World Health Summit 2010

Working Session

Information Technology: New Horizons in Health Care

October 12, 2010

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patientprivacyrights

What does ‘privacy’ mean?

“an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data”.

June 2006, NCVHS Report to Sec. Leavitt, definition from the IOM

10.5 Million Americans Expect Privacy and Security

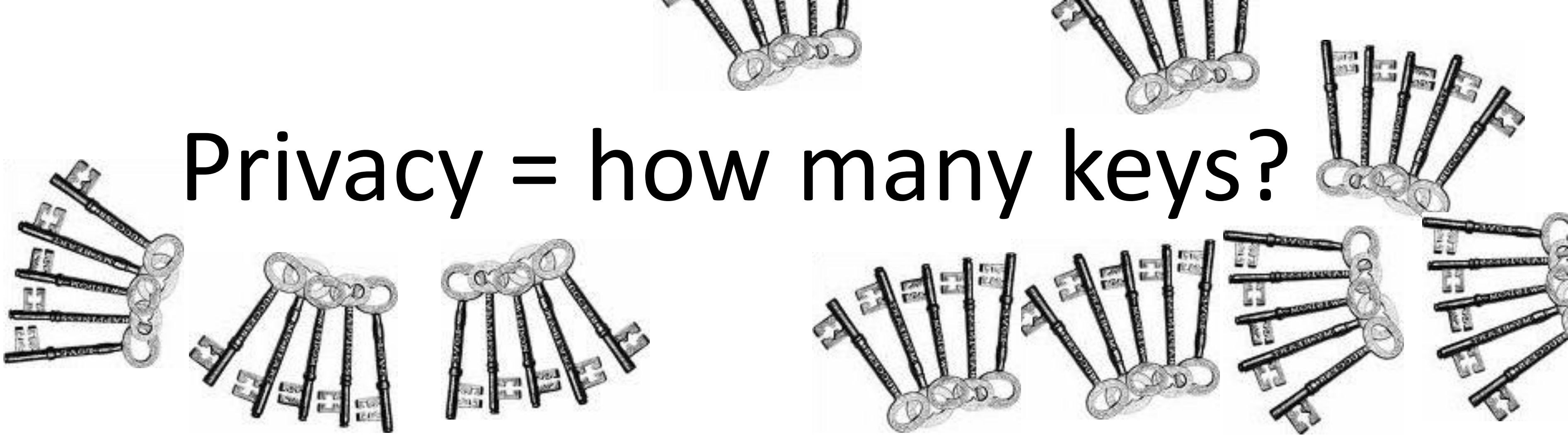
The bipartisan Coalition for Patient Privacy, 2010

AIDS Action
American Association of People with Disabilities
American Association of Practicing Psychiatrists
American Chiropractic Association
American Civil Liberties Union
American Conservative Union
American Psychoanalytic Association
Association of American Physicians and Surgeons
Bazelon Center for Mental Health Law
Bob Barr (former Congressman R-GA)
Citizens for Health
Citizen Outreach Project
Clinical Social Work Association
Consumer Action
Consumers for Health Care Choices
Cyber Privacy Project
Doctors for Open Government
Ethics in Government Group
Fairfax County Privacy Council
Family Research Council
Free Congress Foundation
Georgians for Open Government
Gun Owners of America
Health Administration Responsibility Project, Inc.
Just Health
Multiracial Activist
Microsoft Corporation Inc.
National Center for Transgender Equality
The National Center for Mental Health Prof. & Consumers
National Whistleblower Center
National Workrights Institute
Natural Solutions Foundation
New Grady Coalition
Pain Relief Network
Patient Privacy Rights Foundation
Privacy Activism
Privacy Rights Now Coalition
Private Citizen, Inc.
Republican Liberty Caucus
Student Health Integrity Project
TexPIRG
Thoughtful House Center for Autism
Tolven, Inc.
Tradition, Family, Property, Inc.
Universata, Inc.
U.S. Bill of Rights Foundation
You Take Control, Inc.

privacy = control

privacy ≠ security

Privacy = how many keys?



Security

Americans expect privacy and security, but….

HHS citations: harms from lack of privacy

Harms from lack of Privacy

- HHS estimated that **586,000** Americans did not seek earlier cancer treatment due to privacy concerns.
- HHS estimated that **2,000,000** Americans did not seek treatment for mental illness due to privacy concerns.
- **Millions** of young Americans suffering from sexually transmitted diseases do not seek treatment due to privacy concerns.

65 Fed. Reg. at 82,777

Harms from lack of Privacy

The California Health Care Foundation found that **1 in 8** Americans have put their health at risk *because of privacy concerns*:

- Avoid seeing their regular doctor
- Ask doctor to alter diagnosis
- Pay for a test out-of-pocket
- Avoid tests

http://patientprivacyrights.org/2005/11/national-consumer-health-privacy-survey-2005/

Westin/Harris IOM Survey: People Won’t Participate in Research Without Privacy

- Only 1% agreed that researchers would be free to use personal medical and health information without consent
- Only 19% agreed that personal medical and health information could be used as long as the study “never revealed my personal identity” and it was supervised by an Institutional Review Board.

http://patientprivacyrights.org/media/WestinIOMSrvyRept.pdf?docID=2501

Americans expect privacy and control, but….

Where did this slide come from ? The Medical Information Bureau, which sells your health data to insurers and employers.

HIPAA regs eliminate consent and privacy

1996	Congress passed HIPAA, but did not pass a federal medical privacy statute, so the Dept. of Health and Human Services (HHS) was required to develop regulations that specified patients’ rights to health privacy. **Public Law 104-191**	*“… the Secretary of Health and Human Services shall submit to [Congress]…* ***detailed recommendations on standards with respect to the privacy of individually identifiable health information.”***
2001	President Bush implemented the HIPAA “Privacy Rule” which recognized the “right of consent”. HHS wrote these regulations. **65 Fed. Reg. 82,462**	*“….a covered health care provider* ***must obtain the individual’s consent,*** *in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”*
2002	**HHS amended the HIPAA “Privacy Rule”, eliminating the right of consent.** **67 Fed. Reg. 53,183**	*“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.”*

Austin Bulldog

Hospital Patient Privacy Sacrificed as State Agency Sells or Gives Away Data

Technology Used by For-Profit Companies Strips Away Inadequate Layers of Security

by Suzanne Batchelor

http://www.theaustinbulldog.org/index.php/Main -Articles/Main-Articles/department-of-state-health-services.html

DSHS collects , sells and gives away inpatient hospital data without consent for:

- public-health, medical research, trade groups, lobbyists, businesses, anonymous downloaders boston.com

Electronic health records raise doubt, Google service's inaccuracies may hold wide lesson

By Lisa Wangsness, April 13, 2009

- medical records transferred from Beth Israel Deaconess Medical Center to Google Health
- Google said his cancer spread to either his brain or spine
- "The problem is this kind of information should never be used clinically", said deBronkart's primary doctor
- PHRs…are a promising tool …but inaccuracies could be "a huge problem," said Dr. Paul Tang

http://www.boston.com/news/nation/washington/articles/2009/04/13/electronic_health_records_raise_doubt/

huge markets for health data

+

ease of theft + purchase of health information

→

massive health data mining industry

Do Not Disclose

Register on the National Do Not Disclose List

Let Congress know that you want a Do Not Disclose list.

Do you want:

- To choose who can see and use your personal information, from prescriptions to DNA?
- To protect your children’s health information, so it won’t be used against them in the future for jobs or credit?
- To get a clear explanation of how your information will be used before you decide to share it?

Then sign up to support the “*Do Not Disclose*” campaign!

Sign Up Today!

TELL – A – FRIEND

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patientprivacyrights

Key References:

CONSENT “The Case for Informed Consent” by Deborah C. Peel, MD and Ashley Katz/PPR August 31,2010 at: http://patientprivacyrights.org/2010/08/the-case-for-informed-consent/

EHRs “Your Medical Records Aren't Secure” *by Deborah C. Peel* in the WSJ, March 23, 2010 http://online.wsj.com/article/SB10001424052748703580904575132111888664060.html

TECHNOLOGY SOLUTIONS: At the **Consumer Choices technology Hearing June 29, 2010,** one of the 'granular consent' technologies demonstrated has been exchanging behavioral health records on 4 million patients for over 9 years, in 8 states and 22 jurisdictions. 7 robust open source and proprietary consent and segmentation technologies were showcased “live”. See: http://nmr.rampard.com/hit/20100629/default.html

See transcript of the Hearing and written testimony about the 7 privacy-enhancing technologies at: http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=2833&PageID=19477#062910

HIEs and NHIN “Designing a Trustworthy Nationwide Health Information Network (NHIN) Promises Americans Privacy and Utility, Rather than Falsely Choosing Between Privacy or Utility” *by Latanya Sweeney, PhD,* April 22, 2010, Congressional Briefing on the “Implementation of Health Information Technologies in a Healthcare Environment” http://patientprivacyrights.org/wpcontent/uploads/2101/04/SweeneyCongressTestimony-4-2210.pdf
See NHIN slides at:
http://patientprivacyrights.org/wpcontent/uploads/2010/06/SweeneyTrustworthyNHINDesigns.pdf

Research "Improve Privacy in Research by Eliminating Informed Consent?" IOM Report Misses the Mark. In The Journal of Law, Medicine & Ethics, Volume 37, Issue 3 (p 507-512) by *Mark A. Rothstein.*
http://patientprivacyrights.org/wpcontent/uploads/2010/02/Rothstein-ReIOM-Report.pdf

"IOM Project Survey Findings on Health Research and Privacy" October 2, 2007, by Dr. Alan F. Westin at: http://patientprivacyrights.org/media/WestinIOMSrvyRept.pdf?docID=2501

PHRs "Who can snoop in your PHR? A Personal Health Record Report Card
http://patientprivacyrights.org/personal-health-records/

P2P leaks "Data Hemorrhages in the Health-Care Sector", in *Financial Cryptography and Data Security, February 22-25, 2009 by M. Eric Johnson*
http://patientprivacyrights.org/media/JohnsonHemorrhagesFC09d.pdf

Don Berwick MD, CMS: *What 'Patient-Centered' Should Mean: Confessions Of An Extremist***,** *A seasoned clinician and expert fears the loss of his humanity if he should become a patient.* in *Health Affairs* 28, no. 4 (2009): w555–w565 (published online 19 May 2009; 10.1377/hlthaff.28.4.w555)

UK Lack of Privacy "Database State, A Report Commissioned by the Joseph Rowntree Trust LTD." by Ross Anderson, Ian Brown, Terri Dowty, Philip Inglesant, William Health, Angela Sasse http://www.cl.cam.ac.uk/~rja14/Papers/database-state.pdf

Sweeney on designing privacy in HIT

"Scott McNealy, the CEO of Sun Microsystems, famously quipped, "**Privacy is dead. Get over it**."

Sweeney's response: "Oh privacy is definitely not dead. ***When people say you have to choose, it means they haven't actually thought the problem through or they aren't willing to accept the answer***.

… ***he very much shares that attitude of the computer scientist who built the technology that's invasive; who says, "Well, you want the benefits of my technology, you'll get over privacy". It's exactly the kind of computer scientist we don't want to be graduating in the future."***

http://patientprivacyrights.org/2007/06/privacy-isnt-dead-or-at-least-it-shouldnt-be-a-qa-with-latanya sweeney

Latanya Sweeney on flaws in EHRs and data exchanges

Secondary use of PHI by Business Associates is "unbounded, widespread, hidden, and difficult to trace."

Implementing meaningful use **EHRs will "increase data sharing, but adding the NHIN will massively increase data sharing."**

The two proposed NHIN models to link all Americans' health information online do not offer "utility or privacy".

http://patientprivacyrights.org/wp-content/uploads/2010/04/Sweeney-CongressTestimony-4-22-10.pdf