

Texas Consumer Association

Behavioral Advertising or Invasion of Privacy?

Nov 20, 2008

Deborah C. Peel, MD

[patientprivacyrights](http://patientprivacyrights.org)

"If you drive a Volvo and you do yoga, you are pretty much a Democrat."

"If you drive a Lincoln or a BMW and you own a gun, you're voting for George Bush."

The New York Times

Bush Campaign Manager Views the Electoral Divide

November 19, 2004

By ADAM NAGOURNEY

Ken Mehlman, Bush campaign manager, explained the winning strategy at a Republican Governors Association meeting in New Orleans.



Ken Mehlman, New Orleans.

<http://www.nytimes.com/2004/11/19/politics/19repubs.html>

Sex, Lies and Ken Mehlman

December 6, 2004 by Bill Berkowitz

"**We did what Visa did.** We acquired a lot of consumer data. What magazine do you subscribe to? Do you own a gun? How often do the folks go to church? Where do you send your kids to school? Are you married? Based on that, **we were able to develop an exact kind of consumer model that corporate America does every day to predict how people vote** -- not based on where they live but how they live. That was critically important to our success."

<http://www.dissidentvoice.org/Dec2004/Berkowitz1206-2.htm>



In 2007, [AOL](#) released the queries conducted by more than 650,000 Americans over three months to foster academic research.

While the queries were associated **only with a number**, rather than a computer's address, reporters for The New York Times and others were quickly able to identify some of the people who had done the queries.

The queries released by AOL included searches for deeply private things like “**depression and medical leave**” and “fear that spouse contemplating cheating.”

Ask.Com Puts a Bet on Privacy, New York Times, Dec. 10, 2007

Is this what Americans want?

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a dark blue rectangular background.

Newsfeed

Tom Jones wrote on ***Marisa Smith***'s wall:

“Michael Thompson has herpes according to his latest prescription purchase at Rite Aid. Yikes!”

- Zuckerman: "It took us too long after people started contacting us to change the product...Instead of acting quickly, we took too long to decide on the right solution...People need to be able to **explicitly choose what they share, and they need to be able to turn Beacon off completely if they don't want to use it.**"
- "In a way it kind of reminds me of an abusive husband who says, 'This is the last time I am going to act out.' It very rarely is," said Solove. "At the end of the day, the problem is that Facebook **thought [a] quick opt out will cure the problem. [Privacy] is about people having control over their information.**"

Update: Facebook caves in to Beacon criticism.
Users skeptical the move will allay their privacy concerns; CEO admits 'mistakes'
ComputerWorld, December 5, 2007



AOL, Netflix and the end of open access to research data

Posted by [Chris Soghoian](#)

November 30, 2007 8:30 AM PST

Correction: The authors of the Netflix de-anonymization study contacted me to point out that they [originally published a draft of their results](#) a mere two weeks after Netflix released its dataset. Netflix has known about their study for over a year.

AOL, Netflix and the end of open access to research data

In 2006, Netflix released over 100 million movie ratings made by 500,000 subscribers to their online DVD rental service. The company then offered \$1 million to anyone who could improve the company's system of DVD recommendation. In order to protect its customers' privacy, Netflix anonymized the data set by removing any personal details.

Researchers announced this week that they were able to de-anonymize the data, by comparing the Netflix data against publicly available ratings on the Internet Movie Database (IMDB). Whoops.

http://news.cnet.com/830110784_398266087.html?part=rss&edId=3&subj=news&tag=25471_3-0-5

DRUDGE REPORT

Tue Nov 11 2008 15:34:50 ET



<http://www.drudgereport.com/flashgof.htm>

SICK SURVEILLANCE: GOOGLE REPORTS FLU SEARCHES, LOCATIONS TO FEDS

GOOGLE will launch a new tool that will help federal officials "track sickness".

"Flu Trends" uses search terms that people put into the web giant to figure out where influenza is heating up, and will notify the Centers for Disease Control and Prevention in real time!

GOOGLE, continuing to work closely with government, claims it would keep individual user data confidential: "GOOGLE FLU TRENDS can never be used to identify individual users because we rely on anonymized, aggregated counts of how often certain search queries occur each week."

Engineers will capture keywords and phrases related to the flu, including thermometer, flu symptoms, muscle aches, chest congestion and others.

Dr. Lyn Finelli, chief of influenza surveillance at CDC: "One thing we found last year when we validated this model is it tended to predict surveillance data. The data are really, really timely. They were able to tell us on a day-to-day basis the relative direction of flu activity for a given area. They were about a week ahead of us. They could be used... as early warning signal for flu activity."

Thomas Malone, professor at M.I.T.: "I think we are just scratching the surface of what's possible with collective intelligence."

Eric Schmidt, GOOGLE's chief executive vows: "From a technological perspective, it is the beginning."

Developing...

.... so what else will
Google help the
government track?

Is There a Privacy Risk in Google Flu Trends?

The New York Times

Friday, November 14, 2008

By [Miguel Helft](#)

Google sought to avoid this kind of reaction by talking about how Google Flu Trends [protects the privacy of its users](#). The service relies “on anonymized, aggregated counts of how often certain search queries occur each week,” Google said.

<http://bits.blogs.nytimes.com/2008/11/13/does-google-flu-trends-raisesnewprivacyrisks/?apage=1>

The New York Times

Still, the worries persist. On Wednesday, two advocacy groups, the **Electronic Privacy Information Center** and **Patient Privacy Rights**, sent [a letter](#) to Eric Schmidt, Google's chief executive, raising privacy concerns:

“The question is how to ensure that Google Flu Trends and similar techniques will only produce aggregate data and will not open the door to user-specific investigations, which could be compelled, even over Google's objection, by court order or Presidential authority.” [The letter went on to challenge Google to publish the techniques it has adopted to protect the privacy of search queries used for Flu Trends.](#)

De-regulation and privacy

The challenges of deregulation

Are there parallels between the financial and the healthcare systems?



Greenspan:

I Was Wrong to
Trust Banks

Oct 23, 2008

“Those of us who have looked to the self-interest of lending institutions to protect shareholders' equity (myself especially) are in a state of shocked disbelief.”

Asked if he was wrong to champion deregulation, Greenspan replied, “partially,” explaining he'd believed lending institutions were the ones in the best position to protect their shareholders' interests.

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

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)

The elimination of consent

1996

Congress passed HIPAA, and instructed the Dept. of Health and Human Services (HHS) to address the rights of patients to privacy.

*“Not later than the date that is 12 months after the date of the enactment of this Act, 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 original HIPAA “Privacy Rule” recognizing 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

Amendments to the “Privacy Rule” became effective eliminating “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

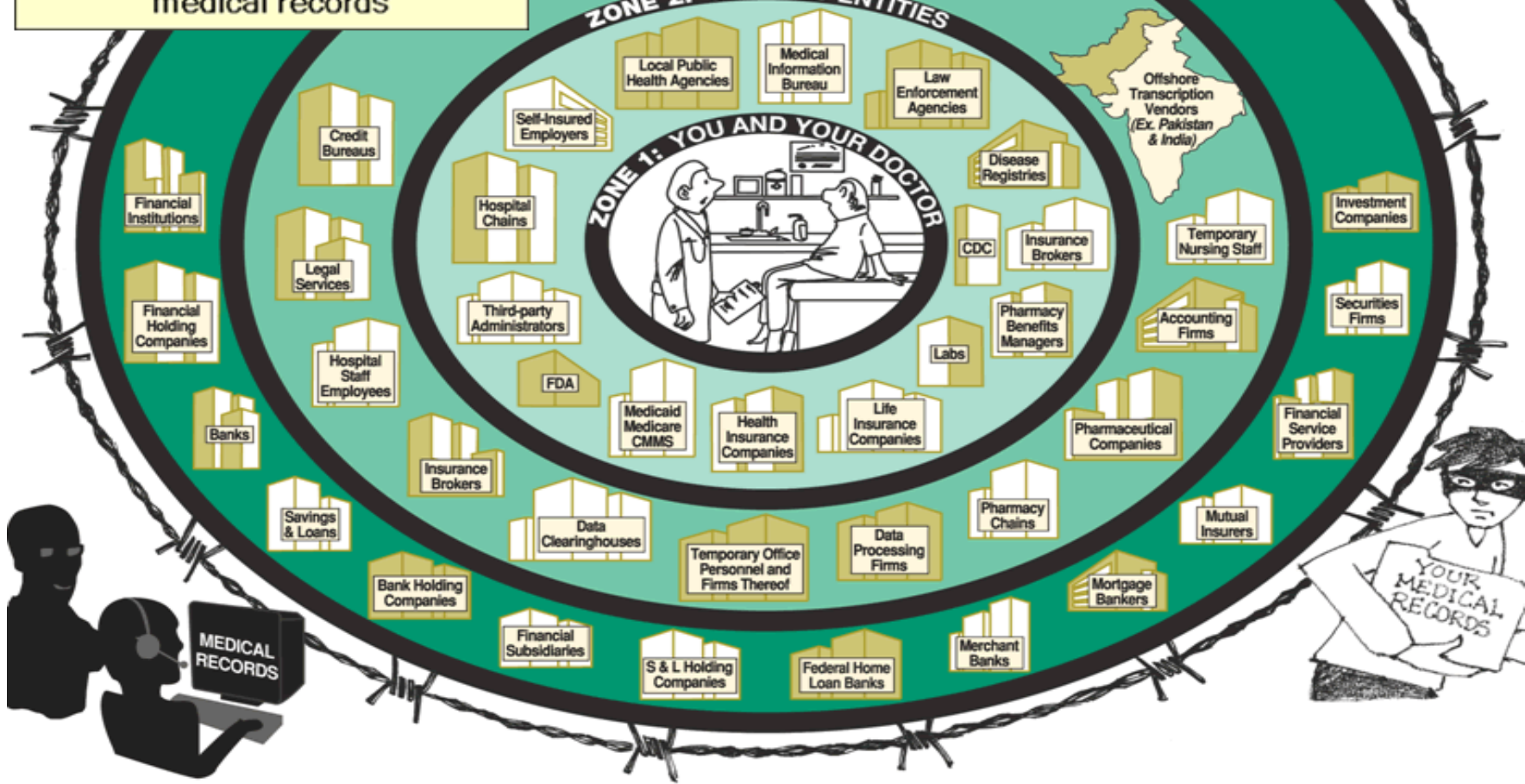
Legal users of YOUR medical records

ZONE 4: GRAMM LEACH BILEY FINANCIAL SERVICES ACT

ZONE 3: BUSINESS ASSOCIATES

ZONE 2: COVERED ENTITIES

ZONE 1: YOU AND YOUR DOCTOR



MEDICAL RECORDS

YOUR MEDICAL RECORDS

A man in a gym setting, wearing a headset and a sign that says "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

Can we trust that
de-identified or
anonymized personal
information is truly
safe?

HIPAA allows use of “de-identified” data without consent

"I had learned that if I had the date of birth, gender and a five-digit zip code of a person, **I could identify 87 percent** of the people in the United States. So even if you don't give me your social security number, I can find out who you are nearly nine out of 10 times."

Latanya Sweeney, PhD, Director, Laboratory for International Data Privacy, School of Computer Science, Carnegie Mellon University

From *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>



Latanya Sweeney

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

Prof. Latanya Sweeney, PhD

*“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.**”*

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

unless YOU act

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



patientprivacytoolkit

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](#)

Patient Privacy Rights

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