

Medical and Health Privacy: A Civil Right?

A Privacy Advocate's Perspective

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Latest News - June 10, 2010

Privacy Issue Attracts Fire in California Attorney General Race

Facebook privacy has become a hot topic in the California race for Attorney General. In the Democratic primary, Kamala Harris has attacked former Facebook Chief Privacy Officer Chris Kelly over the company's privacy practices. But Kelly has recently criticized some of the Facebook changes and said that "instant personalization" should be opt-in. Kelly has also supported a Moveon Facebook campaign though some bloggers have doubts. During the last election cycle, EPIC launched PRIVACY08 to encourage candidates to debate privacy issues. Also see EPIC Facebook Privacy.

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FTC Delays Identity Theft Rule Yet Again

The Federal Trade Commission is delaying, for the fourth time, its enforcement of the "Red Flags Rule." This rule requires creditors and financial institutions to implement programs to identify, detect and respond to the warning signs, or "red flags," that could indicate identity theft. The FTC has decided to delay enforcement through the end of the year in order to give Congress time to enact legislation that could clarify what kind of entities would be considered "creditors" under the rule. For more information, see EPIC: Identity Theft.

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Congress Pursues Investigation of Google and Facebook's Business Practices

Following similar letters from other Congressional leaders, the head of the House Judiciary Committee has asked Google Inc. and Facebook to cooperate with government inquiries into privacy practices at both companies. Rep. Conyers (D-MI) noted that Google's collection of user data "may be the subject of federal and state investigations" and asked Google to retain the

Save the Date



CFP 2010
June 16-18, 2010
San Jose, CA

Program
Registration Page

Take Action



stopdigitalstripssearches.org

More on EPIC and Medical Privacy

- <http://epic.org/privacy/medical/>
- Subscribe to the EPIC Alert:
 - <http://epic.org/alert/subscription.html>

Thank you

What is Privacy?

- Controlling who, when, why, and how others may access personal information
- Privacy is assured through Fair Information Practices (FIPs)
 - Data collection limitations
 - Data retention rules
 - Data use limitations
 - Data security obligations
 - Data transparency to data subject
 - Private right of action to protect data subjects' privacy rights

Civil Rights and Privacy

- Equal treatment under the law
- Discrimination in employment, housing, economic opportunity rested on knowledge regarding ethnicity, race, religion, politics, sexual orientation, marital status, age, and disabilities
- The Color Coded Society
 - How many ways can we say Jewish, African American, Latino, Asian, Native American, old, young, ill, or healthy

HIPAA: Help Insufficient for Privacy Assurance Availability

- 48,768 HIPAA Privacy Complaints HHS Office of Civil Rights
- 20,547 complaints investigated
- 5,047 cases were closed due to no violation
- 9,879 Corrective Action Taken (mostly changes in practices by covered entities)
- Compliant vs. Covered
- Report National Committee on Vital and Health Statistics
<http://www.ncvhs.hhs.gov/100511hipaarpt.pdf>

Health IT

- Networked Computers
 - Makes digital data sharing easier
 - Makes data manipulation harder to detect
 - Makes data accessing less transparent
 - Makes data collection, retention, replication, use, and sharing less transparent
 - Makes interesting challenges for privacy enforcement (patient control, data security, provider role based access controls, de-identification, re-identification, collection, retention, sharing, use, and potential for reuse)

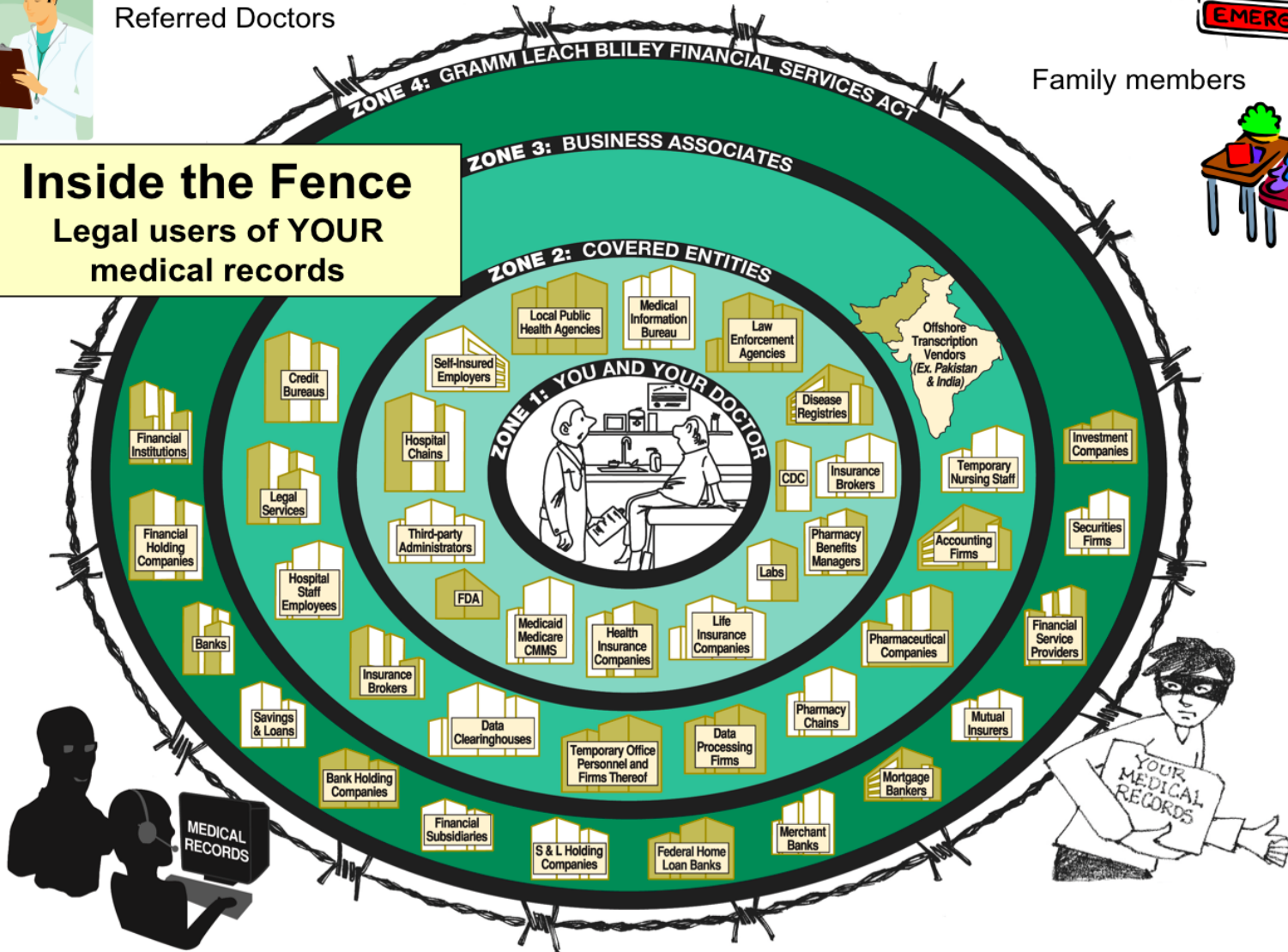


Referred Doctors



Family members

Inside the Fence
Legal users of YOUR medical records



Collecting Health and Sharing Health

- A thousand flowers blooming vs. the Wild Wild West
- Plug and play electronic health record sharing
- What is in it for the patient? (short-term and long-term)
- What is in it for the physician, health care provider, or researcher?
- What should really matter?

Potential Abuses of Research Databases

- Pharmacological databases combine clinical and genetic information of a population overtime
- The way the data is generated means that just about all of it is being repurposed, which present problems for FIPs
- 4th Amendment issues such as law enforcement (forced or voluntary) access to health data

What Comes Next?

- National Health Information Network (NHIN)
 - National electronic records management system
 - Regionally managed health information exchanges
- Advance HIT Consortium at Harvard University an effort to build a trustworthy NHIN
 - Establish universal guarantees that address stakeholder concerns: privacy, accuracy, liability, trustworthiness, cost effectiveness, sustainability, etc.

What You Should Know

- Every state has a Health IT Coordinator funded by the American Recovery and Reinvestment Act
- New: Advance Health Information Technology Consortium at Harvard University
 - Dr. Latanya Sweeney, Director
- <http://Advancehit.org> is the virtual headquarters for the AHITC at Harvard University
 - You are invited to join in this effort.
 - Office of the National Coordinator supports this effort by providing two senior staff members for coordination of the work with their efforts

CFP2010.org San Jose State University June 16-18, 2010

