iHT2 Competing for Patient Trust and Data Privacy in the Age of Big Data

Deborah C. Peel, MD Adrian Gropper, MD Sept 10, 2013

patientprivacyrights

Privacy

"Health information privacy is an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data."

HIPAA – amended to reduce patient engagement

2001

President Bush implemented the HIPAA "Privacy Rule" which recognized the "right of consent". **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

HIPAA amended to eliminate patient's 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."

Privacy is more valuable than security

- a. It's hard to differentiate your practice on security
- b. You can differentiate your practice based on privacy
 - i. Better analytics
 - ii. Better patient engagement
 - iii. Better brand (closer to mission) Greater trust based on transparency and ethics

Fair Information Practice Principles

- Transparency
- Individual Participation

Organizations should involve the individual in the process of using PII and, to the extent practicable, seek individual consent for the collection, use, dissemination, and maintenance of PII.

- Purpose Specification
- Data Minimization
- Use Limitation
- Data Quality and Integrity
- Security
- Accountability and Auditing

http://www.whitehouse.gov/sites/default/files/rss_viewer/NSTICstrategy_041511.pdf

Fair Information Practice Principles

FIPPs

- 1. Since 1973 US Origin, international adoption*
- 2. Minimize collection, minimize transmission, transparency
- 3. HIPAA is not FIPPs
 - TPO maximizes data transfers
 - b. Transparency is almost non-existent (A4D not enforced)
 - c. Coercive practices abound (MPI, "Notice" of Privacy Practices)
 - d. Data quality is often poor (using claims instead of health records)
 - e. Stronger privacy protections in state and federal law and medical ethics are ignored (mental health and addiction, HIV, STDs genetic data, veterans & military families)

^{* &}lt;a href="http://bobgellman.com/rg-docs/rg-FIPShistory.pdf">http://bobgellman.com/rg-docs/rg-FIPShistory.pdf

Patient Portals

- Reduce visits (reduce costs in accountable care models Kaiser)
- Provide continuous data (including home and other providers)
- Engage patients (if bi-directional)
- Improve data quality (VA Blue Button experience)
- Loyalty (Keep patients from straying to competitor portals)

Portals Compete

- Big provider Tethered
- Insurance and PHR Untethered
- Medical Home Managed
- HIE Constrained
- HIE of One Patient Centered
 - BB+
 - Direct Secure email exchange
- Where does your practice fit in?

Analytics and Big Data

- Value in accountable care
 - decision support
 - prevention
 - deduplication
 - risk adjustment
 - quality measures

EHRs are a commodity but analytics can make a competitive difference

Quantity

Data from Everywhere

Patient-Measured - Quantified Self		Your EHR
FitBitRunKeeperWhitings ScaleVarious Apps	Big DataClaims - Prescriptions	Patient-Directed - Blue Button Plus - Home Health Hub
	- Prescriptions- Over-the-counter drugs- Lab tests- Mobile apps	State HIE
	Wellness programsHealth searchesHealth groupsTweets	Patient-Mediated - Blue Button - Patient Entered

Relevance

Trusted Patient Engagement

Attributes

- Educated (licensed)
- Informed (access to all of the relevant patient data)
- Independent (no commercial conflict of interest)
- Accessible (secure email, mobile, 24/7, inexpensive, customer service)
- Transparent (peer-reviewed, substitutable, collaborative)

Roles

- Decision Support
- Informed Consent
- Private Data Management

Examples

- Concierge MD
- Professional Advocate (unlicensed and licensed)

Summary

- Analytics and the Patient Portal strategy will differentiate
 most practices (if you don't run the portal, how do you participate in the portal and get
 the data you need?)
- EHRs will not differentiate your practice (but those that sell patient data, hamper communications, lock you in and restrict your agility will harm you)
- Focus on FIPPs (security is important but not strategic)

Stay open to the patient-perspective, it's your future



patientprivacyrights.org/summit patientprivacyrights.org

dpeelmd@patientprivacyrights.org agropper@patientprivacyrights.org