Right to Privacy and Ownership of Health Data

Deborah C. Peel

Patient Privacy Rights

2002 Amended HIPAA Privacy Rule

67 Fed. Reg. 53,183

"The consent provisions...are replaced with a new provision...that provides regulatory permission for entities to use and disclose protected health information for treatment, payment, and healthcare operations."

2M+ US health data holders treat our data as corporate assets.

Is Project Nightingale the "Cambridge Analytica" of the US 'Healthcare' sector?

◆ WSJ NEWS EXCLUSIVE | TECH

Google's 'Project Nightingale' Gathers Personal Health Data on Millions of Americans

Search giant is amassing health records from Ascension facilities in 21 states; patients not yet informed

Opinion Privacy

I'm the Google whistleblower. The medical data of millions of Americans is at risk Anonymous

What Google Isn't Saying About Your Health Records

- 1. "Google's 'Project Nightingale' Gathers Personal Health Data on Millions of Data on Millions of Americans". By Rob Copeland. WSJ News Exclusive https://www.wsj.com/articles/google-s-secret-project-nightingale-gathers-personal-health-data-on-millions-of-americans-11573496790
- 2. "I'm the Google whistleblower. The medical data of millions of Americans is at risk." By Anonymous. The Guardian www.thegaurdian.com/commentisfree/2019/Nov/14/im-the-google-whistleblower-themedical-data-of-millions-is-at-risk
- 3. HARVARD LAW Petrie-flom Center Bill of Rights by Adrian Gropper. "What Google Isn't Saying About Your Health Records" https://blog.petrieflom.law.harvard.edu/2019/11/14/what-google-isnt-saying-aboutyour-health-records/

Apple's Reach Reshapes Medical Research

The company's tools enable researchers to track huge numbers of people. But doctors do not yet know if it will significantly improve health outcomes.







1. "Apple's Research Reshapes Medical Research" by Natasha Singer. NYT https://www.nytimes.com/2019/11/14/technology/apple-harvard-health-studies.html

Patient Privacy – Survey Findings

 IOM Project Survey Findings on Health Research and Privacy by Dr. Alan F. Westin, Dec 12, 2007 (see slides 23-26): http://216.230.117.100/hmd/~/media/27ED183894D34A1E9DCAECC59D177282.ashx

• Survey of 12,090 adults' attitudes toward providers use of health IT & providers' use of HIT:

https://blackbookmarketresearch.newswire.com/news/healthcares-digital-dividewidens-black-book-consumer-survey-18432252

 Patient Privacy Rights Information Governance Label https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3439701

http://www.healthurl.com/www/Home.html