

patientprivacyrights

Health IT & Privacy: Is there a path to consensus?

“Anyone today who thinks the privacy issue has peaked is greatly mistaken...we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine business practices under the microscope.”

Forrester Research

an independent technology and market company that provides advice to global leaders in business and technology

Dr. Deborah C. Peel

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www.patientprivacyrights.org

The 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 detailing patients rights to 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.”*

“... 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 “that would include at least the following”:

- (1) ***“The rights that an individual who is a subject of individually identifiable health information should have***
- (2) ***The procedures that should be established for the exercise of such rights.***
- (3) The uses and disclosures of such information that should be authorized or required.

Why Does Health Data Even Exist?

- People choose to disclose their most intimate information
- Doctors earn trust by guaranteeing privacy
- No privacy → people avoid treatment, lie or omit information, and GET SICKER.
- No American should ever have to choose between getting healthcare and privacy. **We deserve both.**

Americans Want to Control Who Can See & Use Their Information

- **“Researchers would be free to use my personal medical and health information without my consent at all” 1%**
- **99% of the public want to be asked, even if it is for the “greater good.”**

IOM Survey Findings on Health Research and Privacy, Dr. Alan F. Westin,
October 2, 2007

Employers Discriminate

- **35% of Fortune 500 companies admit to using medical records for hiring and promotions, 65 Fed. Reg. 82,467. (BEFORE the amended Privacy Rule)**

2006 Memorandum to Wal-Mart's Board of Directors:

- “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).”

If you really believe that the public doesn't want informed consent, require full reporting of all disclosures of PHI

Personal health information is for sale



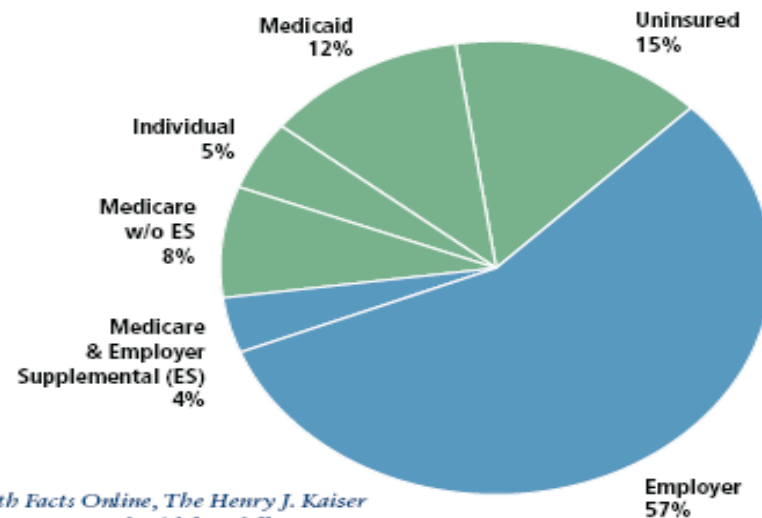
Table 1: Sample Data Elements for Commercial and Medicare Databases

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				

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.

Every Prescription in the U.S. is For Sale



- **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 acting 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.***

Smart Solutions

- ‘Smart’ technology makes privacy, audit trails, etc. *easier—eliminates the administrative burden*
- ‘Smart’ legislation:
 - TRUST Act, HR. 5442 by Markey, Emanuel & Capps
 - Independent Health Record Trust Act HR 2991
- ‘Smart certification’ by *consumer-led organization offering a Good Housekeeping Privacy Seal-of-Approval for HIT systems and products that ensure consumer control of PHI*