Institute for Behavioral Health Informatics

Beyond Security: What We Can Expect to See in Patient Privacy Issues and Challenges From an Obama or McCain Administration

Tuesday, October 30, 2008

Deborah C. Peel, MD

patientprivacyrights

Health IT:

abysmal security

Identity Theft Resource Center

2008 Data Breach Stats – Paper vs. Electronic Summary

Totals for Electronic records:

# of Breaches: 360

# of Records: 21,531,952

# of Health records: 7,033,064

% of Breaches: 80.2

% of Records: 97.5%

Totals for Paper records:

# of Breaches: 89

# of Records: 559,386

% of Breaches: 19.8

% of Records: 2.5%

2008 total breaches of health records (to date)

4,349,087+ Data on the Move

2,241,363+ Subcontractors

12,000+ Hacking

335,805+ Accidental Exposure

94,809+ Insider Theft

7,033,064

Identity Theft Resource Center

http://www.idtheftcenter.org/artman2/publish/lib_survey/ITRC_2008_Breach_List.shtml

Electronic medical records at risk of being hacked, report warns

CIO news

By Linda Tucci, Senior News Writer
19 Sep 2007 | SearchCIO.com

"There was not one system we could not penetrate and gain control of data," said eHVRP board member Daniel S. Nutkis. "These systems were not any worse than banking systems. But the banking systems have elaborate security mechanisms sitting on top of them."

The eHVRP report is based on a 15-month study of more than 850 provider organizations.

The Wall Street Journal

Are Your Medical Records at Risk?

Amid Spate of Security Lapses, Health-Care Industry Weighs Privacy Against Quality Care

By SARAH RUBENSTEIN
April 29, 2008; Page D1

When it comes to protecting the privacy of patients' computerized information, the main threat the health-care industry faces isn't from hackers, but from itself.

Breaches of consumers' confidential data are widespread in the health-care industry.

* At hospitals, a broad range of employees, from nurses to lab technicians, can access patients' information.

Health care isn't the only industry whose slip-ups can upset consumers or expose them to identity theft. But **hospitals are notable for the sheer number and types of employees** – including billing staff, nurses, doctors, researchers and lab technicians -- **who have quick access to individuals' private information**.

http://online.wsj.com/article/SB120941048217350433.html?mod=loomia&loomia_si=t0:a16:g2:r2:c0.156457

Private medical data exposed

Insurance benefit letters sent to wrong addresses by Blue Cross and Blue Shield reveal claim histories, open door to ID theft.

By ANDY MILLER

The Atlanta Journal-Constitution
Published on: 07/29/08

Georgia's largest health insurer sent an estimated 202,000 benefits letters containing personal and health information to the wrong addresses last week, in a privacy breach that also raised concerns about potential identity theft.

http://www.ajc.com/news/content/news/stories/2008/07/29/bluecross.html?cxntnid=amn072908e

Georgia Patients' Records Exposed on Web for Weeks

The New York Times, April 11, 2008, by Brenda Goodman

- A company hired by the State of Georgia to administer health benefits for low-income patients is sending letters to notify tens of thousands of residents that their private records were exposed on the Internet for nearly seven weeks before the error was caught and corrected, a company spokeswoman said on Thursday.

- The records of as many as 71,000 adults and children enrolled in the Medicaid or PeachCare for Kids programs were inadvertently posted on Feb. 12, said Amy Knapp, a spokeswoman for the company, WellCare Health Plans Inc., whose headquarters are in Tampa, Fla.

NIH Data Breaches

- **Barton health records stolen and he's ticked**
  Dallas Morning News, April 3, 2008, by **Todd J. Gillman**
  Rep. Joe Barton revealed Thursday that he is one [of the 3,000+] heart patients whose medical records were on an unencrypted laptop stolen from a National Institutes of Health researcher.

- ***New York Times*** **Editorial re: NIH Breach,** March 26, 2008
  "There should be a federal law imposing strict privacy safeguards on all government and private entities handling medical data. Congress should pass a bill like the Trust Act, introduced by Representative Edward Markey, a Democrat of Massachusetts, imposing mandatory encryption requirements and deadlines for notifying patients when their privacy is breached. As the N.I.H. has shown, medical privacy is too important to be left up to the medical profession."

HIPAA eliminated Americans' rights to health privacy

What does ‘privacy’ mean?

- The *Hippocratic Oath* says “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.”

What does ‘privacy’ mean?

- The *Code of Fair Information Practices (1974)* says “There must be a way for a person to prevent information about the person that was obtained for one purpose from being used or made available for other purposes without the person's consent.”

What does ‘privacy’ mean?

- The *NCVHS* (June 2006, Report to Sec. Leavitt) defined health information privacy as “an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data”. (Definition originally from the IOM)

Elimination of Consent

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.

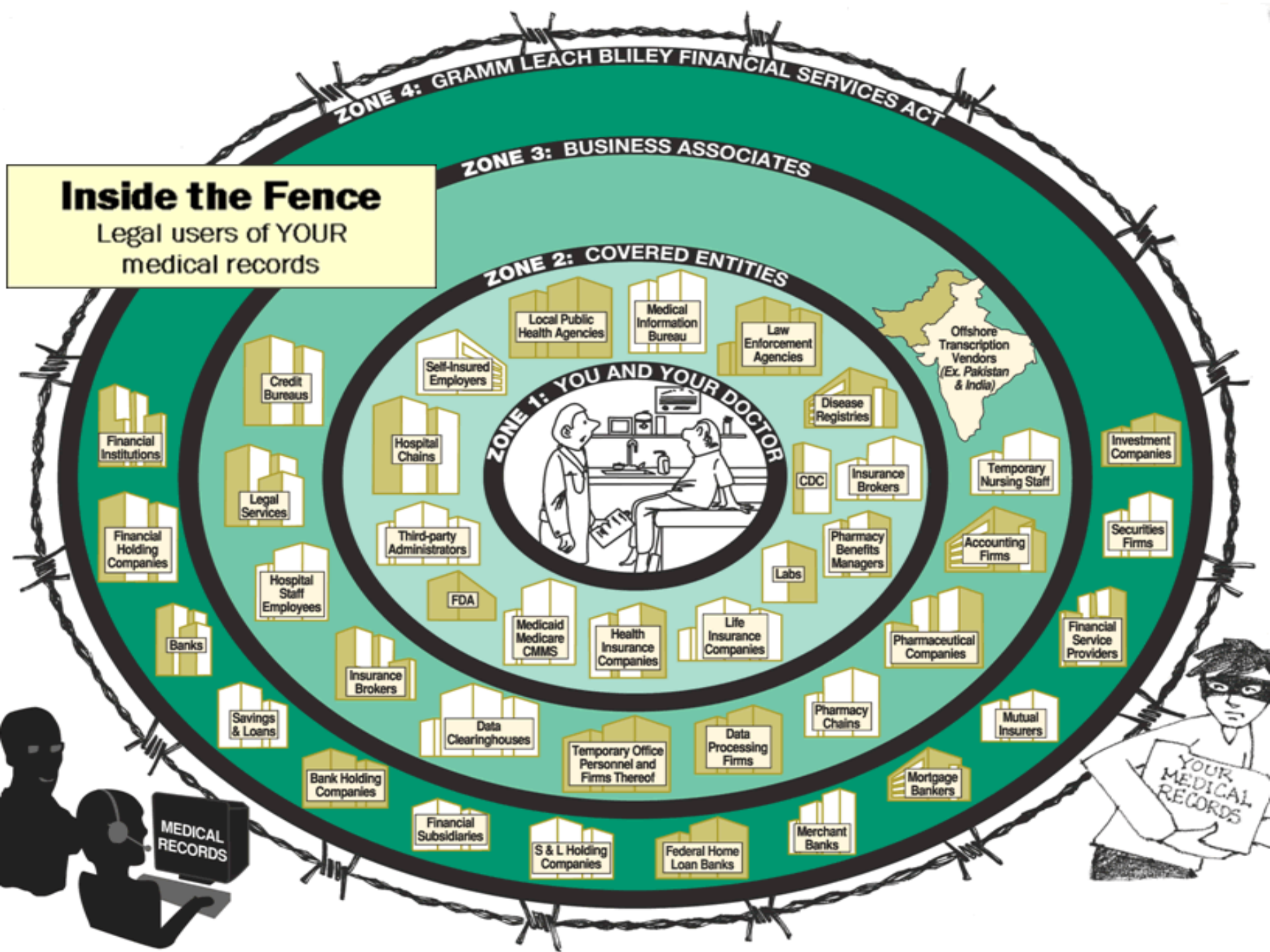
> *"… the Secretary of Health and Human Services shall submit to [Congress]…**detailed recommendations on standards with respect to the privacy of individually identifiable health information."***

2001 President Bush implemented the HHS HIPAA "Privacy Rule" which recognized the "right of consent".

> *"….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".

> *"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."*


ZONE 4: GRAMM LEACH BLILEY FINANCIAL SERVICES ACT
ZONE 3: BUSINESS ASSOCIATES
ZONE 2: COVERED ENTITIES
ZONE 1: YOU AND YOUR DOCTOR
Inside the Fence
Legal users of YOUR medical records
Local Public Health Agencies
Medical Information Bureau
Law Enforcement Agencies
Offshore Transcription Vendors (Ex. Pakistan & India)
Self-Insured Employers
Credit Bureaus
Financial Institutions
Hospital Chains
Disease Registries
Investment Companies
Legal Services
CDC
Insurance Brokers
Temporary Nursing Staff
Financial Holding Companies
Third-party Administrators
Pharmacy Benefits Managers
Securities Firms
Hospital Staff Employees
Accounting Firms
Labs
FDA
Medicaid Medicare CMMS
Health Insurance Companies
Life Insurance Companies
Pharmaceutical Companies
Financial Service Providers
Banks
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
MEDICAL RECORDS
YOUR MEDICAL RECORDS

HIPAA ensures
the unauthorized sale
of health information

Personal health data is for sale

EHRs and PHRs:
No privacy, weak security, data for sale

No privacy

- Over 4 million providers can access protected health information (PHI) for treatment, payment, and healthcare operations (TPO)
- No privacy, ie consumers do not control access to PHI

Weak security

- Easy to hack
- No role-based access, i.e., (insider snooping and theft)
- No strong 2nd factor authentication
- No encryption at rest
- Ease of copying, stealing, losing mobile devices

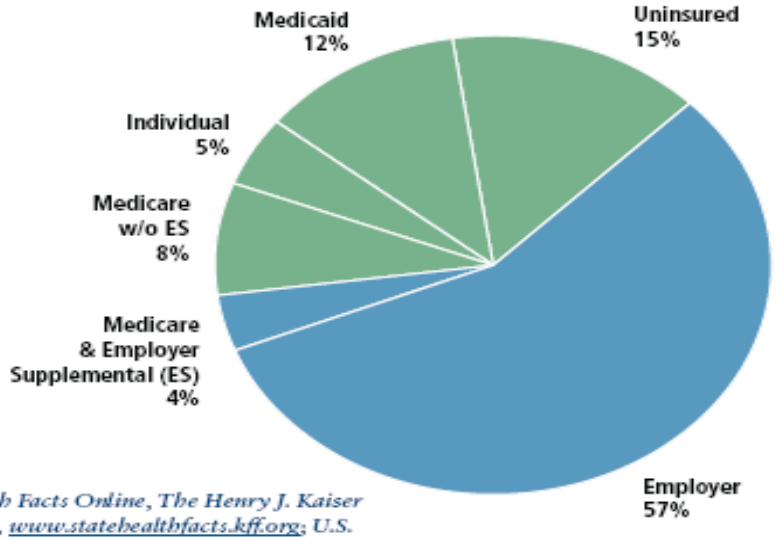
Secondary uses

- The business model for many EHRs and PHRs is selling data for secondary use and data mining

No trusted seal-of-approval for privacy and security (yet)

Medicare and Medicaid data is for sale

Figure 1: Population Distribution by Insurance Status — 2002



Source: State Health Facts Online, The Henry J. Kaiser Family Foundation, www.statehealthfacts.kff.org; U.S. residents – 285,007,110. Note: Percentages do not add to 100% because of rounding.

To address the need for better data on privately insured Americans, Thomson Medstat created the MarketScan® data collection. Since its creation, MarketScan has been expanded to include data on Medicare and Medicaid populations as well, making it one of the largest collections of claims-based patient data in the nation. MarketScan data reflect the real world of treatment patterns and costs by tracking millions of patients as they travel through the healthcare system, offering detailed information about all aspects of care. Data from individual patients are integrated from all providers of care, maintaining all healthcare utilization and cost record connections at the patient level.

Personal health information is for sale

Table 1: Sample Data Elements for Commercial and Medicare Databases

Demographic	Medical Information (Inpatient and Outpatient)	Health Plan Features	Financial Information	Drug Information	Enrollment Information
Patient ID	Admission date and type	Coordination of benefits amount	Total payments	Generic product ID	Date of enrollment
Age	Principal diagnosis code	Deductible amount	Net payments	Average wholesale price	Member days
Gender	Discharge status	Copayment amount	Payments to physician	Prescription drug payment	Date of disenrollment
Employment status and classification (hourly, etc.)	Major diagnostic category	Plan type	Payment to hospital	Therapeutic class	
Relationship of patient to beneficiary	Principal procedure code		Payments—total admission	Days supplied	
Geographic location (state, ZIP Code)	Secondary diagnosis codes (up to 14)			National drug code	
Industry	Secondary procedure codes (up to 14)			Refill number	
	DRG			Therapeutic group	
	Length of stay				
	Place of service				
	Provider ID				
	Quantity of services				

Healthcare IT News

EMR vendor to share patient data with genetics research firm

3/20/2008 by Richard Pizzi

- “Perlegen Sciences, Inc., a company exploring the clinical application of genetic research, plans to collaborate with an undisclosed electronic medical records vendor to identify and develop genetic markers that predict how patients are likely to respond to specific medical treatments.
- Under the terms of the agreement, Perlegen, based in Mountain View, Calif. , will have exclusive access to the EMR vendor's database of U.S. records for the purpose of assessing and selecting patients from whom appropriate genetic samples could be collected.”

HealthcareITNews

Practice Fusion expands, shows signs of rapid growth

By Diana Manos, Senior Editor
12/31/07

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."***

Prescription Data is for sale

Businessweek July 23, 2008: “They Know What's in Your Medicine Cabinet, How insurance companies dig up applicants' prescriptions—and use them to deny coverage"
http://www.businessweek.com/magazine/content/08_31/b4094000643943.htm?chan=magazine+channel_in+depth

DATA ON DEMAND | Two companies dominate the field of selling prescription information to insurance companies:

	MEDPOINT	INTELLISCRIPT
Parent	UnitedHealth Group’s Ingenix	Milliman
Location	Eden Prairie, Minn.	Brookfield, Wis.
History	UnitedHealth acquired MedPoint in 2002 from a small, Utah-based health-technology company, Nex2	Milliman, a Seattle consulting firm, acquired IntelRx and its IntelliScript product in 2005
Fine print	Delivers five-year history of drug purchases, dosages, refills, and possible medical conditions	Similarly provides five-year purchase history, which includes information on pharmacies and treating physicians
Pitch to insurers	“Identify high-risk individuals, reduce costs, lower loss ratios, and increase revenue”	“Clients report financial returns of 5:1, 10:1, even 20:1”

Data: MedPoint and IntelliScript

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.


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

Insurers sell data

In August, 2006, a large insurer, with plans in all 50 states, announced the creation of a new business unit to aggregate and sell the claims and health records of 79 million enrollees:

The Medical Director said that the intended use of the database is to "service the big employers that pay the bills and want to pay smaller bills for health insurance."

He was "very enthralled about the ability to help multi-state employers fix their healthcare costs." During the one and one-half years that the plan had been building the database, he had "never heard about privacy concerns."

Consumers want privacy

7 Million Americans Want Privacy

The Coalition for Patient Privacy, 2008

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 principles consumers want

Coalition for Patient Privacy

- **Recognize that patients have the right to health privacy**
  - Recognize that user interfaces must be accessible so that health consumers with disabilities can individually manage their health records to ensure their health privacy.
- The right to health privacy applies to all health information **regardless of the source, the form it is in, or who handles it**
- Give patients **the right to opt-in and opt-out** of electronic systems
  - Give patients the right to segment sensitive information
  - Give patients control over who can access their electronic health records
- Health information **disclosed for one purpose may not be used for another purpose** before informed consent has been obtained
- Require **audit trails** of every disclosure of patient information

- Require that **patients be notified promptly** of suspected or actual privacy breaches
- **Ensure that consumers can not be compelled to share health information** to obtain employment, insurance, credit, or admission to schools, unless required by statute
- **Deny employers access** to employees' medical records before **informed consent** has been obtained
- Preserve stronger privacy protections in **state laws**
- **No secret health databases**. Consumers need a clean slate. Require all existing holders of health information to disclose if they hold a patient's health information
- Provide **meaningful penalties and enforcement mechanisms** for privacy violations detected by patients, advocates, and government regulators

How to ensure privacy

Privacy solutions

‘Smart’ legislation

‘Smart’ technology

- Health trusts or banks
- Independent consent management tools
- State-of-the art security

‘Smart’ certification

‘Smart’ consumers

‘Smart’ legislation

Smart legislation - not in play

- Independent Health Record Trusts ("*Independent Health Record Trust Act of 2007", H.R.2991*)

- TRUST Act ("Technologies for Restoring Users' Security and Trust in Health Information Act of 2008", *H.R. 5442)*

Current bills under consideration

	Wired S.1693	Pro(TECH)T HR 6357	Health-e IT Act HR 6898
Definition of Privacy	no	no	no
Sale of PHI	allowed	limited	limited
Breach notice	yes	yes	limited
Audit trails	no	no	limited
Segmentation	no	no	limited
Extend HIPAA to BAs	no	no	yes

‘Smart’ technology

Reaping the benefits of HIT *with* privacy

Health Record Bank

Clinician's Bank

Encounter data sent to Health Record Bank

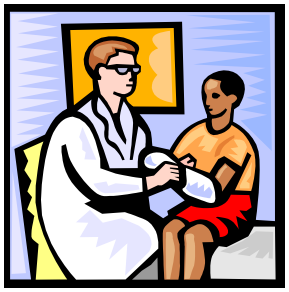
Patient data delivered to Clinician

Optional payment

SECURE PATIENT HEALTH DATA FILES

Clinician EHR System

Encounter Data Entered in EHR



Clinical Encounter

YES

Patient Permission?

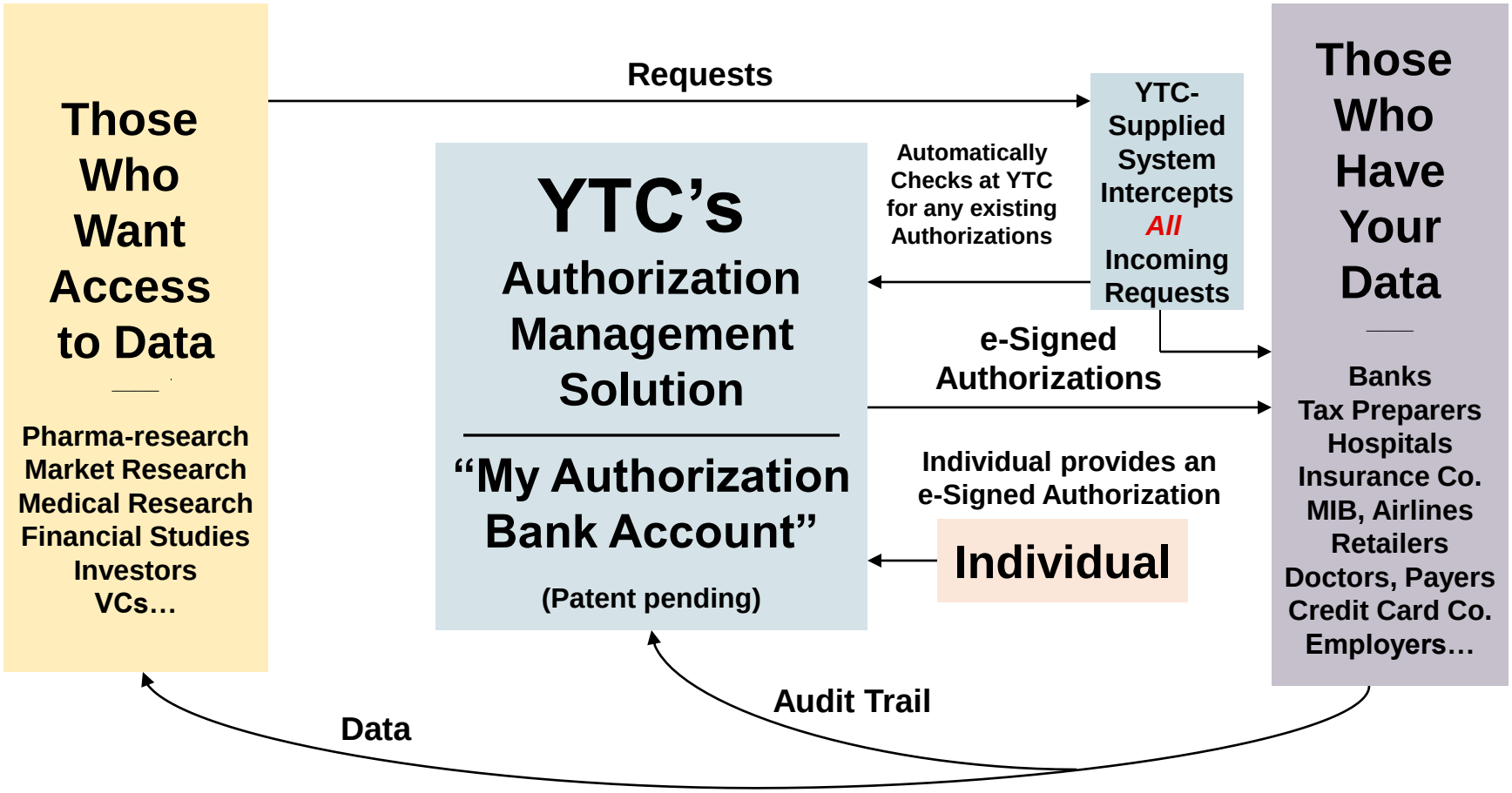
NO

DATA NOT SENT

Health Record Bank

Clinician Inquiry

Independent consent management tools



NOTE: YTC is the Trusted Consumer Advocate in the middle, and YTC never sees, nor stores your data

‘Smart’ certification

‘Smart’ Certification

PrivacyRightsCertified, Inc.

Consumer-led organization offering a Good Housekeeping Privacy Seal-of-Approval for HIT systems and products that ensure consumer control of PHI

Privacy Rights Certified will ensure Americans **UNDERSTAND** PHRs and EHRs, **CHOOSE** wisely, and take steps to **PROTECT** their most intimate information.

‘Smart’ consumers

Forms

- Privacy Instructions: Give to all Providers
- How to Talk to Your Doctor
- For Physicians: Opt out of the AMA Database

Information

- Your Health Privacy Rights
- FAQs

Take Action

- Stay Informed
- Sign the Campaign for Prescription Privacy Petition
- Advocacy 101: How to Talk to the Folks You Vote For (or Against)

Forms

- Complaint Form to HHS
- Withdraw Consent -- *coming soon*

Information

- FAQs

Take Action

- Congress Needs to Hear from You
- Share Your Story

Online Privacy Education

patientprivacyrights

Personal Health Records Latest Battle in Assault on Medical Privacy

Patient Privacy Rights is advising members NOT to sign up for personal health records (PHRs). PHRs are simply the latest battlefront to invade medical privacy.

Despite the promise of great convenience, PHRs have no legal or ethical protections for the sensitive health information patients, insurers, or employers place in them. Today, insurers and employers are rapidly pressing the public to use PHRs in databanks that the publi does NOT own or control. Wal-Mart, Intel, and other major employers formed Dossia to bank employees' PHRs. The major insurers are also setting up PHR databanks they will pre-populate with enrollees' health and claims data (and enrollees may not be able to opt-out of these data banks). Even banks and financial institutions are rushing to get into the business of holding your PHR along with your money. And the public trusts none of them.

So, before signing up for a PHR, Patient Privacy Rights urges all citizens to read this January 5, 2007 review commissioned by the Office of the National Coordinator for Health IT (ONCHIT). It confirms Patient Privacy Rights' cautionary statements against PHRs.

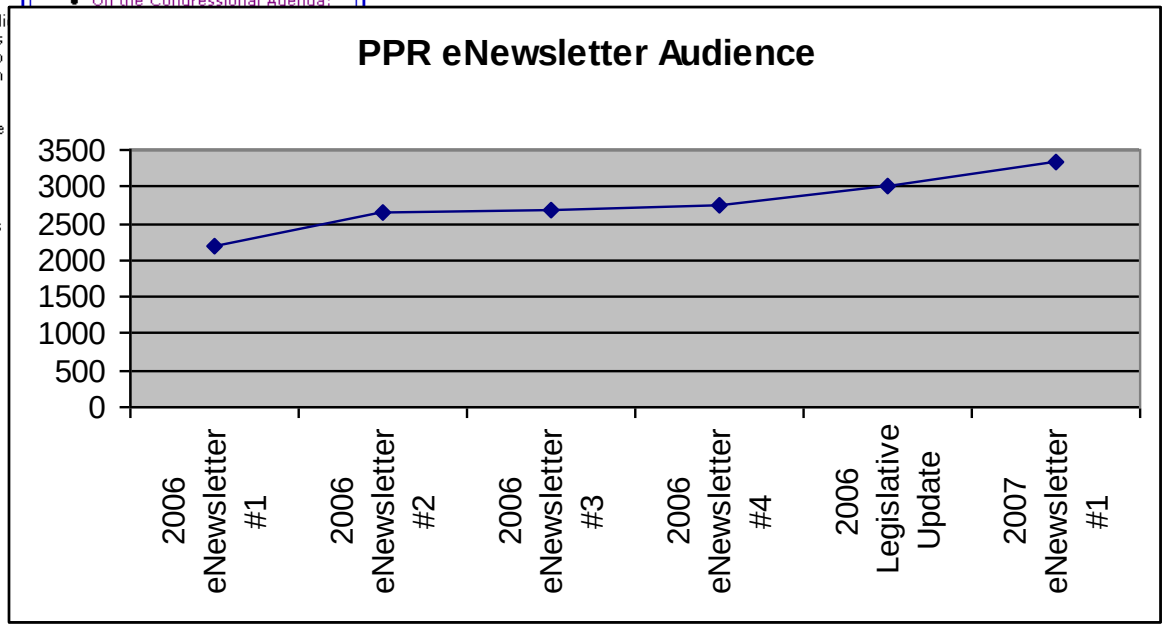
- See Patient Privacy Rights' summary of the ONCHIT report
- See full ONCHIT report
- See Patient Privacy Rights' press release on PHRs

March 2007 Newsletter

In this Newsletter

- Personal Health Records Latest Battle in Assault on Medical Privacy
- On the Congressional Agenda:

- Regular Newsletter keeps general public aware of medical privacy issues.
- Audience continues to grow



On-line resources for consumers

- Online Library
  - Comprehensive medical privacy library of news stories, reports and polls
- On-line resource for policy experts, media and legislative staff
- Ongoing email outreach program to keep consumers engaged

Privacy e-campaigns

SIGN THIS PETITON

- I want to decide who can see and use my medical records
- I do not want my medical records or those of my family's to be seen or used by my employer
- I should never be forced to give up my right to privacy in order to get medical treatment

Yes, I want my medical privacy! '*' = Required Fields

First Last

Name:

* Email:

ZIP / Postal * Code:

Yes, I wou

Privacy Rights

Remember

patientprivacyrights

Tell Congress You Want to Control Who Can Access Your Medical Information

Do you want to control who can access and use your medical information? You won't, unless we act today!

Congress is currently considering legislation to create electronic health networks that would expose our medical records to a web of interests.

Electronic health networks can reduce costs, reduce errors and improve medical care. But without ironclad privacy protections these networks will open our most personal medical records to prying eyes. Employers, banks, marketers, insurers and pharmaceutical corporations can access and use your medical data for purposes that have nothing to do with your medical care (*read Consumers Union "The New Threat to Your Medical Privacy" for more information*).

- "I Want My Medical Privacy" Petition recruited 3,000 individuals to medical privacy efforts

- Use e-campaigns to contact state and federal lawmakers

-Use online polls and surveys engage and educate the public.

3 Things *You* Can Do Now

- Sign up for e-Alerts
- Tell Congress: “Don’t pass health IT legislation without strong privacy protections”
- Use the Consumer Tool Kit, ask providers to sign *your* privacy forms

www.patientprivacyrights.org

Will the next Administration restore privacy?

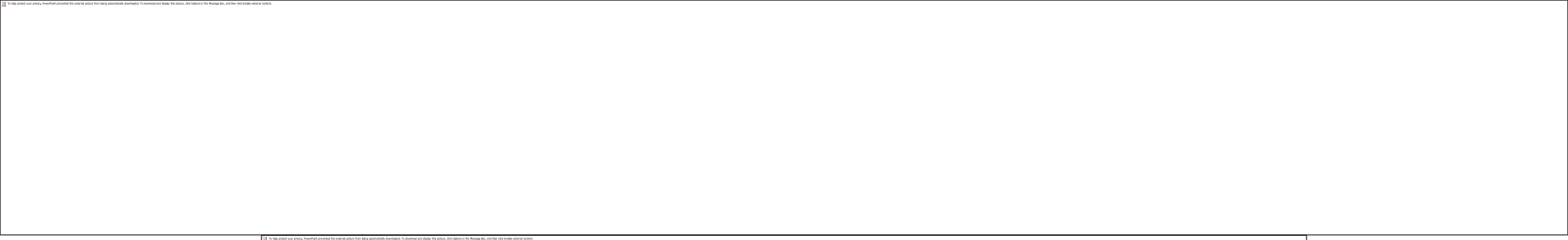
What does ‘privacy’ mean?

Legal definition: ‘privacy’ means control over personal information

No control = no privacy

HHS and Congress have not defined ‘privacy’

The candidates



Dear Abby:

Our next President faces huge challenges, including restoring our trust and control over our health information. We are very concerned that neither Clinton, McCain nor Obama have responded to our Valentine's Day request to tell us where they stand on protecting our most private health records*

The right to protect our most sensitive information belongs at the top of the list of issues the candidates address. Here are ways you can assess the candidates' stances and encourage them to act:

1. Consider Patient Privacy Rights' review of the 3 remaining candidates' written records on health privacy.
2. Ask the candidates to address the need for health information privacy.
3. Make sure you are registered to vote for the November 2008 election.

As you might guess, no candidate *opposes* our right to keep our health records private; **the right to be left alone is as American as apple pie**. However, we can point to very little action that speaks louder than words for the 3 contenders. You can click on the name of each candidate to see any remarks made or bills sponsored related to health privacy.

Sen. Hillary Clinton (D)

Sen. John McCain (R)

Sen. Barak Obama (D)

Take Action

Which Candidates Stand for Privacy?

Patient Privacy Rights submitted a Health Privacy Questionnaire to all Presidential candidates earlier this year. To date, we have not received responses from either candidate. We have compiled the following based on research of each candidates' record. Click on a candidate to view their Health Privacy History. Patient Privacy Rights does not endorse any candidate or party. Ask the candidates to pledge to make progress with privacy a presidential priority. Ask the candidates to pledge to make progress with privacy a presidential priority.

http://www.patientprivacyrights.org/site/PageServer?pagename=Candidates_on_Privacy

Sen. Barack Obama (D-IL) Remarks on Health Privacy:

Patient Privacy Rights could not find any specific statements about what he would do to ensure health privacy.

Policy & Legislative Record:

Wired for Healthcare Quality Act of 2008, S. 1693 (Co-Sponsor) (Status: pending in committee). Obama is a sponsor of the bill and did not object to its passage via unanimous consent – essentially a vote for the legislation.

Obama's healthcare plan: **Plan for a Healthy America** of 2008 includes in the Health IT portion the single statement "Obama will ensure that patients' privacy is protected."

Policy & Legislative Record:

According to the Obama website, in the Technology section you will find the following regarding privacy in general with some mention of health privacy specifically:

"Safeguard our Right to Privacy: The open information platforms of the 21st century can also tempt institutions to violate the privacy of citizens. Dramatic increases in computing power, decreases in storage costs and huge flows of information that characterize the digital age bring enormous benefits, but also create risk of abuse. We need sensible safeguards that protect privacy in this dynamic new world. ***As president, Barack Obama will strengthen privacy protections for the digital age and will harness the power of technology to hold government and business accountable for violations of personal privacy***.

- Obama supports updating surveillance laws and ensuring that law enforcement investigations and intelligence-gathering relating to U.S. citizens are done only under the rule of law.
- Obama will also work to provide robust protection against misuses of particularly sensitive kinds of information, such as e-health records and location data that do not fit comfortably within sector-specific privacy laws.
- Obama will increase the Federal Trade Commission's enforcement budget and will step up international cooperation to track down cyber-criminals so that U.S. law enforcement can better prevent and punish spam, spyware, telemarketing and phishing intrusions into the privacy of American homes and computers."

Sen. John McCain (R-AZ) Remarks on Health Privacy:

Patient Privacy Rights could not find any specific statements about what he would do to ensure health privacy.

Policy & Legislative Record:

Wired for Healthcare Quality Act of 2008, S. 1693 (Status: pending in committee). McCain did not object to the bill's passage via unanimous consent – essentially a vote for the legislation.

McCain's website has some mention of his suggestions for healthcare reform that include lowering the cost of health insurance, making insurance more accessible and making easier for individuals to receive health insurance through means other than their employers. We did not find a clear statement supporting health IT and a national electronic health information network, or any mention of health privacy.

This Administration

This Administration

- HIT Strategic Plan: all EHRs and PHRs will be data mined for “population health”
- GAO: HHS has not ensured that privacy principles are addressed and may fail to establish the public’s trust
- NCVHS promotes "secondary uses" of PHI without contemporaneous, informed consent
- ONC Report on Data Quality recommends open access to all EHRs by health plans to detect fraud

HHS/ONC Federal Health IT Strategic Plan: 2008-2012

June 3, 2008

HIT Strategic Plan: privacy problems

- “Population health” use of data trumps American’s rights to health privacy
- All EHRs and PHRs are to be designed for data mining and use without consent for “population health”
- The American public has never debated the question of whether ALL electronic health records should be open for research and “population health” uses without informed consent

Goal One – *Enable Patient-focused Health Care*

Enable the transformation to higher-quality, more cost-efficient, patient-focused health care through electronic health information access and use by care providers, and by patients and their designees.

Goal Two – *Improve Population Health*

Enable the appropriate, authorized, and timely access and use of electronic health information to benefit public health, biomedical research, quality improvement, and emergency preparedness.

Strategies for Objective 2.2

The following illustrative action steps *seek to advance EHR interoperability to include standards, technical architecture and certification requirements that support data sharing and use for population health purposes*:

Define and prioritize a set of consensus based data and *technical standards for EHRs* that are needed to enable population health uses through interoperable health information networks.

Strategies for Objective 2.2

Strategy 2.2.2: Allow for flexibility in the models for the exchange of health information (organizational, geographic, and personally controlled), while still advancing the specific standards and policies necessary to ensure that they all work together to meet population health needs.

GAO report
Sept 2008

Health Information Technology: HHS Has Taken Important Steps to Address Privacy Principles and Challenges, Although More Work Remains

GAO conclusions

Unless HHS's privacy approach includes a defined process for assessing and prioritizing the many privacy-related initiatives, the department may not be able to ensure that key privacy principles and challenges will be fully and adequately addressed.

Further, stakeholders may lack the overall policies and guidance needed to assist them in their efforts to ensure that privacy protection measures are consistently built into health IT programs and applications.

As a result, the department may miss an opportunity to establish the high degree of public confidence and trust needed to help ensure the success of a nationwide health information network.

NCVHS Report 2007

Report to the Secretary of the U.S. Department of Health and Human Services

on

Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data

October 21, 2007

NCVHS

The report recommends that HHS allow "secondary uses" of our PHI without contemporaneous, informed consent.

"Secondary uses" include research, marketing, monitoring, data mining and profiling.

- sale of PHI is allowed
- your right of consent is eliminated
- expands access to your data
- enables tracking of you and your doctors
- enables data mining, patient profiling and data linking

Recommended Requirements for Enhancing Data Quality in Electronic Health Records

Final Report

May 2007

The Office of the National Coordinator for Health Information Technology

Prepared by **RTI International**

ONC/RTI Report May 2007

In 2003, losses due to fraud were $51 billion to $170 billion.

Moving to an electronic environment has the potential to greatly increase fraud.

The use of advanced analytics software built into the NHIN is critical to fraud loss reduction.

Fraud is due to unauthorized access to EHRs

THE ONC SOLUTION: Build open access into EHRs so ***payers*** can detect fraudulent patterns. Payers (insurers, employers, and government) are granted full access to PHI to detect fraud.

THE PRIVACY SOLUTION: Consumers prevent fraud by limiting improper/unwanted access to their EHRs using electronic consent management tools.

Key Quotes from ONC/RTI Report

Detection of a fraudulent claim is often difficult when a payer has access only to EHR information for a single encounter.

Reviewing information over an entire episode of care for a single patient allows greater ability to detect fraud.

The next Congress and Administration are not likely to restore privacy…..

unless YOU act

Progress with Privacy
Patient Privacy Rights

www.patientprivacyrights.org

Deborah C. Peel, MD
Founder and Chair
dpeelmd@patientprivacyrights.org

Ashley Katz, MSW
Executive Director
akatz@patientprivacyrights.org

512.732.0033 (office)

England Changes Stance on Patient Consent Policy for Electronic Records

FT.com FINANCIAL TIMES

Electronic medical records a step closer

By Nicholas Timmins, Public Policy Editor Published: September 19 2008 05:31

Patients will now be **given the chance to opt out before a summary record is created**.

Patients will be **asked at each consultation if the clinician can look at their record** and will have the **right at that point to opt out entirely, to refuse for that episode *of* care, or to agree to the record being viewed**. They will also be able to agree to the record being permanently available to accredited clinicians.

The default position will be “Ask me first”.

http://www.ft.com/cms/s/0/ff2823e8-85d0-11dda1ac0000779fd18c.html?nclick_check=1