

# Concerns of a Privacy Advocate – and How to Respond

Deven McGraw

CENTER FOR DEMOCRACY & TECHNOLOGY

---

# The Health Privacy Project at CDT

- ❑ Health IT and electronic health information exchange are the engines of health reform & have tremendous potential to improve health care quality, reduce costs, and empower consumers.
- ❑ Some progress has been made on resolving the privacy and security issues raised by e-health – but gaps remain and implementation challenges loom.
- ❑ Project's aim: Develop and promote workable privacy and security policy solutions for personal health information.

---

# People want Health IT - but also have significant privacy concerns

- ▣ Survey data shows the public wants electronic access to their personal health information.
- ▣ But a majority - 67% - also have significant concerns about the privacy of their medical records (California Healthcare Foundation 2005; more recent AHRQ focus groups confirm).

---

# Consequences of Failing to Act

- Protecting privacy is important
  - Prevents harm
  - Good health care depends on accurate and reliable information
- Without privacy protections, people will engage in “privacy-protective behaviors” to avoid having their information used inappropriately.
  - 1 in 6 adults withhold information from providers due to privacy concerns. (Harris Interactive 2007)
  - Persons in poor health, and racial and ethnic minorities, report even higher levels of concern and are more likely to engage in privacy-protective behaviors. (CHF 2005)

---

# Health IT Can Protect Privacy - But Also Magnifies Risk

- ❑ Technology can enhance protections for health data (for example, encryption; role-based access; identity proofing & authentication)
- ❑ But moving & storing health information in electronic form - in the absence of strong privacy and security safeguards - magnifies the risks.
  - ❑ Recent thefts of laptops, inadvertent posting of data on the Internet, “snooping”
  - ❑ Cumulative effect of these reports deepens consumer distrust

---

# A Comprehensive Approach is Needed

- Privacy and security protections are not the obstacle - enhanced privacy and security can be an **enabler** to health IT.
- A comprehensive privacy and security framework is needed to facilitate health IT and health information exchange.
  - Fair information practices – strong data stewardship model
  - Sound network design
  - Accountability/Oversight

---

# “Next Generation” of Health Privacy

- ❑ Build on HIPAA for traditional health care entities (ARRA took first steps here)
- ❑ Establish new protections to address concerns raised by access to information outside of the health care system
- ❑ Hold all who handle health data accountable for complying with baseline protections

---

# ARRA (Title XIII- HITECH)

- ❑ Broke the privacy “logjam”
- ❑ Most significant change to the healthcare privacy and security environment since the original HIPAA privacy rule
- ❑ Not a change to everything about HIPAA – but some significant changes that will need to be addressed by many entities handling health care information
- ❑ Most provisions require further regulatory clarification

---

# Provisions of HITECH/ARRA

- ❑ Filled a number of gaps in HIPAA
  - ❑ “Business associates” now directly accountable for complying with most (but not all) HIPAA privacy and security regs (and HIEs/RHIOs are considered to be BAs)
  - ❑ Breach notification provisions go into effect on September 23, 2009; exception for data that is encrypted
  - ❑ Strengthened right for patients to receive an accounting of disclosures from their record
  - ❑ Patients who pay out of pocket can request that data not be sent to their health plan
  - ❑ Prohibition on sales of protected health information
  - ❑ Strengthened rules re: use of data for marketing
  - ❑ Patient right to receive electronic copy from electronic health/medical record

---

# Filling gaps in HIPAA (cont.)

## □ Stronger enforcement

- State AGs now authorized to enforce
- Civil monetary penalties increased
- HHS required to impose penalties in cases of willful neglect
- HHS required to do privacy and security audits

---

# Still Work to be Done

## □ Personal Health Records

- Currently not covered by HIPAA if offered by Microsoft, Google, Dossia, WebMD & others (except if HIPAA business associate provisions apply)
- ARRA established breach notification requirements, strengthened right to receive electronic copy of data
- HHS (working with FTC) to provide recommendations to Congress by 2/2010 on privacy & security protections

---

# Work to be Done (cont.) - PHRs

- ❑ Need consistent regulation – but HIPAA as currently structured is not the answer
  - ❑ Treatment, payment & operations exception makes little sense for PHRs, which should be consumer controlled
  - ❑ Reliance on authorization for marketing & business uses provides weak protection
  - ❑ Markle Common Framework for Networked Personal Health Information provides good model
  - ❑ FTC should play a role in regulating PHRs

---

# Work to be Done (cont.)

- ❑ Successful implementation of new rules
- ❑ Addressing downstream or “secondary” uses of data by trading partners
- ❑ Tight implementation of new marketing provisions
- ❑ Addressing “identifiability” of data through minimum necessary guidance and better de-identification policy – plus strict penalties for re-identification
- ❑ Sound policies to govern (and build trust in) exchange through networks

For privacy to enable health IT, we  
need to “enable” privacy

[deven@cdt.org](mailto:deven@cdt.org)