.29).
Top 10 Privacy Practices

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Disclosures of patient information should be auditable in real time.
Ensure that personal medical information cannot be used coercively or discriminatorily by prohibiting compelled disclosure of such information to obtain employment, insurance, credit, or admission to schools, unless it is required by statute.
5

Prohibit secret health databases. Require all existing holders of health information to disclose what data they have to the data subjects.
Top 10 Privacy Practices

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Health information disclosed for one purpose may not be used for another purpose without informed consent.
3

Give consumers control over their medical information by means of technologies that firmly puts the right of consent over access to that information in their hands.
Top 10 Privacy Practices

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Apply the right to privacy to ALL health information regardless of the source, the form it is in, or who handles it.
1

Recognize a right to the privacy of medical information, as defined in the June 22, 2006 Report of the NCVHS to HHS Secretary Leavitt: “Health information privacy is an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data.”
References & Resources

HIPAA
- HIPAA Privacy Rule: 45 CFR 160, 164
  - A recent survey of 1095 consumers, conducted by IDC’s [International Data Corporation] Health Industry Insights, reveals a significant number of respondents (70%) are unaware of the U.S. government’s initiative to make Electronic Health Records (EHRs) available to citizens by 2014.”
- The Electronic Privacy Information Center’s (EPIC) Medical Privacy page: [http://www.epic.org/privacy/medical/](http://www.epic.org/privacy/medical/)

PRIVACY AND SECURITY
- NCVHS Subcommittee on Privacy and Confidentiality, Letter to Secretary Leavitt titled, “Recommendations re Privacy and Confidentiality in the NHIN.” June 22, 2006; [http://www.ncvhs.hhs.gov/060622lt.htm](http://www.ncvhs.hhs.gov/060622lt.htm)
“Electronic Health Record Use and the Quality of Ambulatory Care in the United States,” by Jeffrey A. Linder, MD, MPH; Jun Ma, MD, RD, PhD; David W. Bates, MD, MSc; Blackford Middleton, MD, MPH, MSc; Randall S. Stafford, MD, PhD, *Archives of Internal Medicine*, 2007;167:1400-1405; [http://archinte.ama-assn.org/cgi/content/short/167/13/1400](http://archinte.ama-assn.org/cgi/content/short/167/13/1400). Report concluding that, “As implemented, EHRs were not associated with better quality ambulatory care.”

“Electronic Health Records Don’t Aid Patient Care: Study of 1.8 billion doctor visits showed no real advantage over paper files,” Reuters, July 9, 2007; [http://www.msnbc.msn.com/id/19684970/](http://www.msnbc.msn.com/id/19684970/)


“The Surveillance-Industrial Complex: How the American Government is Conscripting Businesses and Individuals in the Construction of a Surveillance Society,” by Jay Stanley, ACLU, August 9, 2004; [http://www.aclu.org/safefree/resources/18512res20040809.html](http://www.aclu.org/safefree/resources/18512res20040809.html). Report on relationships between government and business that are “privatizing” surveillance through recruitment of companies (like the telcos facilitating NSA communications surveillance) or use of commercial data and data mining.