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HIPAA Privacy: Perspective of a Privacy Advocate

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- Health IT and electronic health information exchange are engines of health reform with tremendous potential to improve health, reduce costs and empower patients.
- 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 (papers) and promote (advocacy) 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 and 2011 Markle survey confirm high degree of concern).





Consequences of Failing to Act

- 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 Risks

- Technology can enhance protections for health data (for ex., encryption; role-based access; identity proofing & authentication; audit trails)
- But moving and storing health information in electronic form – in the absence of strong privacy and security safeguards – magnifies the risks
 - Thefts of laptops, inadvertent posting of data on the Internet, reports of internal “snooping”
 - Increased media attention to data captured on the Internet
 - 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.
 - The essence of what we mean by “workable” protections
- A comprehensive privacy and security framework is needed to facilitate health IT and health information exchange.
 - Fair information practices – strong data stewardship model; consent plays important role but is not linchpin
 - Sound network design
 - Accountability/Oversight





Fair Information Practices

- Openness and transparency
- Purpose specification and minimization
- Collection limitation
- Use limitation
- Individual participation and control
- Data integrity and quality
- Security safeguards and controls
- Accountability and Oversight
- Remedies





Role for Individual Consent

- Public debates about privacy protection tend to focus on whether patients should be asked to authorize all uses of their information.
- Individual control is an important component of fair information practices - but it is just one component.
- Providing greater authorization rights is not the best way to protect privacy and security.



“Next Generation” of Health Privacy

- Build on HIPAA for traditional health care entities – no need to rip and replace (HITECH took the first step here)
- Establish protections for health information that migrates outside of the HIPAA bubble
- Address concerns raised by new HIT infrastructure (such as HIEs)
- Essentially, hold all entities who handle health data accountable for complying with baseline protections





Emerging Issues/Agenda for the Future

- Successful implementation of new HITECH privacy provisions
- Address issues raised by the use of HIEs or data exchange “intermediaries”
 - Are business associate rules sufficient?
- Protections for health data that is outside the HIPAA bubble
 - Will new consumer privacy efforts (FTC & White House reports, HHS Roundtable on PHRs, draft legislation) pay off for health information?
- Framework for “secondary” uses of EHR data
 - Distributed data networks



Agenda for the future (cont.)

- Policies for de-identified data – focus on robust methodologies, prohibit re-identification
 - Also – encouraging use of “less identifiable” data for routine purposes; possible interpretation of minimum necessary standard?
- Better enforcement & active policy “stewardship” by regulators
 - Issuance of guidance, clarifications, FAQs
 - Safe Harbors?
 - Regulation of business associates



Questions?

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