

The Texas Library Association

**Advocacy:
Restoring Health Privacy**

Deborah C. Peel, MD

April 9, 2014

patientprivacyrights

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.”

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

privacy \neq security



What does 'privacy' mean in healthcare?

“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 from the IOM

Privacy = how many keys?



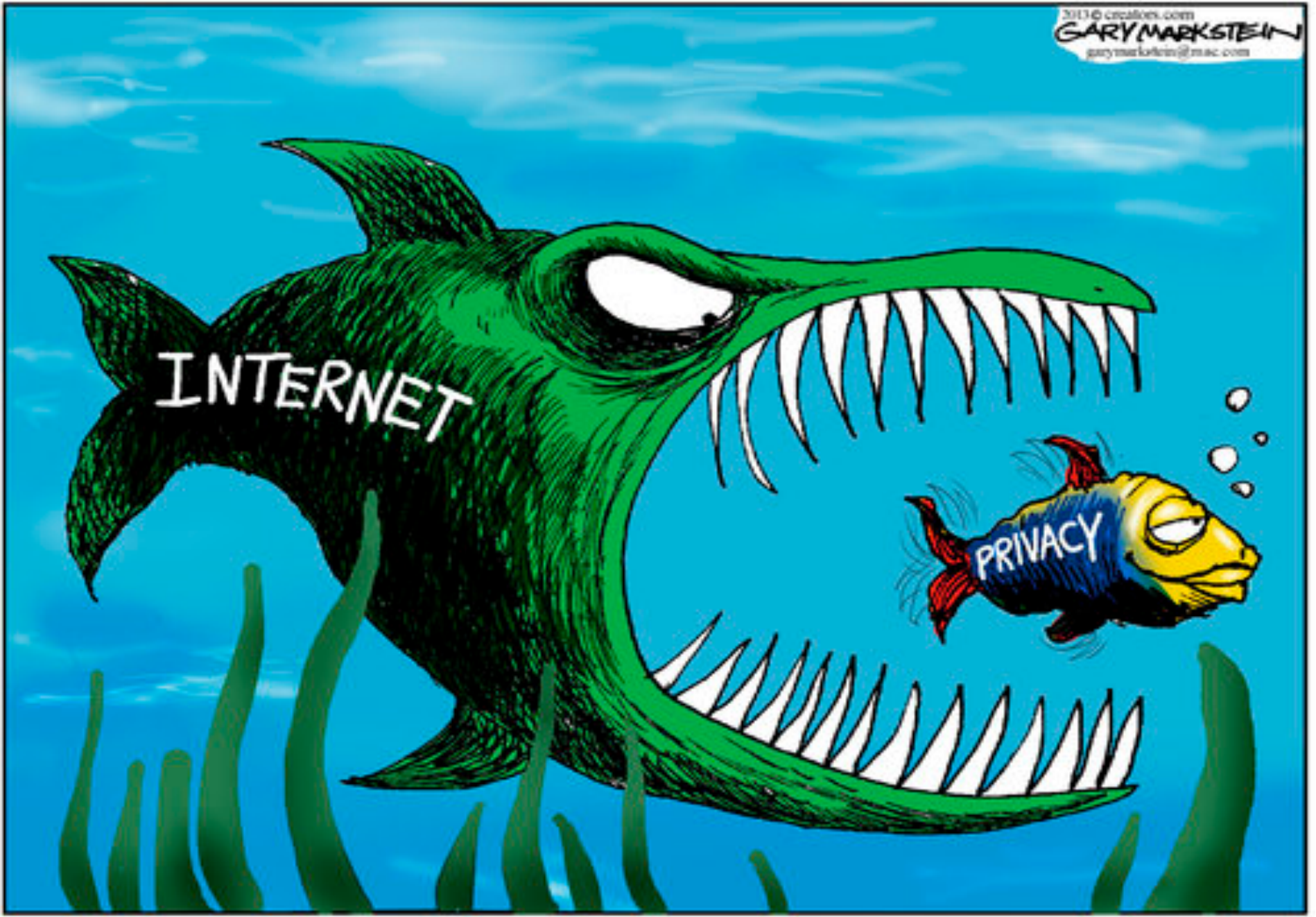
Security

what happened?

big data

or...

surveillance



Gary Markstein Milwaukee Journal Sentinel Sept 11, 2013

the surveillance economy

government fusion centers
corporate data brokers

theguardian

NSA collecting phone records of millions of Verizon customers daily

Exclusive: Top secret court order requiring Verizon to hand over all call data shows scale of domestic surveillance under Obama

[Read the Verizon court order in full here](#)

[Obama administration justifies surveillance](#)

<http://www.guardian.co.uk/world/2013/jun/06/nsa-phone-records-verizon-court-order>

NSA

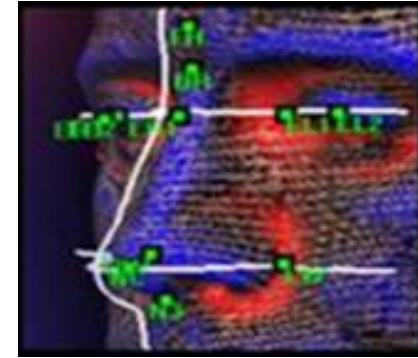


'Peeping while you're sleeping' T-shirt drew ire of NSA lawyers

<http://www.dailymail.co.uk/news/article-2487418/NSA-tries-BAN-T-shirt-brands-the-government-listens.html>



Fusion Centers



BEYOND FINGERPRINTS, Biometric Databases and Quantitative Privacy

by Danielle Citron September 8, 2012

\$1B Next Gen ID system, multimodal biometrics: palm prints, fingerprints, iris, retina, voice, face, gait

Federal, state, & local fusion centers mine information posted online; private security camera footage; systems of private partners; data from state, local, & federal law enforcement; mug shots; DNA databases; and driver ID photographs

<http://www.concurringopinions.com/archives/2012/09/biometric-databases-and-quantitative-privacy.html#more-65882>

The New York Times Not Track? Advertisers

Say 'Don't Tread on Us'

By NATASHA SINGER

October 13, 2012

http://www.nytimes.com/2012/10/14/technology/do-not-track-movement-drawing-advertisers-fire.html?_r=1&ref=natashasinger



campaign to defang the “Do Not Track” movement began late last month

“what is really at stake here is the future of the surveillance economy”

House to FTC: ‘Do Not Track’ might restrict “the flow of data at the heart of the Internet’s success.”

[open letter from the board of the Association of National Advertisers](#): Microsoft’s action is wrong. The entire media

ecosystem has condemned this action”

The New York Times

How Companies Learn Your Secrets

By Charles Duhigg

Published: February 16, 2012

“If we wanted to figure out if a customer is pregnant even if she didn’t want us to know, can you do that? ”



<http://www.nytimes.com/2012/02/19/magazine/shoppinghabits.html?pagewanted=all>

You for Sale: Mapping, and Sharing, the Consumer Genome

June 16, 2012

Justin Bolle, New York Times

Acxiom: world's largest consumer database



- 50 trillion data transactions/year.
- 500M consumers worldwide, a majority of US adults
- **sales of \$1.13B**
- **1,500 data points per person**

http://www.nytimes.com/2012/06/17/technology/acxiom-the-quiet-giant-of-consumer-database-marketing.html?_r=3&ref=todayspaper

<http://blogs.wsj.com/digits/2013/12/18/brokers-trade-on-sensitive-medical-data-with-little-oversight-senate-says/>



Brokers Trade on Sensitive Medical Data with Little Oversight, Senate Says

By [Elizabeth Dwoskin](#)

Dec 18, 2013

Marketers maintain databases that purport to track and sell the names of people who have diabetes, depression, and osteoporosis, as well as how often women visit a gynecologist, according to a Senate report published Wednesday. The companies are part of a multibillion-dollar industry of “data brokers” that lives largely under the radar, the report says. The report by the Senate Commerce Committee says individuals don’t have a right to know what types of data the companies collect, how people are placed in categories, or who buys the information.

Americans expect privacy and control



but....

HIPAA eliminated 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."*

Latanya Sweeney on flaws in EHRs and data exchanges (HIEs)

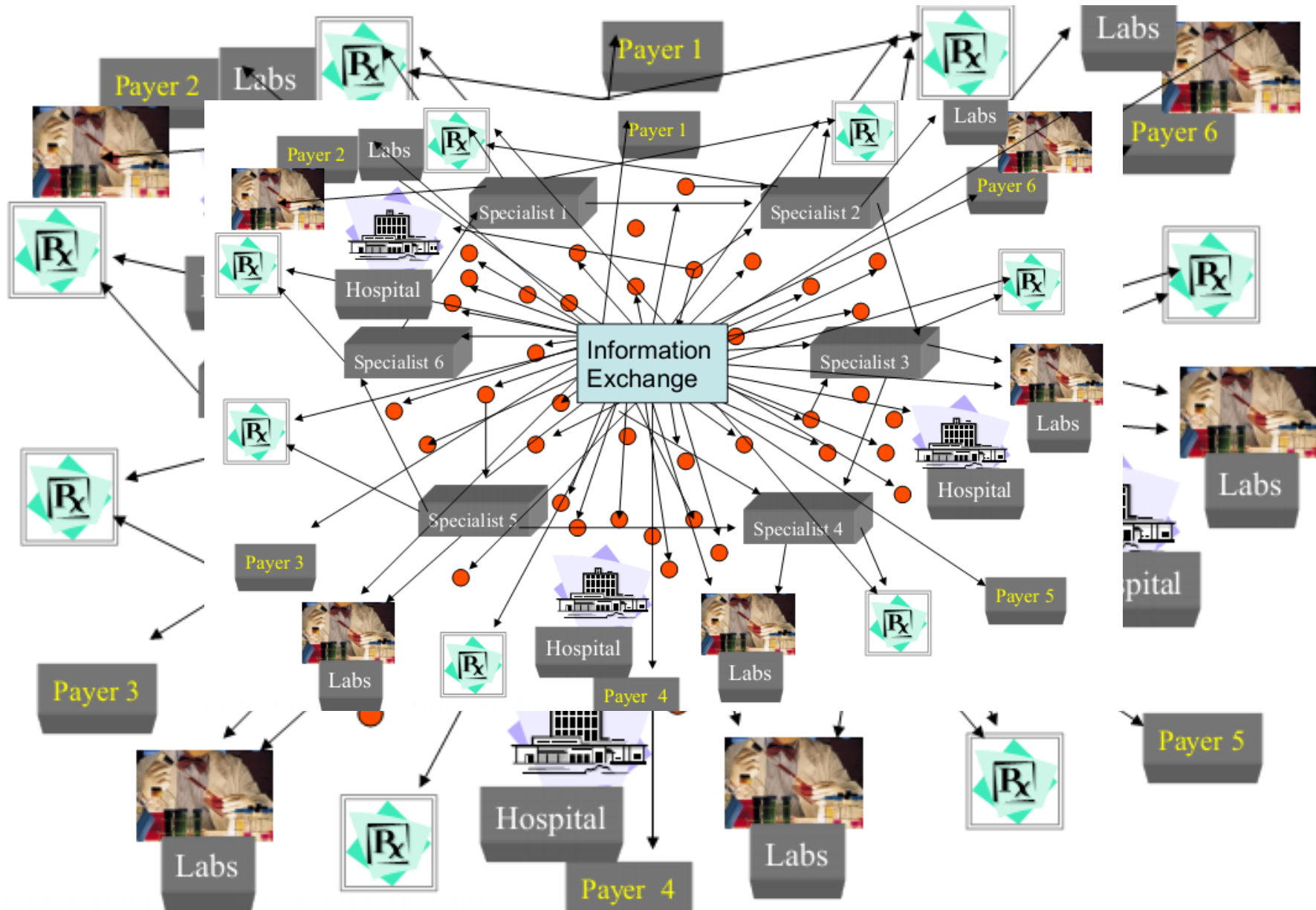
Secondary use of PHI by Business Associates is “unbounded, widespread, hidden, and difficult to trace.”

Implementing ‘meaningful use’ EHRs will “increase data sharing, but adding the NHIN will massively increase data sharing.”

Proposed data exchange 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>

HIEs → more hidden disclosures



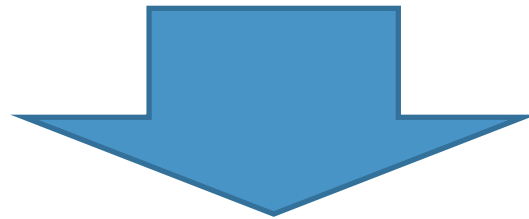
elimination of consent

+

HIPAA 'research' and
'public health' loopholes



theft & sale of health data



health data mining industry



IMS Health Holdings IPO 2014

<http://patientprivacyrights.org/2014/01/ims-health-files-ipo-legal/>

- IMS buys and aggregates sensitive “prescription and promotional” records, “electronic medical records,” “claims data,” “social media” and more to create “comprehensive,” “longitudinal” health records on “400 million” patients from “100K data suppliers” covering “780K daily data feeds”
- IMS sells health data to “5,000 clients,” including US Government
- All purchases and sales of personal health records are hidden from patients. Patients are not asked for informed consent or given meaningful notice.



[Learn how »](#)

500+
million

patient-anonymous records



Real-World Evidence. Real-World Impact.

Patients' journeys through the healthcare system are complex, crossing multiple care settings and often comprising multiple diseases and treatments. What really works is not easy to see.

Real-world evidence shows how treatments perform in the real world, beyond what we see in an artificial clinical trial environment. Insights from this growing body of scientifically credible evidence help decision makers across the healthcare system improve outcomes and better manage costs.

<http://www.imshealth.com/portal/site/imshealth>



Giving you a 360° View of Risks and Opportunities

IMS Health is uniquely positioned at the center of the healthcare system —connected to stakeholders from every sector.

Drawing from over 100,000 data sources, we connect islands of information to provide the most complete global view of patients, treatments, providers and the market. We help clients get the right information, determine what it means for their business, and then act on it to drive performance.

Medical Information Bureau MIB



Slide from the Medical Information Bureau, which sells health data to insurers and employers.

Newborn Bloodspots for sale

THE TEXAS TRIBUNE

- “TX Dept of State Health Services transferred 100’s of infant blood spots to the Armed Forces for a national & international mitochondrial DNA registry”
- DHHS & TX A&M sold blood spots w/o consent

<http://www.texastribune.org/2010/02/22/dshs-turned-over-hundreds-of-dna-samples-to-feds/>





EHRs,
PHRs,

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



Clinical Data Services



one of largest anonymized clinical databases in the US provides access to real-world longitudinal patient information.

customers who share patients' data pay a discounted rate to use Athena's health record software.

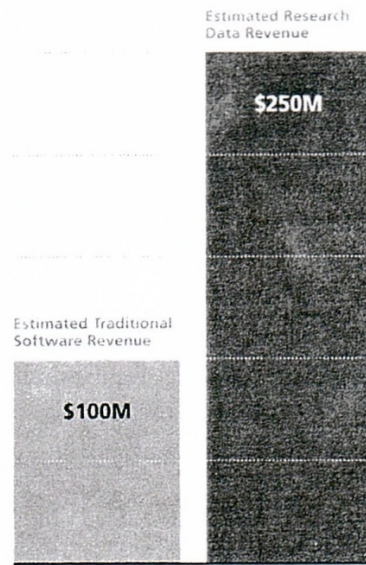
makes clinical research participation a revenue source

sells billions of anonymous patient records collected via data-sharing agreements with 125 software clients to pharmaceutical companies and researchers

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?

Selling 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.

"WITH THE COST OF DISTRIBUTION RELENTLESSLY DRIVING TOWARD ZERO, CHRIS ANDERSON HAS ONCE AGAIN IDENTIFIED THE NEXT BIG THING." —ERIC SCHMIDT, CEO, GOOGLE

FREE

THE FUTURE OF A
RADICAL PRICE



CHRIS ANDERSON

AUTHOR OF THE NEW YORK TIMES BESTSELLER *THE LONG TAIL*

IBM research project

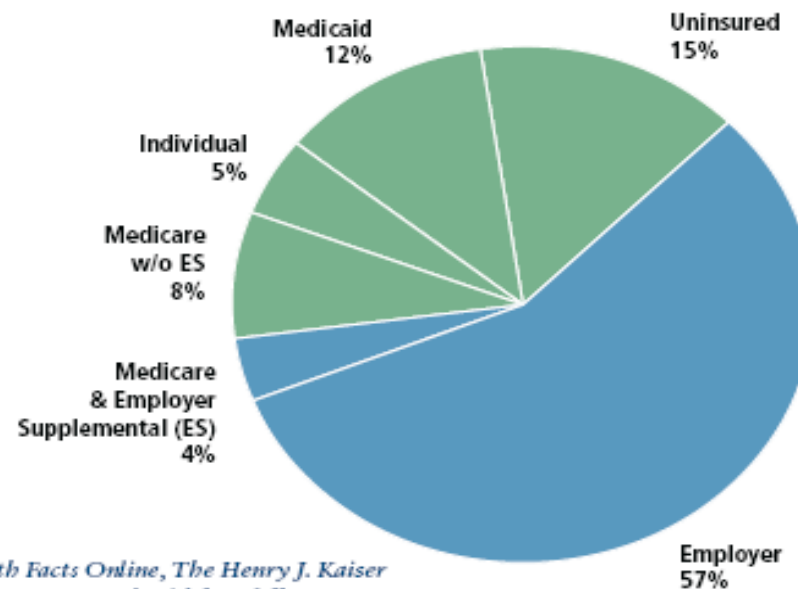
Healthcare **IT** News

May 06, 2010 | Diana Manos

Data from “finance, urban planning, individual behavior, disease transmission, clinical research, media and many others” will be collected and analyzed to help obese children without informed consent

<http://www.healthcareitnews.com/news/ibm-launches-massive-health-data-research-project>

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.



- **longitudinal data on 54 million BCBS members [obtained without consent]**
- reporting not only by MSA, industry and product type, ***Diagnosis Related Groups (DRGs)*** code, ***age group*** and ***gender***

Intended use: “service the big employers that pay the bills and want to pay smaller bills for health insurance.”

“Prescription Profile” Highway

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.

Clinical Data Services



The CDS Advantage

Codified Medical Problems
Prescriptions/Historical Meds
Patient Allergies, Medical
Orders and Events
Vital Signs and Physical
Findings
Lab Values

Disease Counts in Database

Hypertension 2,284,249
Hyperlipidemia 2,212,629
Depression 1,185,828
Cardiovascular Disease 1,004,214
GERD 984,864
Diabetes 922,169
Asthma 750,963
Osteoarthritis 602,043
COPD 319,310
ADD/ADHD/HKD 188,424
Rheumatoid Arthritis 85,757
Alzheimer's 35,790
Parkinson's 22,017

<https://www2.gehealthcare.com/portal/site/usen/menuitem.b399d8492e44a6765c09cbd58c829330/?vgnextoid=ae0f4fb9eff5210VgnVCM100000382b3903RCRD&fromChannel=7e0f4fb9eff5210VgnVCM100000382b3903>

Mayo Clinic launches 'bedside analytics'

Healthcare IT News

Backed by [Rock Health](#) and the Social+Capital Partnership, the venture develops decision support tools for intensive care units, operating rooms and emergency departments. Its technologies, which were developed at the Mayo Clinic, enable real-time access to process-of-care information and analytics

<http://www.healthcareitnews.com/news/mayo-clinic-launches-bedside-analytics>

Healthcare.gov

The screenshot shows the Healthcare.gov homepage. A Ghostery browser extension overlay is visible, listing 7 trackers found on the page. The trackers are: Crazy Egg (Analytics), DoubleClick (Advertising), Google Analytics (Analytics), Google Tag Manager (Widgets), Optimizely (Beacons), and Pingdom (Beacons). The overlay also shows a 'Whitelist Site' button and a 'Pause Blocking' button. A red circle highlights the Ghostery overlay, and a red arrow points from a text box to it.

Tracker Name	Category	Status
Crazy Egg	Analytics	Blocked
DoubleClick	Advertising	Blocked
Google Analytics	Analytics	Blocked
Google Tag Manager	Widgets	Blocked
Optimizely	Beacons	Blocked
Pingdom	Beacons	Blocked

7 trackers just on the first page. Including Google and other Non-Government 3rd parties

no data map

=

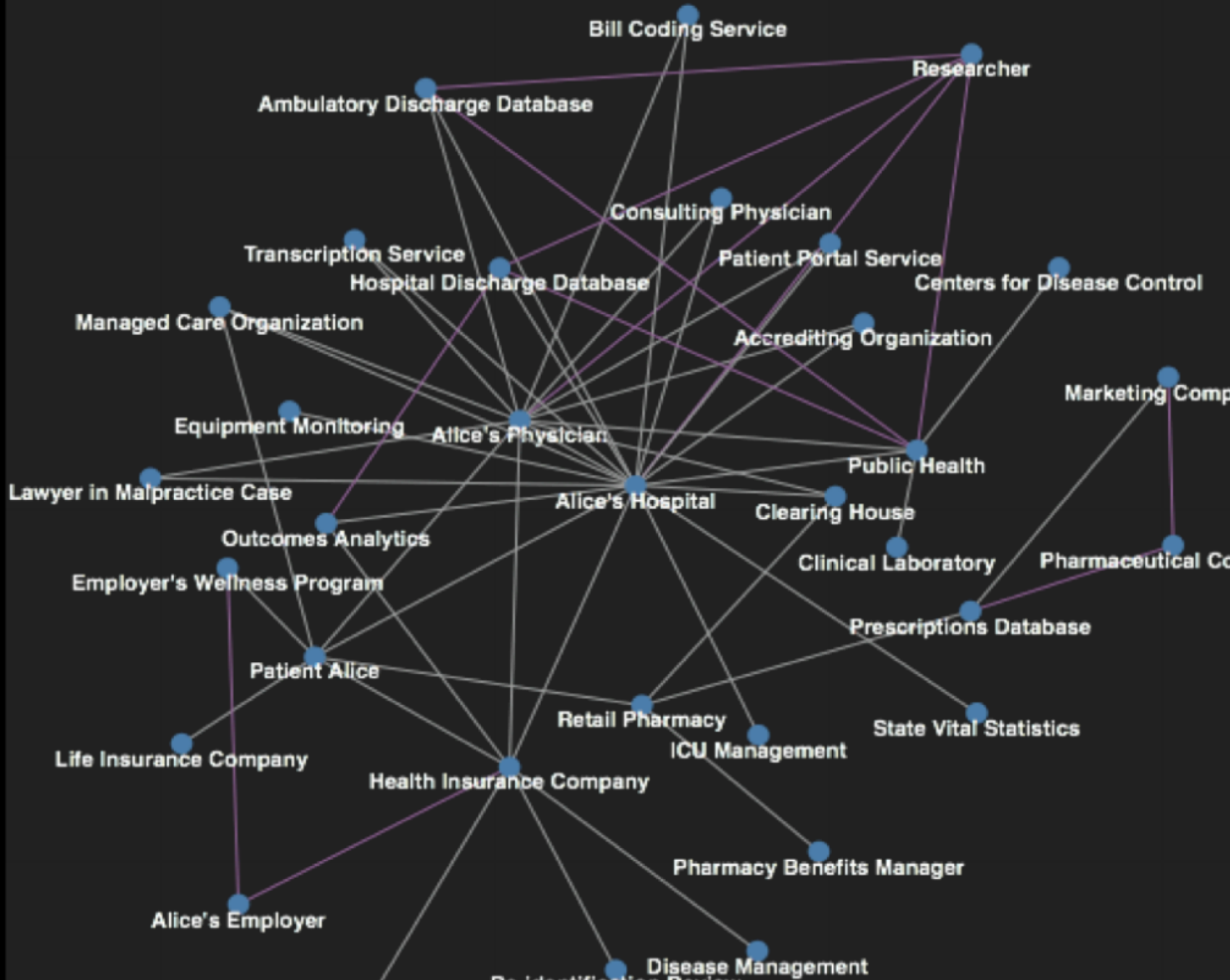
can't weigh risks v
benefits of health IT

START by mapping the
problem

theDataMap.org



<http://www.healthprivacysummit.org/events/2012-health-privacy-summit/custom-138-ec40d08a35f947e487f68a5f534a9e82.aspx>



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

65 Fed. Reg. 82,467



The New York Times

Wal-Mart Memo Suggests Ways to Cut Employee Benefit Costs



“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).” October 26, 2005

The Wall Street Journal

Insurers Test Data Profiles to Identify Risky Clients

By Leslie Scism and Mark Maremont

NOVEMBER 19, 2010

Life insurers use vast dossiers of data being amassed on Americans: predicting people's longevity.

Data-gathering companies have such extensive files on most U.S. consumers that some insurers are exploring whether data can reveal nearly as much about a person as a lab analysis of their bodily fluids.

<http://online.wsj.com/article/SB10001424052748704648604575620750998072986.html>

Can Marketing Data Predict Life Spans?

Deloitte Consulting uses a hypothetical 'Sarah' and 'Beth' to promote technology for life insurers that promises to help size up people's health risk using offline and online dossiers rather than blood tests.



SARAH

Some data collected

SECOND CHILD BORN LAST YEAR
 HIGH INVESTMENT RISK TOLERANCE
 LIVED IN HOME - TWO YEARS
 OWNS HOME
 COMMUTING DISTANCE - ONE MILE
READS DESIGN AND TRAVEL MAGAZINES
 URBAN SINGLE CLUSTER
 PREMIUM BANK CARD
GOOD FINANCIAL INDICATORS
ACTIVE LIFESTYLE: RUN, BIKE, TENNIS, AEROBICS
HEALTHY FOOD CHOICES
LITTLE TO NO TELEVISION CONSUMPTION

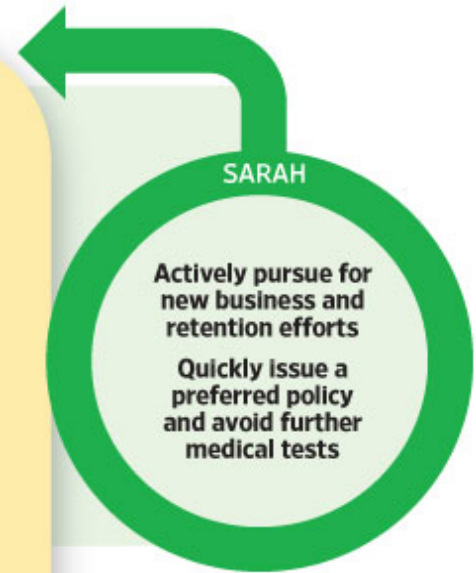
Some risk-assessment factors

- Good financial indicators
- Strong ties to community/location
- High activity indicators
- Foreign traveler
- Healthy food choices
- Avid outdoor enthusiast
- Avid golfer
- Little television consumption
- Occasional tobacco user
- Average commute
- Poor financial indicators
- Purchases tied to obesity
- High television consumption
- Lack of exercise
- Long commute



BETH

CURRENT RESIDENCE - FOUR YEARS
 LIVED IN SAME HOMETOWN - 15 YEARS
 CURRENTLY RENTING
COMMUTING DISTANCE - 45 MILES
 WORKS AS ADMINISTRATIVE ASSISTANT
 DIVORCED WITH NO CHILDREN
FORECLOSURE/BANKRUPTCY INDICATORS
 AVID BOOK READER
FAST-FOOD PURCHASER
PURCHASES DIET, WEIGHT LOSS EQUIPMENT
 WALKS FOR HEALTH
HIGH TELEVISION CONSUMPTION
 LOW REGIONAL ECONOMIC GROWTH



SARAH

Actively pursue for new business and retention efforts
Quickly issue a preferred policy and avoid further medical tests

Potential actions by insurers



BETH

Do not send offers
Do not pursue aggressive retention efforts
Collect more information; send to senior staffer for review

harms

- Destroys trust—human need to control boundaries
- People act to protect privacy risking health and life
- Discrimination (Pewen)

Angela Merkel



**Merkel says
US spying
on allies has
shattered
trust in
Obama**

<http://www.dailymail.co.uk/news/article-2475792/Angela-Merkel-leads-anger-Obama-US-spying-EU-summit.html>

is current law
enough to protect
privacy?



Solution: Key Fair Information Practices

- Transparency & accountability
- Individual control
- Data Minimization



PREMIUM



Search for people, jobs, companies, and more...



Advanced



Home

Profile

Connections

Jobs

Interests

Business Services

Upgrade



Deborah C. Peel, MD

The way to save privacy in the US is to defend the toughest rights we have to control pii: our rights to control personal health information. Tell everyone you know: doctors, lawmakers, & journalists this MUST end. Unless we RESTORE control over health data, we will never get this right for... more

Take action,
before your
privacy
completely fades
away

The Privacy Surgeon

Like (5) • Comment • Share • 2d ago

Jonathan Ezor, Andrea Jackson and 3 others

Add a comment...

[See All Updates »](#)

Take action,
before your
privacy
completely fades
away

The Pr|vacy Surgeon



Save privacy in the US by defending
our strongest rights to control pii....
our rights to control personal health
information

Tell everyone you know: doctors,
lawmakers, & journalists this **MUST**
end. Unless we **RESTORE** control over
health data, we will never get this right
for other pii.

Summary

- tell everyone
- campaign for health privacy?
- 4th International Summit on the
Future of Health Privacy
June 4-5 2014

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

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

watch the video ▶

CAMPAIGN *for*
**PRESCRIPTION
PRIVACY**



healthprivacysummit

www.patientprivacyrights.org/summit

www.patientprivacyrights.org

dpeelmd@patientprivacyrights.org



Ensuring YOU control your sensitive health information

Search this website...

SEARCH



Home

Who We Are ▾

What We Do ▾

How You Can Help ▾

Summit

Blog

Events

2014 Health Privacy Summit

The 4th International Summit on the Future of Health Privacy
Controlling Your Personal Health Information: Now Is the Time

The 2014 Health Privacy Summit brings together a diverse group of professionals for two days of lively intellectual exchange.

Healthcare providers, IT innovators, national and international privacy experts from academia, industry, and government will gather to hear insights, ideas, and analysis from leaders in the health privacy community. The program includes a variety of guest speakers and keynotes to provide expert advice and practical recommendations related to the future of health privacy.

Engage with thought-provoking lectures, interactive panels, networking and discussion during the two-day Summit. Areas of discussion will include: Patient ID, Blue Button +, Consumer Education, Mobile App Privacy, HIEs, International Cybersecurity, Data for Research, Ethics, and Business Models.

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healthprivacysummit

Deborah C. Peel, MD

Founder and Chair

Patient Privacy Rights

O: (512) 732-0033

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www.patientprivacyrights.org

patientprivacyrights



Ensuring YOU control your sensitive health information

Search this website... SEARCH



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- Who We Are ▾
- What We Do ▾
- How You Can Help ▾
- Summit
- Blog
- Events



Whoooooo is snooping in your digital health records?

HIPAA “research loophole”

- The term “**research**” is defined at 45 C.F.R. 164.501 as “systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.”
- Information is not PHI and not subject to the HIPAA Privacy Rule if it is “de-identified” as provided in 45 C.F.R. 164.514(b). An organization can use a “limited data set” for research if they strip out certain identifiers and enter into a “data use agreement” under 164.514(e).

THE TEXAS TRIBUNE



DNA Deception

by [Emily Ramshaw](#)

February 22, 2010

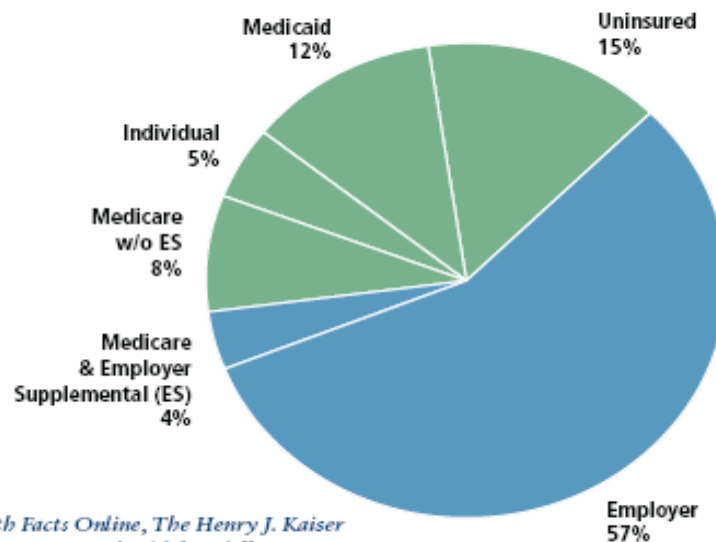
[Department of State Health Services](#) transferred 100's of infant blood spots to the Armed Forces for a national and, someday, international mitochondrial DNA (mtDNA) registry

newborn bloodspots were sold by DHHS & TX A&M Univ. without consent

Medicare and Medicaid data for sale

“at the patient level”

Figure 1: Population Distribution by Insurance Status — 2002

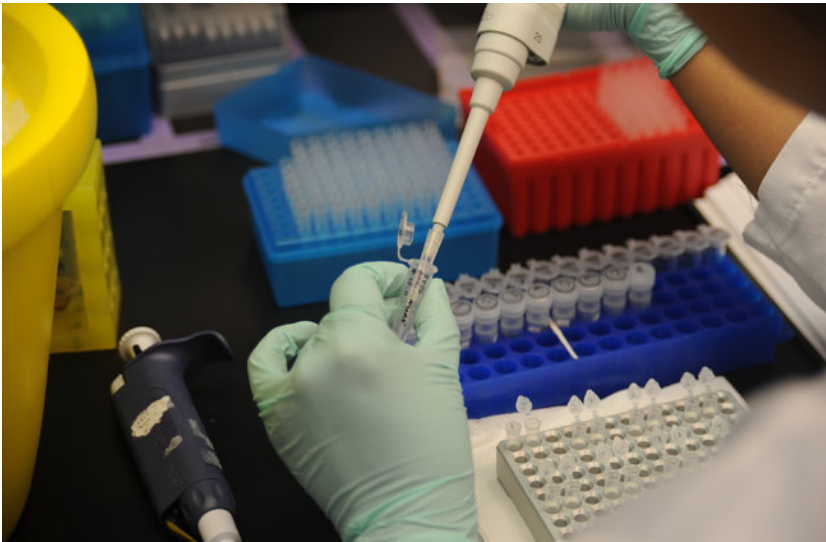


Source: State Health Facts Online, The Henry J. Kaiser Family Foundation, www.statehealthfacts.kff.org; U.S. residents – 285,007,110. Note: Percentages do not add to 100% because of rounding.

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The New York Times

Web Hunt for DNA Sequences Leaves Privacy Compromised



A genetics researcher re-identified 5 random people from strings of billions of DNA letters from over 1,000 people & found their families, re-identifying 50 more people, even though none were in the study

http://www.nytimes.com/2013/01/18/health/search-of-dna-sequences-reveals-full-identities.html?_r=0

Forbes

NSA's Verizon Spying Order Specifically Targeted Americans, Not Foreigners

....the latest revelation of the extent of the NSA's surveillance shows that it has focused specifically on Americans, to the degree that its data collection has in at least one major spying incident explicitly *excluded* those outside the United States.



<http://www.forbes.com/sites/andygreenberg/2013/06/05/nsas-verizon-spying-order-specifically-targeted-americans-not-foreigners/>