

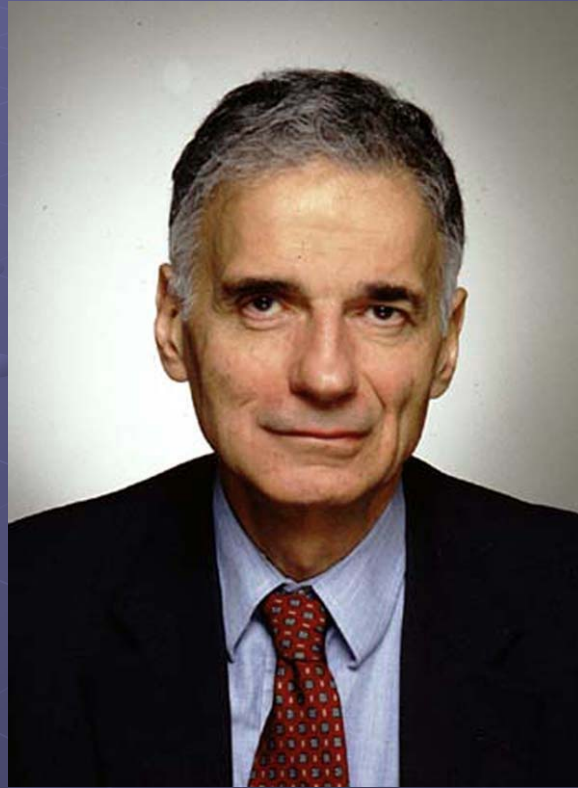
A Consumer Perspective on Healthcare Privacy

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Wanted: Digital Ralph



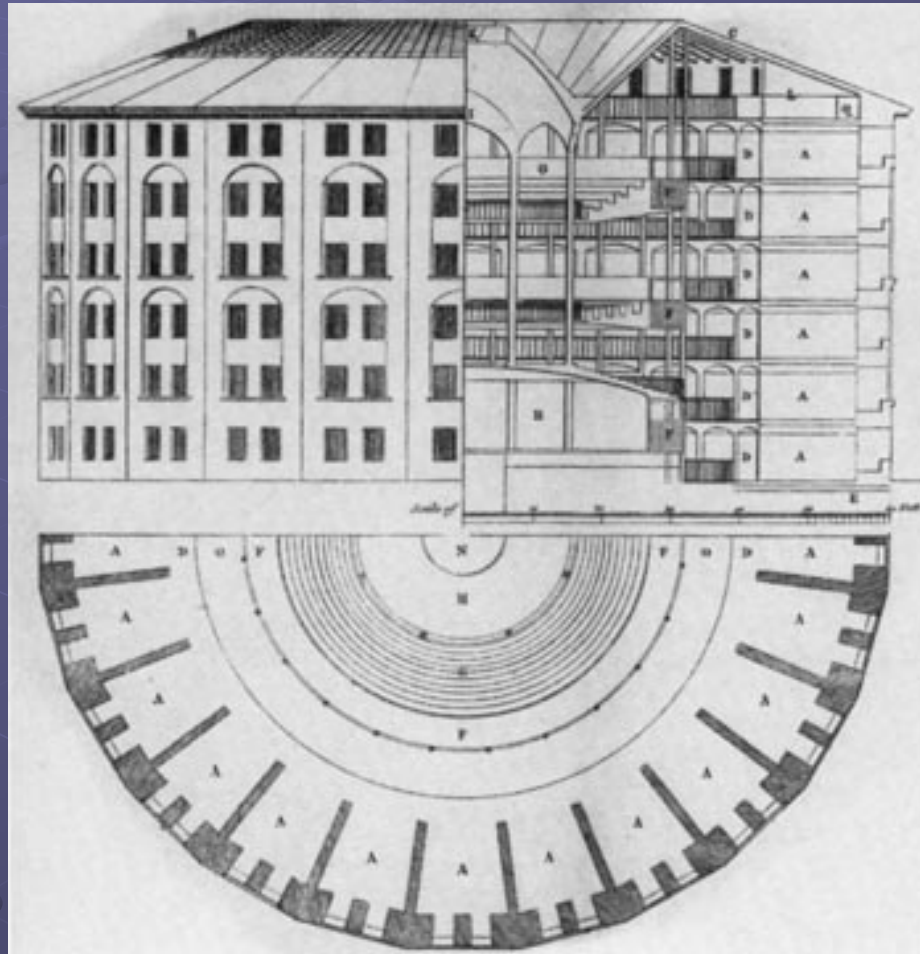
“Privacy is an inherent human right, and a requirement for maintaining the human condition with dignity and respect.”

--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

GAO Report, "Health Information Technology:
Early Efforts Initiated But Comprehensive
Privacy Approach Needed for National
Strategy" --February 1, 2007

"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."

NCVHS Privacy and Security Recommendations—June 2006

- 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.

NCVHS Privacy and Security Recommendations—June 2006

- 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.

NCVHS Privacy and Security Recommendations—June 2006

- 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.

NCVHS Privacy and Security Recommendations—June 2006

- 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.

2005 Westin Survey: “How the Public Health Views Health Care, Privacy and Information”

65% of those surveyed would not disclose information to their provider because they worried it would go into computerized records.

2000 California HealthCare Foundation Survey: “Ethics Survey of Consumer Attitudes about Health Web Sites”

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%)

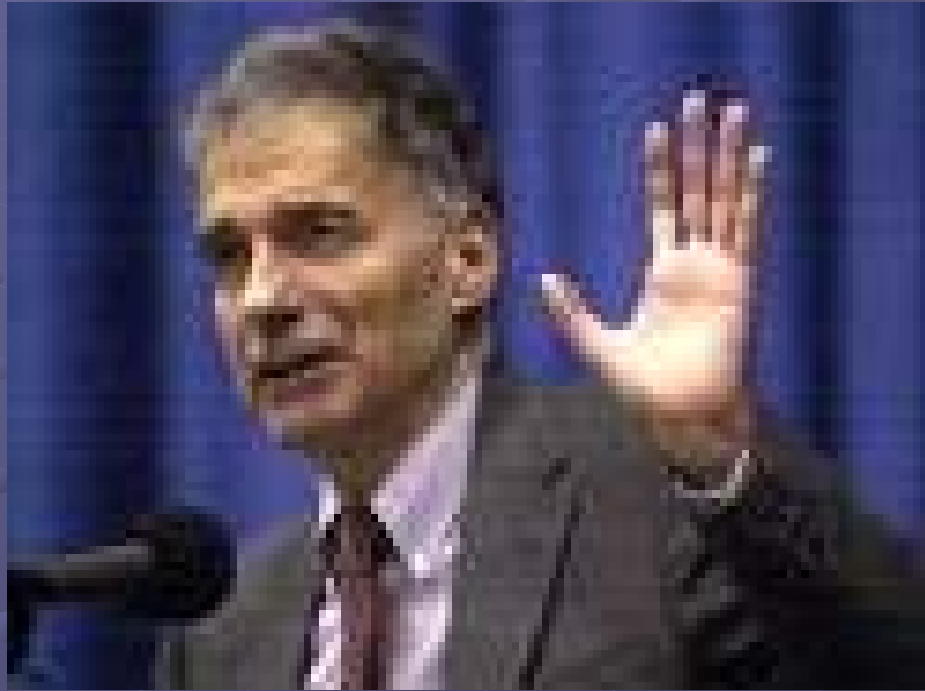
Latest HHS/NHIN RFP seeks technology to:

- 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

9

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

Top 10 Privacy Practices

8

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

7

Disclosures of patient information should be auditable in real time.

Top 10 Privacy Practices

6

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.

Top 10 Privacy Practices

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

4

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

Top 10 Privacy Practices

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

2

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

Top 10 Privacy Practices

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
- Summary of the HIPAA Privacy Rule: <http://www.hhs.gov/ocr/privacysummary.pdf>
- CRM Today, "Health Industry Insights Survey Reveals Consumers are Unaware of Government's Electronic Health Records Initiative," February 13, 2006;
- <http://www.crm2day.com/news/crm/117351.php> . "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."
- Consumer Reports, "The new threat to your medical privacy," March 2006; <http://www.consumerreports.org/cro/health-fitness/health-care/electronic-medical-records-306/overview/index.htm>. A brief, cautionary report on the privacy risks of a National Health Information Network and the privacy lacunae of HIPAA.
- The Electronic Privacy Information Center's (EPIC) Medical Privacy page: <http://www.epic.org/privacy/medical/>

PRIVACY AND SECURITY

- CalOHI and CalRHIO, "Privacy and Security Solutions for Interoperable Health Information Exchange," submitted to the Research Triangle Institute, March 30, 2007; http://www.calrhio.org/crweb-files/docs-privacy/FAASR_03302007_Final.pdf
- Government Accountability Office, "Health Information Technology: Early Efforts Initiated But Comprehensive Privacy Approach Needed for National Strategy." GAO-07-400T, February 1, 2007; <http://www.gao.gov/new.items/d07400t.pdf>
- "How the Public Sees Health Records and an EMR Program," Harris Interactive survey conducted for The Program on Information Technology, Health Records and Privacy, study # 23283, February 16, 2005; <http://laico.org/v2020resource/files/Healthtopline.pdf>
- 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>
- TOP 10 Health Record Security Breaches in 2006: http://www.aishealth.com/Compliance/Hipaa/RPP_2006_Security_Breaches.html
- "Warnings Over Privacy of U.S. Health Network," Robert Pear, NY Times, February 18, 2007; <http://www.nytimes.com/2007/02/18/washington/18health.html?ex=1180324800&en=b458411426a6558f&ei=5070>

References & Resources

MISCELLANEOUS

- “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>. 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/>
- “The Eternal Value of Privacy,” by Bruce Schneier, Wired News, May 18, 2006;
<http://www.schneier.com/essay-114.html>
- “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>. 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.