

HIMSS '09

Session 52

**Patient-controlled Health Record
Banks: An Answer to the HIT
Privacy Problem?**

Why Privacy?

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

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.”

Constitutional rights to privacy

"The right to be let alone is the most comprehensive of rights and the right most valued by civilized men.

To protect that right, every unjustifiable intrusion by the government upon the privacy of the individual, whatever the means employed, must be deemed a violation of the [Constitution]."

Olmstead v. United States, 277 U.S. 438, 478, 48 S.Ct. 564, 572 (1928) (Brandeis dissenting)

“In fact, *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).

ethics
privileges
common law

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

“Since the time of Hippocrates physicians have pledged to maintain the secrecy of information they learn about their patients, disclosing information only with the authorization of the patient or when necessary to protect an overriding public interest, such as public health.

Comparable provisions are now contained in the codes of ethics of virtually all health professionals.”

Report to HHS, NCVHS (June 22, 2006)

Research ethics

In medical research on human subjects, considerations related to **the well-being of the human subject should take precedence over the needs and interests of society.**

Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patients information, and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

World Medical Association Declaration of Helsinki June 1964

Privileges

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

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

A psychotherapist-patient privilege is recognized in the laws of all 50 states and the District of Columbia.

Jaffee v. Redmond, 116 S. Ct. 1923, 1929 (1996)

Common Law

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.

HIPAA

definition of privacy

The Code of Fair Information Practices (1974)

“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.”

NCVHS

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

June 2006, Report to Sec. Leavitt

What does 'privacy' mean?

Legal definition: 'privacy' means control over personal information

No control = no privacy

HHS and Congress have not defined 'privacy'

HHS 'deregulated'
Americans' rights to
health privacy in
2002

Deregulating 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.”*

Inside the Fence

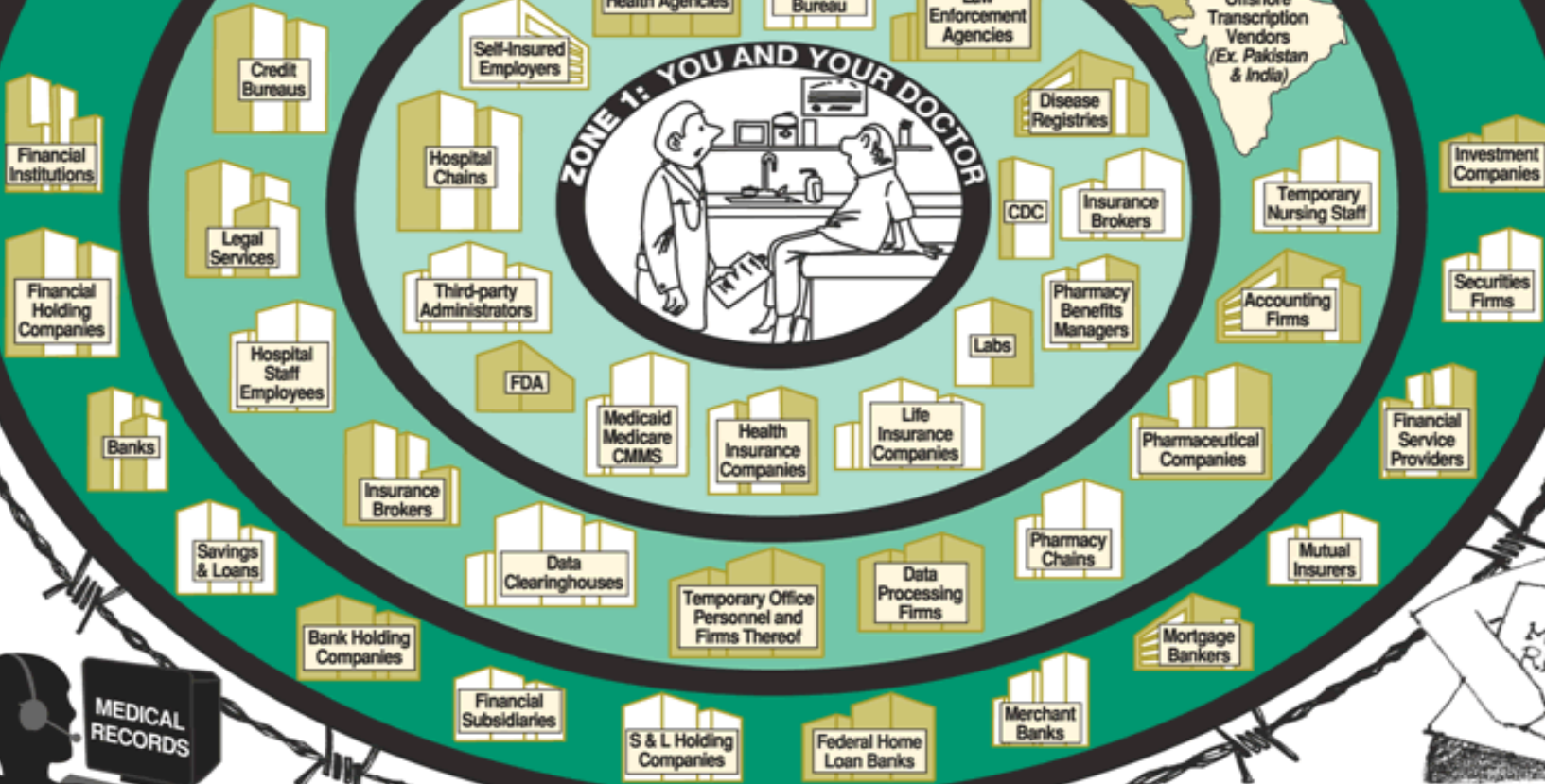
Legal users of YOUR medical records

ZONE 4: GRAMM LEACH BLILEY FINANCIAL SERVICES ACT

ZONE 3: BUSINESS ASSOCIATES

ZONE 2: COVERED ENTITIES

ZONE 1: YOU AND YOUR DOCTOR

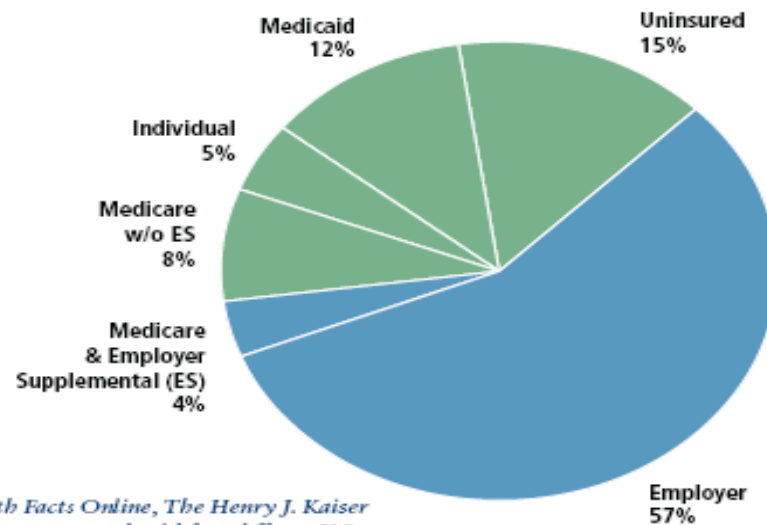


HIPAA 'deregulation'
ensured
the commoditization
of personal health
information

Personal health data
is for sale

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				

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.”

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	INTELLISCRIPIT
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.

Prescription data mining

The top three publicly-held prescription data mining and sales corporations in the US reported revenues in 2007 of \$65 billion dollars.

See Fortune 500's data on their revenues at:

<http://money.cnn.com/magazines/fortune/fortune500/2008/snapshots/10630.html>.

A man in a gym setting, wearing a headset and a sign that reads "VIAGRA FOR ERECTILE DYSFUNCTION". The background shows a blurred figure of a woman on a treadmill.

TAKE **YOUR**
HEALTH DATA
"OFF THE MARKET".

watch the video ▶

CAMPAIGN *for*
PRESCRIPTION
PRIVACY

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.”

Consequences of deregulating privacy

Lack of consumer
trust in HIT

COALITION FOR PATIENT PRIVACY

A.C.T. letter to Congress Jan 09

AIDS Action Council

Alliance for Patient Safety

American Association for People with Disabilities

American Civil Liberties Union

Arizona Eagle Forum

Bazelon Center for Mental Health Law

Bill of Rights Defense Committee

Citizens for Health

Citizen Outreach Project

Clinical Social Work Association

Confederation of Independent Psychoanalytic Societies

Consumer Action

Cyber Privacy Project

Esther Dyson

Electronic Privacy Information Center

Fairfax County Privacy Council

Government Accountability Project

Health Administration Responsibility Project, Inc.

International Association of Whistleblowers

Senator Karen Johnson (AZ)

JustHealth

Justice Through Music

Liberty Coalition

Microsoft Corporation, Inc

The Multiracial Activist

Representative Elliot Naishtat (TX)

National Association of Social Workers

National Center for Transgender Equality

The National Coalition for Mental Health Professionals and Consumers

National Workrights Institute

Senator Marc Pacheco (MA)

Patient Privacy Rights

Private Citizen, Inc

Representative Cindy Rosenwald (NH)

Bruce Schneier

Thoughtful House Center for Children

Tolven

U.S. Bill of Rights Foundation

Velvet Revolution

ACCOUNTABILITY – Hold every entity with access to health information accountable

- Those who collect, store or use personal health information should help ensure that the data is accurate, reliable and secure. Min. standards: encrypt data at rest and in transit, limit access to specific individuals via informed, electronic consent and audit trails.
- Authorize and fund HHS and FTC to increase their oversight of industry including random audits of contracts.
- Require breach notification, privacy safeguards and whistleblower protections, including meaningful enforcement of privacy rights.

CONTROL – Ensure individuals control the use of their personal health information.

- Codify a federal right to health information Privacy.
- Ensure individuals can segment sensitive information and safeguards for medical information are built in up front.
- Provide incentives for health IT systems to use electronic informed consent, innovative consumer privacy controls and for user interfaces to be accessible for patients with disabilities.

TRANSPARENCY – Protect consumers from abusive practices

- Prohibit direct or indirect remuneration for the sharing, disclosure or use of personal health information with limited exceptions for research and public health.
- Ensure that corporations cannot obtain exclusive or contractual rights to own or control personal health information.
- Personal health information obtained for one purpose must not be used for other purposes without informed consent. Even when consent is obtained, privacy obligations such as security and prevention of misuse, continue.

HIT stimulus package as of 1/28/09

- Ban on sales of PHI from EHRs
- Audit trails of some transactions
- Right to prohibit disclosure of PHI for payment and HCO if private-pay
- Right to segment sensitive information
- Breach reporting
- Encryption of data at rest

England Changes Stance on Patient Consent Policy for Electronic Records



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

Progress with Privacy Patient Privacy Rights

www.patientprivacyrights.org

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