The Texas Library Association

Advocacy:
Restoring Health Privacy

Deborah C. Peel, MD
April 9, 2014

Hippocrates

“Whatsoever I shall see or hear of the lives of men or women which is not fitting to be spoken, I will keep inviolably secret.”

2,400 years of consensus on privacy reflected in law and ethics
privacy ≠ security

What does ‘privacy’ mean in healthcare?

“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

Privacy = how many keys?
what happened?

big data
or...
surveillance

the surveillance economy

government fusion centers
corporate data brokers
NSA collecting phone records of millions of Verizon customers daily

Exclusive: Top secret court order requiring Verizon to hand over all call data shows scale of domestic surveillance under Obama

Read the Verizon court order in full here
Obama administration justifies surveillance
http://www.guardian.co.uk/world/2013/jun/06/nsa-phone-records-verizon-court-order

‘Peeping while you’re sleeping’ T-shirt drew ire of NSA lawyers

Fusion Centers
BEYOND FINGERPRINTS, Biometric Databases and Quantitative Privacy
by Danielle Citron, September 8, 2012

$1B Next Gen ID system, multimodal biometrics: palm prints, fingerprints, iris, retina, voice, face, gait

Federal, state, & local fusion centers mine information posted online; private security camera footage; systems of private partners; data from state, local, & federal law enforcement; mug shots; DNA databases; and driver ID photographs

Not Track? Advertisers Say ‘Don’t Tread on Us’

By NATASHA SINGER


campaign to defang the “Do Not Track” movement began late last month

“what is really at stake here is the future of the surveillance economy”

House to FTC: ‘Do Not Track’ might restrict “the flow of data at the heart of the Internet’s success.”

open letter from the board of the Association of National Advertisers: Microsoft’s action is wrong. The entire media ecosystem has condemned this action”

How Companies Learn Your Secrets

By Charles Duhigg

Published: February 16, 2012

“If we wanted to figure out if a customer is pregnant even if she didn’t want us to know, can you do that?”

http://www.nytimes.com/2012/02/19/magazine/shoppinghabits.html?pagewanted=all

You for Sale: Mapping, and Sharing, the Consumer Genome

June 16, 2012 Justin Bolle, New York Times

Acxiom: world’s largest consumer database

- 50 trillion data transactions/year.
- 500M consumers worldwide, a majority of US adults
- sales of $1.13B
- 1,500 data points per person

Brokers Trade on Sensitive Medical Data with Little Oversight, Senate Says
By Elizabeth Dwoskin
Dec 18, 2013

Marketers maintain databases that purport to track and sell the names of people who have diabetes, depression, and osteoporosis, as well as how often women visit a gynecologist, according to a Senate report published Wednesday. The companies are part of a multibillion-dollar industry of “data brokers” that lives largely under the radar, the report says. The report by the Senate Commerce Committee says individuals don’t have a right to know what types of data the companies collect, how people are placed in categories, or who buys the information.

Americans expect privacy and control

but....

HIPAA eliminated consent and privacy

Congress passed HIPAA, but did not pass a federal medical privacy law. The Department of Health and Human Services (HHS) was required to develop regulations that specified patients’ rights to health privacy. Public Law 104-191

President Bush implemented the HIPAA “Privacy Rule,” which protected health information. HHS wrote these regulations. 65 Fed. Reg. 82,462

But 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. 67 Fed. Reg. 53,183

..., 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. 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. 67 Fed. Reg. 53,183

...
Latanya Sweeney on flaws in EHRs and data exchanges (HIEs)

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.”

Proposed data exchange models to “link all Americans’ health information online do not offer “utility or privacy”.

elimination of consent
+
HIPAA ‘research’ and ‘public health’ loopholes

→

theft & sale of health data

health data mining industry

IMS Health Holdings IPO 2014

http://patientprivacyrights.org/2014/01/ims-health-files-ipo-legal/

- IMS buys and aggregates sensitive “prescription and promotional” records, “electronic medical records,” “claims data,” “social media” and more to create “comprehensive,” “longitudinal” health records on “400 million” patients from “100K data suppliers” covering “780K daily data feeds”
- IMS sells health data to “5,000 clients,” including US Government
- All purchases and sales of personal health records are hidden from patients. Patients are not asked for informed consent or given meaningful notice.
Patients’ journeys through the healthcare system are complex, crossing multiple care settings and often comprising multiple diseases and treatments. What really works is not easy to see. Real-world evidence shows how treatments perform in the real world, beyond what we see in an artificial clinical trial environment. Insights from this growing body of scientifically credible evidence help decision makers across the healthcare system improve outcomes and better manage costs.

http://www.imshealth.com/portal/site/imshealth

IMS Health is uniquely positioned at the center of the healthcare system—connected to stakeholders from every sector. Drawing from over 100,000 data sources, we connect islands of information to provide the most complete global view of patients, treatments, providers and the market. We help clients get the right information, determine what it means for their business, and then act on it to drive performance.

Slide from the Medical Information Bureau, which sells health data to insurers and employers.
33 states sell or give away health data

Newborn Bloodspots for sale

- "TX Dept of State Health Services transferred 100’s of infant blood spots to the Armed Forces for a national & international mitochondrial DNAregistry"
- DHHS & TX A&M sold blood spots w/o consent
  [link](http://www.texastribune.org/2010/02/22/dshs-turned-over-hundreds-of-dna-samples-to-feds/)

**FOR SALE**

- EHRs, PHRs
- claims data, lab data, prescriptions, health searches, etc
one of largest anonymized clinical databases in the US provides access to real-world longitudinal patient information.
customers who share patients’ data pay a discounted rate to use Athena’s health record software
makes clinical research participation a revenue source
sells billions of anonymous patient records collected via data-sharing agreements with 125 software clients to pharmaceutical companies and researchers

IBM research project

Healthcare IT News  
May 06, 2010 | Diana Manos

Data from “finance, urban planning, individual behavior, disease transmission, clinical research, media and many others” will be collected and analyzed to help obese children without informed consent
longitudinal data on 54 million BCBS members [obtained without consent]

- reporting not only by MSA, industry and product type, Diagnosis Related Groups (DRGs) code, age group and gender

Intended use: “service the big employers that pay the bills and want to pay smaller bills for health insurance.”


“Prescription Profile” Highway

Nex2, Inc. (Sold to United Healthcare in 2002)

In stealth-mode, Nex2 built what are arguably the largest, near-realtime drug history databases in the world, with over 200 million Americans’ five-year running drug histories online (over 12 TB total). The databases are updated every 24 hours by every retail pharmacy in America via the PBMs... [these] prescription profiles act as a powerful surrogate for the medical record itself.

All of this is HIPAA compliant because the insurance company always has the release, signed by the individual applicant.

United Healthcare’s Ingenix unit now runs these massive virtual database operations, still in stealth-mode, for obvious reasons.
Clinical Data Services

The CDS Advantage

Disease Counts in Database
Hypertension 2,284,249
Hyperlipidemia 2,212,629
Depression 1,185,828
Cardiovascular Disease 1,004,214
GERD 984,864
Diabetes 922,169
Asthma 750,963
Osteoarthritis 602,043
COPD 319,310
ADD/ADHD/HKD 188,424
Rheumatoid Arthritis 85,757
Alzheimer’s 35,790
Parkinson’s 22,017

Mayo Clinic launches ‘bedside analytics’

Backed by Rock Health and the Social+Capital Partnership, the venture develops decision support tools for intensive care units, operating rooms and emergency departments. Its technologies, which were developed at the Mayo Clinic, enable real-time access to process-of-care information and analytics.


Healthcare.gov

760x760
no data map
  =
  can’t weigh risks v benefits of health IT

START by mapping the problem

theDataMap.org

http://www.healthprivacysummit.org/events/2012-health-privacy-summit/custom-138-6e20d3a150544a8976cd7f34af4d972.aspx
35% of Fortune 500 companies admit to using medical records for hiring and promotions

65 Fed. Reg. 82,467

The New York Times
Wal-Mart Memo Suggests Ways to Cut Employee Benefit Costs

"Redesign benefits and other aspects of the Associate experience, such as job design, to attract a healthier, more productive workforce."

"The team is also considering additional initiatives to support this objective, including: all jobs to include some physical activity (e.g., all cashiers do some cart gathering)." October 26, 2005

The Wall Street Journal
Insurers Test Data Profiles to Identify Risky Clients
By Leslie Scism and Mark Maremont

Life insurers use vast dossiers of data being amassed on Americans: predicting people’s longevity.

Data-gathering companies have such extensive files on most U.S. consumers that some insurers are exploring whether data can reveal nearly as much about a person as a lab analysis of their bodily fluids.

http://online.wsj.com/article/SB10001424052748704648604575620750948072986.html
harms

- Destroys trust—human need to control boundaries
- People act to protect privacy risking health and life
- Discrimination (Pewen)

Angela Merkel

Merkel says US spying on allies has shattered trust in Obama

is current law enough to protect privacy?

Solution: Key Fair Information Practices

- Transparency & accountability
- Individual control
- Data Minimization
Save privacy in the US by defending our strongest rights to control pii.... our rights to control personal health information

Tell everyone you know: doctors, lawmakers, & journalists this MUST end. Unless we RESTORE control over health data, we will never get this right for other pii.
Summary

● tell everyone
● campaign for health privacy?
● 4th International Summit on the Future of Health Privacy
  June 4-5 2014

www.patientprivacyrights.org/summit
www.patientprivacyrights.org
dpeelmd@patientprivacyrights.org
2014 Health Privacy Summit

The 4th International Summit on the Future of Health Privacy: Controlling Your Personal Health Information: Now is the Time

The 2014 Health Privacy Summit brings together a diverse group of professionals for two days of timely information exchange.

Healthcare providers, IT innovators, national and international privacy experts from academia, industry, and government will gather to hear insights, ideas, and critical discussion on matters in the health privacy community. The program includes a variety of keynote speakers and workshops to provide expert education and provide real-world implementations related to the future of health privacy.

Engage with thought-provoking lectures, interactive panels, networking and discussion during the two-day Summit. Areas of discussion will include: Patient DIY, Blue Button +, Consumer Engagement, Mobile Apps Privacy, InfoSec, International Cybersecurity, Data for Research, Ethics, and Entremise Health.

Deborah C. Peel, MD
Founder and Chair

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@PrivacySummit
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www.patientprivacyrights.org
HIPAA “research loophole”

• The term “research” is defined at 45 C.F.R. 164.501 as “systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.”

• Information is not PHI and not subject to the HIPAA Privacy Rule if it is “de-identified” as provided in 45 C.F.R. 164.514(b). An organization can use a “limited data set” for research if they strip out certain identifiers and enter into a “data use agreement” under 164.514(e).

THE TEXAS TRIBUNE

DNA Deception

by Emily Ramshaw
February 22, 2010

Department of State Health Services transferred 100’s of infant blood spots to the Armed Forces for a national and, someday, international mitochondrial DNA (mtDNA) registry.

newborn bloodspots were sold by DHHS & TX A&M Univ. without consent

Medicare and Medicaid data for sale

“at the patient level”
Web Hunt for DNA Sequences Leaves Privacy Compromised

A genetics researcher re-identified 5 random people from strings of billions of DNA letters from over 1,000 people & found their families, re-identifying 50 more people, even though none were in the study

http://www.nytimes.com/2013/01/18/health/search-of-dna-sequences-reveals-full-identities.html?_r=0

NSA’s Verizon Spying Order Specifically Targeted Americans, Not Foreigners

...the latest revelation of the extent of the NSA’s surveillance shows that it has focused specifically on Americans, to the degree that its data collection has in at least one major spying incident explicitly excluded those outside the United States.

http://www.forbes.com/sites/andygreenberg/2013/06/05/nsas-verizon-spying-order-specifically-targeted-americans-not-foreigners/