

The Sharing, Selling, Re-selling and Unauthorized Use of our Personal Health Information

Identifiable Data, “De-Identifiable Data,” and Why it Matters.

As demonstrated through excerpts below, patients' personal health information and electronic health records are routinely being shared, sold, and re-sold to third parties wholly uninvolved in each patient's diagnosis, treatment or payment for services. This secondary information market violates patient privacy by turning personal health information into a commodity. Congress should act to restrict this secondary market in private, personal health information.

When patients lack control of their personal health information that information can be used to wrongly deny employment, insurance, credit, education and other life opportunities.

Use of Identifiable Data

Many EHR Vendor Contracts Stipulate Ownership, Exclusive Access, and a Right to Sell Data

Nationally prominent physician informaticist, Paul Tang, MD, member of AHIC and NCVHS, reported he had personally seen the contract language. Vendors of both large and small, inpatient and outpatient systems have contracts stipulating they *“have ownership to the data. There are contracts that say they will have real-time access to the database, that they will have exclusive access to the data, that they can resell the data.”*¹

“There is an industry out there that is wide open...at some point privacy has got to catch up...because once it is implemented undoing it and getting everybody to go back and change it...is not something that works well in this world.”

-Harry Reynolds, VP of HIPAA & Information Compliance for Blue Cross Blue Shield of North Carolina

“Health information is valuable and it looks like they are buying and selling it like any other commercial commodity. What’s to stop them? OCR doesn’t have authority over the vendors, and even if they did, what’s the risk of getting caught?”

-Joy Pritts, Health Policy Institute at Georgetown University

There are Massive Databases of Individual Prescription Profiles

Likely the largest database is Nex2, sold to United Healthcare in 2002. According to Nex2's creator: “In stealth-mode, Nex2 built the largest drug history databases in the world, with over 200 million Americans' five-year running drug histories online. The databases are updated every 24 hours by every retail pharmacy in America.”²

¹ Modern Healthcare, “IT guru says some e-vendor contracts violate privacy” by Joseph Conn – July 19, 2007

² Richard Dick, PhD, Founder of Nex2, Inc.

The use of this data falls under the “Treatment, Payment and Operations” provision of HIPAA.

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

- Richard Dick, PhD, Founder of Nex2, Inc.

Prescription Records are Auctioned Off and Sold to the Highest Bidder

A patient discovered her long-time pharmacy had closed and that her entire family's medical records were sold to Target. HIPAA allows pharmacies to “auction off” customer records (prescriptions, diagnoses, social security numbers and insurance records) “to the highest bidder,” said Sen. Charles Schumer (D-NY).³

“The practice of selling off records is a nationwide problem.”

-Sen. Charles Schumer (D-NY)

Identifiable Information is Purchased from Grocery Stores and Pharmacies for Marketing

Grocery store chain, Albertsons, as alleged in *Weisz v. Albertsons, Inc.* collects and sells its customers' confidential medical information (primarily prescriptions) in a database including addresses, phone numbers and drug regimen. **The information is sold to pharmaceutical companies** that use the information for mailings and phone calls encouraging use of certain medications and marketing alternative brand name medications.⁴ Motions to Dismiss and Strike this case have been denied and it is proceeding through discovery.

Albertsons, Inc. is paid at least \$3.00 - \$4.50 per letter it sends...Hundreds of thousands of communications are sent annually and the pharmaceutical companies accordingly pay millions of dollars to Albertsons annually.

- Privacy Rights Clearinghouse website, Plaintiff in *Weisz v. Albertsons, Inc.* filed on May 17, 2004

Identifiable Information is Sold to Pharmaceutical Companies for Detailing

In 2007, West Virginia's Public Employees Insurance Agency discovered Express Scripts was selling their prescription data to data-mining organizations to better target physicians and increase prescribing of certain brand name drugs.⁵

³ Newsday, “Patient info for sale” by Magdalene Perez – June 19, 2007

⁴ *Weisz v. Albertsons Inc.*, (San Diego Superior Court Case No. GIC 830069) and Privacy Rights Clearinghouse, <http://www.privacyrights.org/ar/PharmQA.htm>

⁵ *The Charleston Gazette*, “For sale. Public Employees Insurance Agency drug data” – November 27, 2007

Medical Information Is In Your Credit Report

According to the *Wall Street Journal*, medical data can be found in your credit report. "It means your banker, after seeing that credit-card payment you made to the local psychiatrist, might decide he would rather not give you a loan."⁶

"De-Identifiable" Data is Incredibly Rare

87% of the population in the U.S. can be re-identified if there is a Date of Birth, Gender and Zip Code...Data that may look anonymous is not necessarily anonymous.

-Prof. Latanya Sweeney, PhD Director, Laboratory for International Data Privacy, School of Computer Science, Carnegie Mellon University in her testimony before DHS, June 15, 2005

In *Southern Illinoisan v. Illinois Dept. of Public Health*, Dr. Sweeney testified that it was "very easy for anyone to identify persons from the [Illinois Department of Public Health's] Cancer Registry using public data sets...all I used was commonly available PC technology, readily available software...simple [spreadsheets]."⁷

In 2005 Dr. Sweeney testified before the Department of Homeland Security noting that in 1997 she was able to find the medical record of Former Gov. William Weld (MA) by using just his date of birth, gender and zip code.⁸ With just a few bits of information, Prof. Sweeney can re-identify **9 out of 10** people.⁹

*"Many details about our lives are documented on computers and when this information is linked together, the resulting profiles can be **as identifying as fingerprints** even when the information contains no explicit identifiers such as name and address..."*

*The time is right to seriously examine data collection and sharing practices...**The time to make policy changes is now in order to prevent data holders and governments from succumbing to the financial incentives that encourage sales of data."***

-Prof. Latanya Sweeney, PhD

"Information Explosion" Confidentiality, Disclosure and Data Access: Theory and Practical Applications for Statistical Agencies, L. Zayatz, P. Doyle, J. Theeuwes, and J. Lane (eds), Urban Institute, Washington DC, 2001

⁶ *Wall Street Journal*, "Medical Data Can Show Up In a Person's Credit Report" by Sean Marciniak – August 6, 2003

⁷ 218 Ill.2d 390, 844 N.E. 2d 1, 300 Ill. Dec.329

⁸ Testimony of Latanya Sweeney, PhD before the Privacy and Integrity Advisory Committee of DHS, "Privacy Technologies for Homeland Security" – June 15, 2006

⁹ *Scientific American* "Privacy Isn't Dead, or At Least It Shouldn't Be: A Q&A with Latanya Sweeney"
<http://www.sciam.com/article.cfm?id=privacy-isnt-dead&page=3>

Sample Data Elements from Thomson Medstat MarketScan Health & Productivity Management “De-Identified” Database¹⁰

Table 2: Sample Data Elements in MarketScan Health and Productivity Management Database

Demographic Information	Short-Term Disability	Workers' Compensation	Workplace Absence	Health Plan Features	Financial Information	Inpatient & Outpatient Medical Information	Drug Information
Patient ID	Case days	Body part injured	Dates and hours of absence	Coordination of benefits amount	Total payments	Admission date and type	Generic product ID
Age	Disability type	Case diagnosis	Absence type (sick, disability, vacation, etc.)	Deductible amount	Net payments	Principal diagnosis code	Average wholesale price
Gender	Case diagnosis	Indemnity payments		Copayment amount	Payments to physician	Discharge status	Prescription drug payment
Employment status and classification (hourly, etc.)	Total payments	Case days		Plan type	Payments to hospital	Major diagnostic category	Therapeutic class
Relationship of patient to beneficiary		Cause of injury			Payments total admission	Principal procedure code	Days supplied
Geographic location (state, ZIP Code)		Medical payments				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	

The only barrier to determining the identity of 9 out of 10 employees with the Thomson Medstat data set is a date of birth that an employer would already have. DOB can also be easily obtained from a variety of public reports and databases. Further, when an employer knows the date of absence, employment classification, age and zip code, it would be easy to individually identify an employee.

Anonymity Online is Equally Rare, If Not Impossible

Technology companies track users and compile “digital dossiers.” According to the *New York Times*, “There is no guarantee that the information will stay with the company that collected it. It can be sold to employers or insurance companies, which have financial motives for wanting to know if their employees and policyholders are alcoholics or have AIDS.”¹¹

¹⁰ Thomson Medstat White Paper, “Health Research Data for the Real World: The MarketScan Databases” by David M. Adamson, PhD, Stella Chang, MPH and Leigh G. Hansen, MS, MBA – January 2006

¹¹ *The New York Times*, “the Already Big Thing on the Internet: Spying on Users” by Adam Cohen – April 5, 2008

Use of “De-Identifiable” Data

Free EMRs Sell De-Identified Data to Insurance Groups, Researchers and Pharmaceutical Companies

For example, Practice Fusion subsidizes its free EMRs by selling de-identified data and advertising within the EMR.¹²

“Every healthcare vendor is selling data.”

-Ryan Howard, CEO, Practice Fusion

Data Miners Conduct Robust Studies of Employees’ Health and Mental Health Records

According to their White Paper, Thomson Medstat conducted the following studies¹³:

- Examination of the “Top 10” physical and mental health conditions affecting six large U.S. employers to identify high-cost conditions.
- Examination of the impact of treatment for depression on workplace productivity. The study measured in terms of days present on the job studying employees with a diagnosis of depression and taking anti-depressants.

Why It’s Important

No American should be denied opportunities because of their own personal health or that of their families.

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

- 65 Fed. Reg. 82,467. (BEFORE the amended HIPAA Privacy Rule)

If more than 1/3 of large employers admitted to peeking at their job applicants’ or employees’ health records before HIPAA granted broad access to those records for “Treatment, Payment and Healthcare Operations,” *how many are snooping now that they have blanket permission?*

Answer: We wouldn’t know. No one is required to ask.

Compiled by Patient Privacy Rights. For more information contact Ashley Katz, Executive Director: akatz@patientprivacyrights.org (512) 732-0033

¹² Healthcare IT News, “Practice Fusion expands, shows rapid sign of growth” by Diana Manos – December 31, 2007

¹³ ¹⁴ Thomson Medstat White Paper, “Health Research Data for the Real World: The MarketScan Databases” (p16) by David M. Adamson, PhD, Stella Chang, MPH and Leigh G. Hansen, MS, MBA – January 2006