Across the Pond: An Update on Health Privacy and Health Data Security. How are American patients faring?

University of Cambridge
Wednesday 20 October 2010

Deborah C. Peel, MD

patientprivacyrights

security and privacy

clinical justification for security

- patients' expectations/rights
- liability/reputation

privacy-enabling security
(encryption, authentication/segmentation, etc)

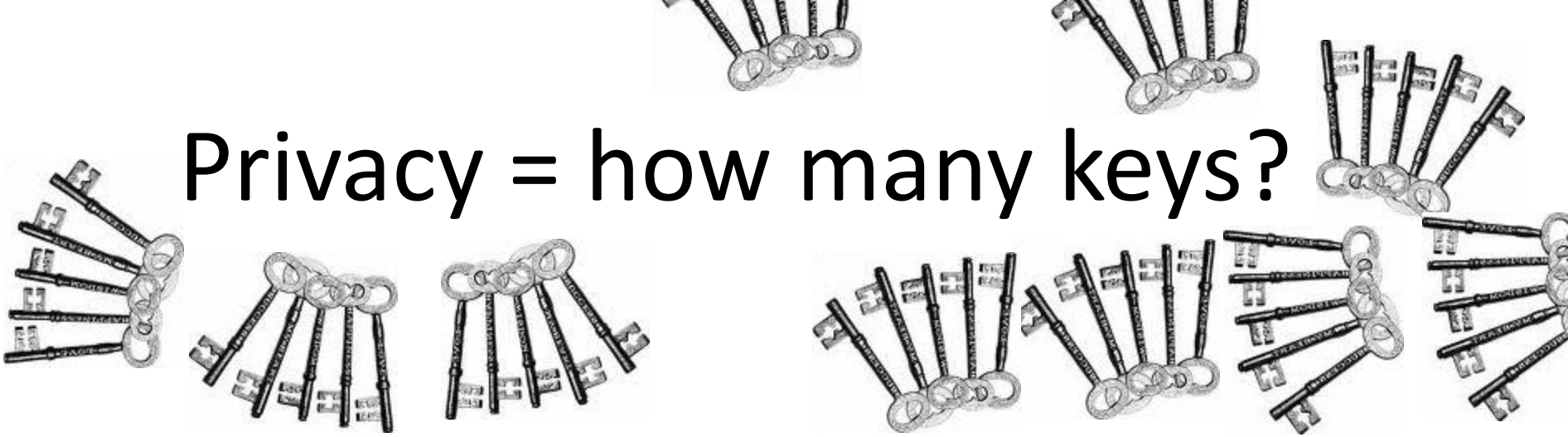
HITECH: consumer protections

Consumer Choices Tech Hearing

ideal HIT systems

security ≠ privacy

Privacy = how many keys?



Security

What does ‘privacy’ mean?

The *NCVHS* defined health information privacy as

“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 originally from the IOM)

privacy = control

comprehensive and
meaningful
privacy
and security

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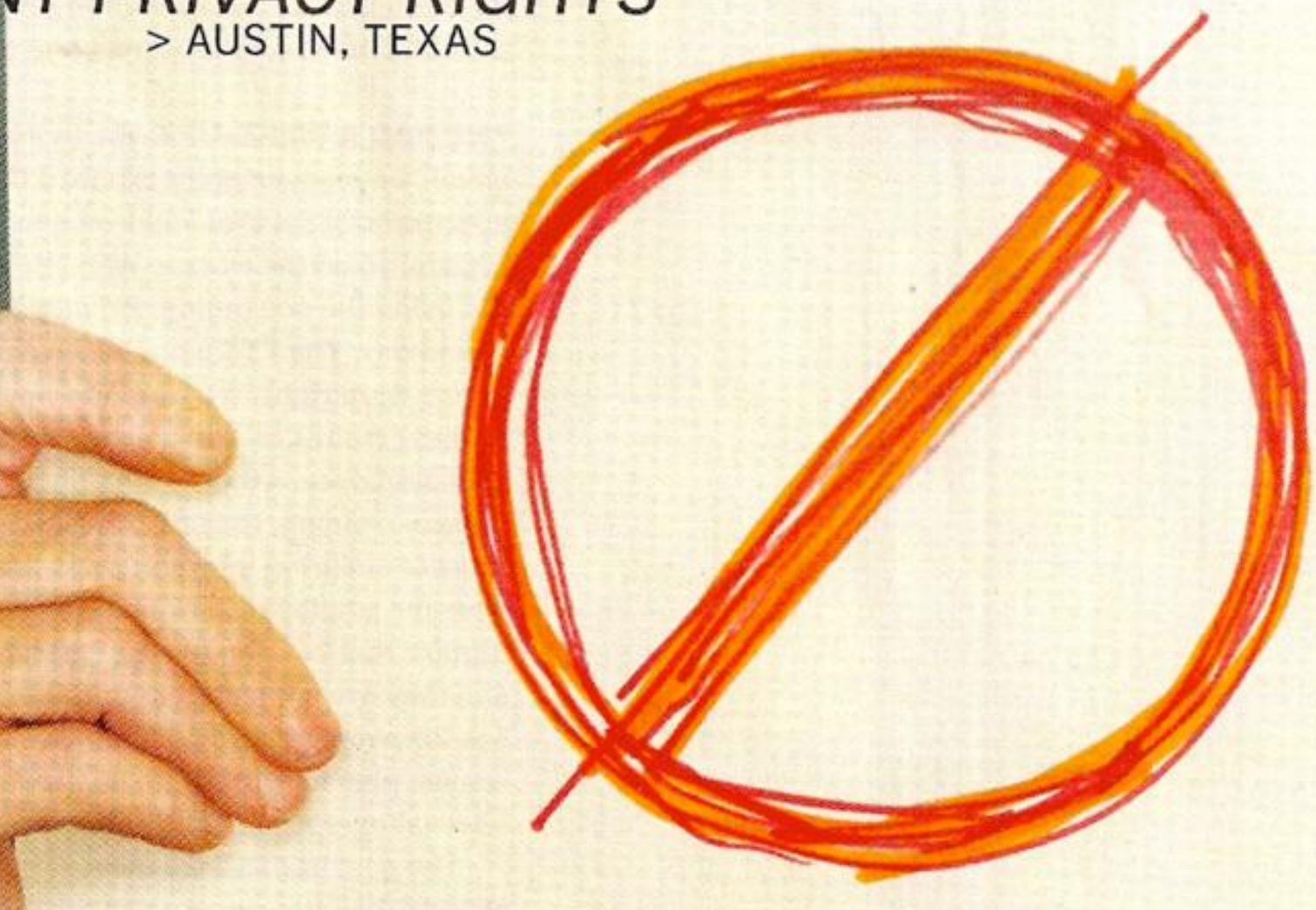


The threat is no
cybercrime. You do
hack in to get this
private information
sale. Exposed heal
become the most p
of discrimination.
judicial decisions,
strongly held priva
health related. All
disintegrating."

10 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.

clinical justification for security: patients' expectations and rights

AHRQ: 2009
20 focus groups expect control

- A majority want to "own" their health data, and to decide what goes into and who has access to their medical records. (AHRQ p. 6)

- A majority believe their medical data is "no one else's business" and should not be shared without their permission….not about sensitive data but "a matter of principle". (AHRQ p. 18)

AHRQ: 2009
20 focus groups expect control

- no support for general rules that apply to all consumers

- consumers should exert control over their own health information **individually, rather than collectively**.(AHRQ p. 29)

AHRQ Publication No. 09-0081-EF "Final Report: Consumer Engagement in Developing Electronic Health Information Systems" Prepared by: Westat, (July 2009)

http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_888520_0_0_18/09-0081-EF.pdf

2006 Privacy and EHR Systems: Can We Avoid A Looming Conflict?

42% of public feels potential privacy ***risks outweigh*** potential EHR ***benefits***

60% of public wants to know EHR impacts and the ***right to choose*** how records used

Dr. Alan F. Westin
Professor of Public Law and
Government Emeritus, Columbia University

Markle Conference on "Connecting Americans to Their Health Care," Washington, D.C. Dec 7-8, 2006

2009 NPR/Kaiser/Harvard Poll

The Public and the Health Care Delivery System

59% are ***NOT confident*** online medical ***records will remain confidential***

76% believe ***unauthorized persons will access*** their online medical records

http://www.kff.org/kaiserpolls/upload/7888.pdf

The right of privacy is a personal and fundamental right in the United States

See Department of Justice v. Reporters Committee for Freedom of the Press, 489 U.S. 749, 763 (1989) ("both the common law and the literal understandings of privacy encompass the individual's control of information concerning his or her person"); *Whalen v. Roe*, 429 U.S. 589, 605 (1977); *United States v. Katz*, 389 U.S. 347 (1967); *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting).

The opportunities to secure employment, insurance, and credit, to obtain medical services and the rights of due process may be jeopardized by the misuse of personal information.

Fed. Trade Comm'n, *Consumer Sentinel Network Data Book* 11 (2009) (charts describing how identity theft victims' information have been misused).

As the Supreme Court has made clear, and the DC Circuit Court of Appeals recently held, "both the common law and the literal understanding of privacy encompass the individual's control of information concerning his or her person."

U.S. Dep't of Justice v. Reporters Comm. for Freedom of the Press, 489 U.S. 749, 763 (1989), cited in *Nat'l Cable & Tele. Assn. v. Fed. Commc'ns. Comm'n*, No. 07-1312 (D.C. Cir. Feb. 13, 2009).

"the constitutionally protected right to privacy of highly personal information is so well established that no reasonable person could be unaware of it."

Sterling v. Borough of Minersville, 232 F.3d 190, 198 (3rd Cir. 2000).

ethical and human rights to privacy

legal privileges common law

The Madrid Privacy Declaration of November 2009 affirms that **privacy is a basic human right**, and notes“ corporations are acquiring vast amounts of personal data without independent oversight”

The Madrid Privacy Declaration: Global Privacy Standards for a Global World, Nov. 3, 2009, *see* http://thepublicvoice.org/madrid-declaration/ .

Professional and research ethics

The ethical codes of all health professions require informed consent before use or disclosures of personal health information.

Report to HHS, NCVHS (June 22, 2006)

"the well- being of the human subject should take precedence over the needs and interests of society"

World Medical Association Declaration of Helsinki June 1964

Ethical Principles for Medical Research Involving Human Subjects

Privileges and Common Law

A physician-patient privilege is recognized in the laws of 43 states and the District of Columbia.

The State of Health Privacy, Health Privacy Project (2000)

All 50 states and the District of Columbia recognize in tort law a common law or statutory right to privacy of personal information.

HHS finding 65 Fed. Reg. at 82,464

Ten states have a right to privacy expressly recognized in their state constitutions.

Americans expect privacy and control, but….

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."*

Referred Doctors

Family members

Inside the Fence

Legal users of YOUR medical records

ZONE 4: GRAMM LEACH BLILEY FINANCIAL SERVICES ACT

ZONE 3: BUSINESS ASSOCIATES

ZONE 2: COVERED ENTITIES

ZONE 1: YOU AND YOUR DOCTOR

Local Public Health Agencies
Medical Information Bureau
Law Enforcement Agencies
Offshore Transcription Vendors (Ex. Pakistan & India)
Self-Insured Employers
Credit Bureaus
Disease Registries
Financial Institutions
Hospital Chains
Investment Companies
CDC
Insurance Brokers
Temporary Nursing Staff
Legal Services
Securities Firms
Financial Holding Companies
Third-party Administrators
Pharmacy Benefits Managers
Accounting Firms
Hospital Staff Employees
Labs
FDA
Banks
Medicaid Medicare CMMS
Health Insurance Companies
Life Insurance Companies
Pharmaceutical Companies
Financial Service Providers
Insurance Brokers
Savings & Loans
Data Clearinghouses
Pharmacy Chains
Mutual Insurers
Temporary Office Personnel and Firms Thereof
Data Processing Firms
Bank Holding Companies
Mortgage Bankers
Financial Subsidiaries
S & L Holding Companies
Federal Home Loan Banks
Merchant Banks

www.patientprivacyrights.org

Americans expect privacy and security,

but....

Where did this slide come from ? The Medical Information Bureau website. The MBI sells claims/health data to insurers and employers.

35% of Fortune 500 companies admit to using medical records for hiring and promotions

65 Fed. Reg. 82,467.

huge market for health data

+

theft and sale of health data

health data mining industry

2010: Top Fortune 500 Companies health data mining industry

4 General Electric (GE Centricity EHR/HIT systems, ***sells clinical data***) revenue 157B

14 McKesson (***sells Rx data***) revenue 107B

18 CVS Caremark (***sells Rx data***) revenue 99B

21 UnitedHealth Group (***sells RX data*** thru Ingenix subsidiary) revenue 87B

31 WellPoint (***sells claims/clinical data*** via BHI) revenue 65B

http://money.cnn.com/magazines/fortune/fortune500/2010/full_list/

2010: Top Fortune 500 Health Care: Pharmacy and Other Services (health data mining industry)

Rank	Company/500 rank	Revenues($ billions)	
1	Medco Health Solutions #35	59.8	(sells Rx data)
2	HCA (largest US hospital chain) #77	30	(?? sells hospital and Rx data)
3	Express Scripts #96	25	(sells Rx data)
4	Quest Diagnostics #303	7	(sells data/sends data to HIEs?)

"transforms millions of test results into valuable information products"
http://www.questdiagnostics.com/brand/careers/index.html#services

5	Omnicare #347	6.3	(???)

(leading Rx provider for seniors)"we capture a tremendous amount of data"
..combines data with outcomes algorithm technology

6	Lab Corp. of America #442	4.7	(sells data??/sends data to HIEs)

EHRs, PHRs, claims data, lab data, prescriptions, health searches, etc

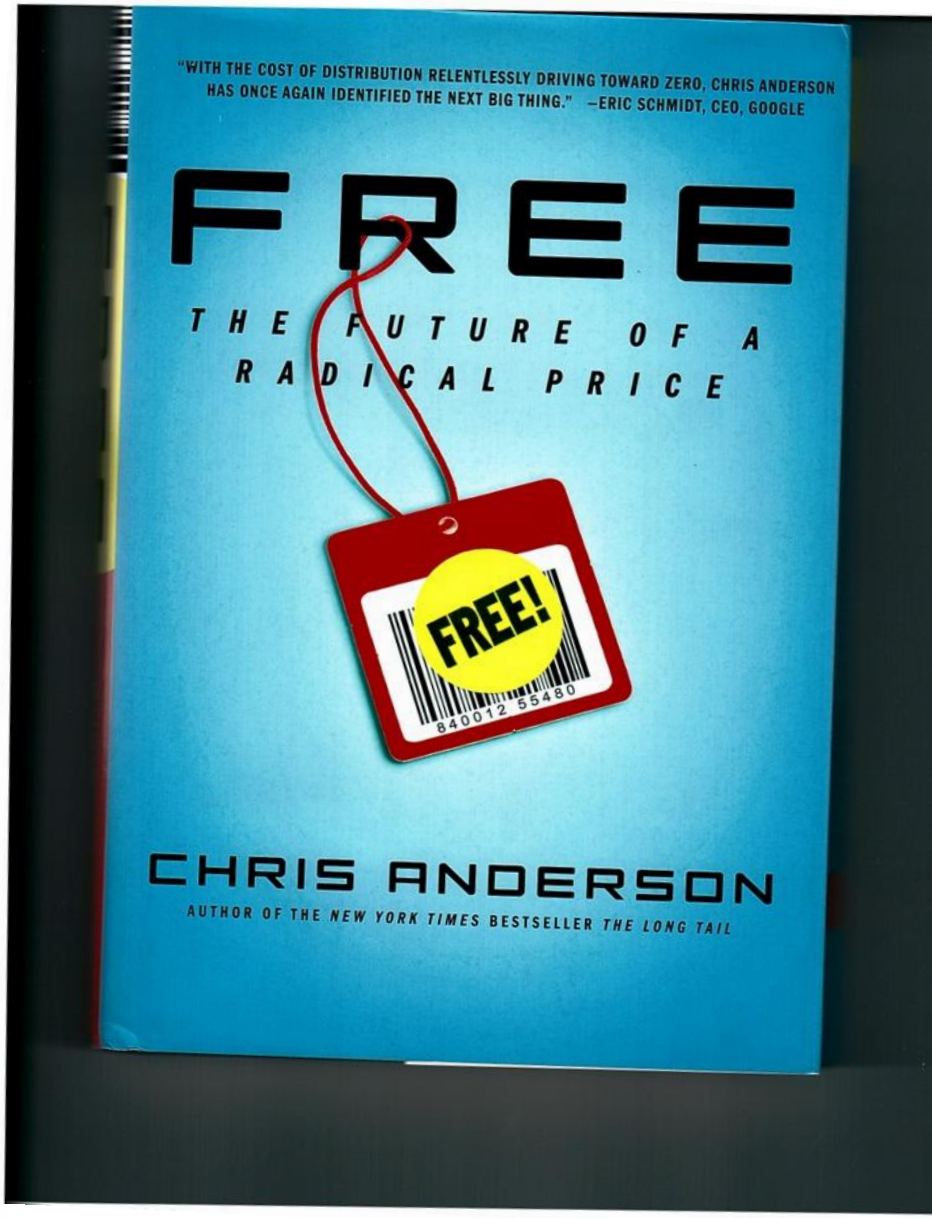
HOW CAN HEALTHCARE SOFTWARE BE FREE?

Since November 2007, thousands of physicians have signed up to receive free electronic health record and practice management software from San Francisco-based start-up Practice Fusion. Enterprise software for medical practices can cost $50,000. How can one company give away its e-record system at no charge?

Sellling data can be more profitable than selling software.

▸ **Freemium + advertising.** Tapping the freemium model, Practice Fusion offers two versions of its software: a free one that serves ads (à la Google AdSense), and an ad-free one that costs $100 per month. Of the first 2,000 doctors to adopt Practice Fusion's e-record system, less than 10 percent opted to pay. But the real revenue lies elsewhere...

▸ **Sell access to your data.** Using free software, Practice Fusion attracts a critical mass of users (doctors) who, in turn, create a growing database of patients. Medical associations conducting research on specific conditions require longitudinal health records for a large set of patients. Depending on the focus of a study (think: white, middle-aged, obese males suffering from asthma), each patient's anonymized chart could fetch anywhere from $50 to $500. A physician typically sees about 250 patients, so Practice Fusion's first 2,000 clients translates to 500,000 records. Each chart can be sold multiple times for any number of studies being conducted by various institutions. If each chart generates $500 over time, that revenue would be greater than if Practice Fusion sold the same 2,000 practices software for a one-time fee of $50,000.



HealthcareIT News

By Diana Manos, Senior Editor
12/31/07

Practice Fusion expands, shows signs of rapid growth

Practice Fusion subsidizes its free EMRs by selling de-identified data to insurance groups, clinical researchers and pharmaceutical companies.

Howard said he does not expect data-sharing will be a concern to physicians who use Practice Fusion's EMRs. ***"Every healthcare vendor is selling data."***


TAKE YOUR
HEALTH DATA
"OFF THE MARKET".
watch the video ▶
CAMPAIGN for
PRESCRIPTION
PRIVACY
VIAGRA
FOR
ERECTILE
DYSFUNCTION

wait….it gets worse

health IT security is

ABYSMAL

security breaches

weak security → breaches

- easy to hack
- weak authentication
- weak ‘role-based’ authorization → ‘insider’ snooping and theft
- data is not encrypted despite HITECH
- P2P software leaks data
- web apps (SaaS/SSL) leak data*
- ease of copying, stealing, losing mobile devices
- de-identification and anonymization don’t work
- unsafe clouds

* http://www.informatics.indiana.edu/xw7/WebAppSideChannel-final.pdf

InformationWeek

Sep 19, 2010

Steady Bleed: State of HealthCare Data Breaches

Posted by George Hulme Study reveals that, for many healthcare providers, patient data breaches continue - month after month - at an alarming rate.

- 200-bed hospital 24/mo
- 20-clinic physician practice 29/mo
- UK major teaching hospital 129/mo
- Top 50 U.S. Health System 125/mo

http://www.informationweek.com/blog/main/archives/2010/09/steady_bleed_st.html

Los Angeles Times

Fawcett's cancer file breached

The incident occurred months before UCLA hospital employees were caught snooping in Britney Spears' files.

By Charles Ornstein April 3, 2008

Cost of Security Breaches

EXAMPLE: In 2006, Providence Health & Services paid a $95,000 penalty and provided two years of free credit monitoring to thousands of people after a car prowler broke into the van of a Providence employee who had left computer disks and data tapes inside. The records, some going back 20 years, contained Social Security numbers and medical information for 365,000 people. Providence spent $8-9M defending against a class action lawsuit.

- **Average direct, indirect, and opportunity costs to companies that experienced a data breach was $14 million/company.**
- average cost: $140/customer with breached data
- 100,000 is the average number of customers affected by security breaches

Laptop Data Breaches: Mitigating Risks Through Encryption and Liability Insurance

By Julie Machal-Fulks and Robert J. Scott,

http://www.scottandscottllp.com/main/uploadedFiles/resources/Articles/ArticleLaptop_Data_Breaches.pdf

Weak security results in massive fraud

Department of Justice Press Release

For Immediate Release
October 13, 2010

United States Attorney's Office
Southern District of New York

Manhattan U.S. Attorney Charges 44 Members and Associates of an Armenian-American Organized Crime Enterprise with $100 Million Medicare Fraud

Defendants Also Charged with Racketeering, Identity Theft, and Money Laundering Crimes Armenian "Vor" Charged with Protecting Alleged Medicare Fraud Scheme

Cybercrime—Why Steal Healthcare Data?

- Harder to detect:
  - Medical id theft/fraud: 2x longer to detect than id theft
  - Victims cannot delete or change their personal information, medical records or Hx of prescription use
- It pays:
  - The World Privacy Forum reports cost of stolen **medical information is $50** v. $1 per #SS
  - Avg payout for medical id theft = $20,000 v. $2,000 for id theft

RSA White Paper: Cybercrime and the Healthcare Industry

Cybercrime—How to Use Healthcare Data

Cybercriminals target not only consumer data but data from healthcare providers, insurers, and pharmaceutical industry.

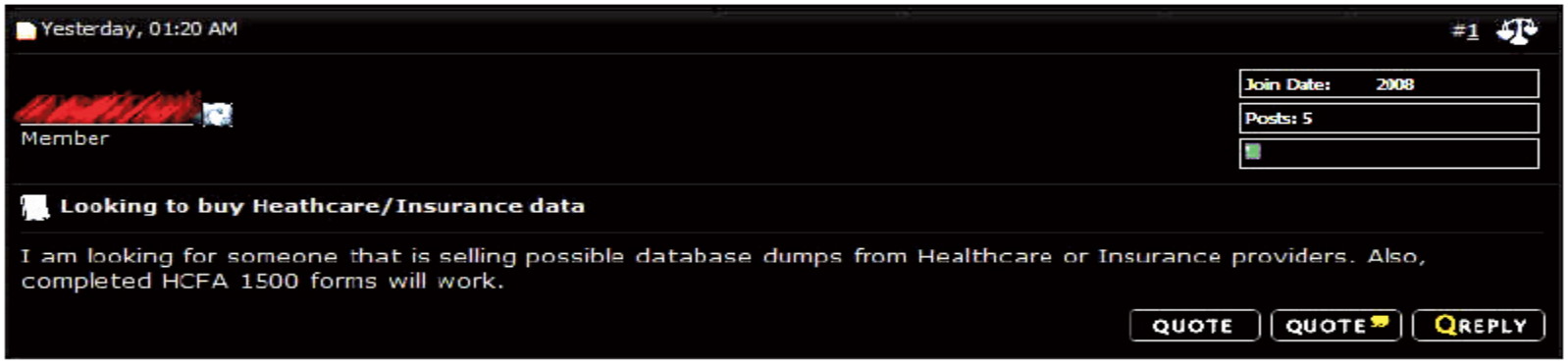
Types of fraud:

- use patient info to file false patient claims with insurers, Medicare, and Medicaid
- sell individual patient medical records in the black market
- use physician info to submit fake prescriptions at multiple pharmacies and resell the medicine
- use physician data to set up fake clinics and bill for treatment using stolen patient info

RSA White Paper: Cybercrime and the Healthcare Industry

Cybercrime—Example 1

- seeks data to file false medical claims:



RSA White Paper: Cybercrime and the Healthcare Industry

Cybercrime—Example 2

- post seeks buyers for > 6,500 medical records

6561 individuals claims notification report medical records

6561 individuals claims notification report medical records

I have a large file that contains 6561 individuals claims notification report medical records.

File comes with these fields for each person.
---
certnc
group
deductible
tpa
lcm
treaty
insured
patient name
ssn
status1
status2
status3
icd9
diagnosis - This field contains their diagnosis such as AIDS, HIV, Left Heart Failure, Diabetes, etc
tpa_paid
med_expense
transplant

Here are some examples of Diagnosis from the file
- HIV W/SPECIF INFECTIONS
- Malignant Neoplasm Of Lateral Wall Of Urinary Bladder
- Morbid Obesity; chronic nonalcoholic liver disease
- Alcoholic Cirrhosis Of Liver, other spec intestinal malabsorption
- HIV, cachexia, HTLV-1, neoplasm of uns. nature of digestive system
- Liver Replaced By Transplant
- Excessive Or Frequent Menstruation

- Price: make offers

RSA White Paper: Cybercrime and the Healthcare Industry

HITECH: historic new consumer protections, but...

ARRA—new privacy rights and MU

Old rights under HIPAA:

- Providers may offer consent (Original HIPAA Privacy Rule), so patients can restrict disclosures---not addressed in MU
- Psychotherapy Notes require consent to disclose---not addressed in MU

New rights under ARRA:

- Ban on sales of PHI (Protected Health Information)---2010 (waiting for comments on NPR and final rule)
- Segmentation---delayed
- Audit trails x 3 years---2011 or later
- Breach notice---2010 (added "harm" standard violates HITECH)
- Encryption---2010 but industry is not doing this
- Patient can prevent disclosures of PHI for 'payment and healthcare operations' if pays out-of-pocket---not addressed
- Consent Technologies---2014 or later

“Meaningful Use” isn’t meaningful to patients

Latanya Sweeney on flaws in MU EHR criteria and NHIN/HIEs

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

Implementing **MU 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

Sweeney on designing privacy in HIT

Observation: "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

54 " Tall

54 " Tall

54 " Ta

Will we finally get meaningful and comprehensive privacy and security?

Consumer Choices Technology Hearing

7 privacy-enhancing technologies ‘live’ demonstrations

Washington DC, June 29, 2010

video: http://nmr.rampard.com/hit/20100629/default.html

transcript and written testimony:

http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=2833&PageID=19477#062910

federal privacy precedents

- TITLE 38 - PART V , CHAPTER 73 - SUBCHAPTER III - PROTECTION OF PATIENTRIGHTS

  § 7332. (a) (1) **Confidentiality of certain medical records** drug abuse, alcoholism or alcohol abuse, HIV, sickle cell anemia

- 42 CFR Part 2

July 8, 2010 ***New*** Privacy Policy:

Sec. Sebelius: "Administration-wide commitment to make sure no one has access to your personal information unless you want them to".

Dr. Blumenthal: "we want to make sure it is possible for patients to have maximal control over PHI."

See: http://patientprivacyrights.org/2010/07/ppr-impressed-with-hhs-privacy-approach/

Patient-centered HIT systems

1. universal online consent tools--benefits
   - dynamic, not static
   - fine-grained decisions, like online banking "Bill Pay"
     -automatic rules (like monthly payments), or case-by-case
   - ability to share selectively (in accord with laws, rights, expectations)
   - no need to update consents in many locations
   - no need for MPI or single patient ID
   - independent audit trails of all uses and disclosures via use of authentication and authorization systems

   (employees have unique access codes and can see selected data)

Patient-centered HIT system

2. health banks--benefits
   - ironclad security and architecture
   - today there is no place w/ a complete and accurate copy of our health records
   - patients control access and use of PHI
   - ***only*** patients can collect complete and <u>accurate</u> PHI
   - 'safer' research, less risk of exposing data
     - like census bureau: run research queries on individual data
     - unlike census bureau, **no research without consent**
     - sensitive data is NOT released
   - no need for MPI or UPIN (single ID)---patients have separate ID at each location = better privacy protections (stolen data has less value)

Patient-centered HIT systems

3. other systems--benefits

- decentralized consents with centralized control. In this situation, patients can make local data sharing decisions at the time and place of service, but have a universal portal to update or change consents as needed

- an NHIN that works likes a filing cabinet. In this situation, all patient information goes to a common location, and the patient can make decisions about sharing at that storage location

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Key References:

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

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

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-4-22-10.pdf

See Sweeney's NHIN slides at: http://patientprivacyrights.org/wp-content/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.*