


“How Broader Privacy Policy Issues Impact Healthcare”

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Overview

- My background
- Role of privacy & security in the development of the National Health Information Network
- Three key issues, informed by non-health experiences:
 - Preemption
 - Enforcement
 - Consumer-centered approaches
- Explain the consumer, industry, & political perspectives on these issues
- Conclusion: the choice we face

Swire Background

- Now law professor, based in D.C.
 - Active in many privacy & security activities
 - Chief Counselor for Privacy, 1999-2001
 - U.S. Office of Management & Budget
 - WH coordinator, HIPAA privacy rule
 - Financial, Internet, government agency privacy
 - National security & FISA
 - Computer security
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Health Care Background

- Health care since 2001:
 - Written on health privacy & security topics, at www.peterswire.net
 - Consulted on HIPAA implementation
 - Morrison & Foerster, LLP
 - Markle, Connecting for Health
 - Deidentification white paper for IBM

Privacy, Security & the NHIN

- As public policy matter, crucial to get the benefits of data flows (electronic health records) while minimizing the risks (privacy and security)
- As political matter, privacy and security are the greatest obstacles to adoption
 - Focus group – the emergency room while out of town as the *only* scenario that got substantial majority to favor EHRs
 - Many individuals see risks > rewards of EHRs

Implications of Public Concern

- All those who support EHRs must have good answers to the privacy and security questions that will be posed at every step
- “Trust us” not likely to be a winning strategy
 - The need for demonstrable, effective protections
 - The system must be strong enough to survive the inevitable data breaches & resultant bad publicity

Preemption

➤ Industry perspective:

- Benefits of data sharing high – “paper kills”
- Shift to electronic clinical records is inevitable; that shift has occurred in other sectors
- Can only run a national system if have a national set of rules
- Preemption is essential – a “no brainer”

Preemption: Consumer View

- Janlori Goldman, Health Privacy Project
- A *lot* of state privacy laws
 - HIV
 - Other STDs
 - Mental health (beyond psychotherapy notes)
 - Substance abuse & alcohol
 - Reproductive & contraceptive care (where states vary widely in policy)
 - Public health & other state agencies
- HIPAA simply doesn't have provisions for these topics
 - if preempt, then *big* drop in privacy protection

Consumers & Preemption

- Link of reporting and privacy
 - HIV and other public health reporting *based* on privacy promises
 - So, objections if do reporting w/out privacy
- Concrete problems of multi-state?
 - Many RHIOs have only one or a few states
 - Build out from there
 - State laws both as “burdens” (industry) and “protections” (consumers)

Preemption & Politics

- Consumer and privacy advocates see states as the engine for innovation
- Current example: data breach
 - California went first, and now Congress is trying to catch up with a uniform standard
- Basic political dynamic – industry gets preemption in exchange for raising standards nationally

Preemption in Other Sectors

- Gramm-Leach-Bliley: no preemption
 - But, Fair Credit 2003 does some of that
- Wiretap (ECPA): no preemption
- Data breach: proposed preemption
- FTC unfair/deceptive enforcement: no preemption
- CAN-SPAM: significant preemption
- Conclusion -- variation

Key Issues in Preemption

- Scope of preemption matters & can vary
- One policy baseline: scope of preemption matches the scope of the federal regime
 - If the scope is for networked health IT, then preemption about that, not entire health system
- Preserve state tort and contract law?
- Preserve state unfair & deceptive enforcement?
- Grandfather existing state laws? Some of them?

Summary on Preemption

- Strong pressures for preemption in national, networked system
- If simply preempt and apply HIPAA, then have a dramatic reduction in privacy & security
- This is a major & complicated policy challenge that is not likely to have a simple outcome

Enforcement

- The current “no enforcement” system
- Key question for the NHIN:
 - Can the current no-enforcement system be a credible basis for EHRs and the NHIN?

The No Enforcement System

- Imagine some other area of law that you care about – violations are serious.
- Batting average: 0 enforcement actions for over 20,000 complaints
- Enforcement policy: one free violation
- Criminal enforcement:
 - DOJ cut back scope of criminal penalties
 - *No* prosecution for the > 300 criminal referrals
 - 3 cases brought by local federal prosecutors

Effects of No Enforcement

- Signals work
 - Surveys already showing lower efforts at HIPAA compliance and lower reported actual compliance by covered entities
 - Contrast internal HIPAA efforts and budget (low enforcement) with compliance efforts on Medicare fraud & abuse (hi enforcement)
- Why should Congress and consumer groups trust compliance with HIPAA, much less with new rules for the NHIN?

Other Privacy Enforcement

- Fair Credit, stored communications, video rentals, cable TV
 - Federal plus private right of action
- Deceptive practices, CAN-SPAM, COPPA, proposed data breach
 - Federal, plus state AG
- HIPAA as outlier, with federal-only enforcement
 - If feds don't do it, then have no enforcement of the HIPAA rules themselves


Customer-Centered Records

- For other sectors, strong ability for customers to see & manage their own accounts
 - Online banking
 - Online insurance
 - Status of orders from retailers
- Integration of records into personal software
 - E.g., all financial records feed into your tax records
- Access controls – rules on who gets the records, such as accountant but not former spouse

Patient-Centered Records

- Huge lag, once again, for health records
- HIPAA access rule an important step for patients to have a *right* to see their records
- Importance of records for some groups:
 - Chronic conditions
 - Parents for kids' immunizations, etc.
 - Care of elderly by remote relatives
 - Anyone who sees multiple providers

Patient-Centered Records

- Almost no public policy debates in past few years about how to ensure that patients have effective access to their own medical records
 - Such access is assumed in other sectors
 - What will it take for it to occur for health care?
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What We Have Learned

- Within health IT debates, consensus statements often sound like this:
 - Need preemption to do the national network
 - Should not punish/enforce against covered entities, when they are struggling in good faith to implement new HIPAA mandates
 - Of course, privacy and security should be part of the NHIN, but likely don't go beyond HIPAA requirements

What We Have Learned

- That trio of conclusions, based on experience in other sectors, may face serious political obstacles:
 - Preemption is likely to be partial and require new federal standards in some areas
 - The “no-enforcement system” will be hard to sustain
 - New privacy/security protections quite likely will accompany new NHIN data flows
 - Customer-centered is the norm elsewhere

Conclusion: Your Choice

➤ Option 1: Play Hardball

- Decide the costs of privacy & security are too high to be built into the NHIN
- Push a strategy of high preemption and low enforcement
- Grudgingly give only the bare minimum on privacy/security when the political system forces it onto industry

The Better Choice

- Option 2: A NHIN to Be Proud Of
 - Incorporate the key values of state laws – especially for sensitive data – into the NHIN
 - Support reasonable enforcement, so that bad actors are deterred and good actors within covered entities get support
 - Build privacy & security into the fabric of new systems, not just as a patch later
 - Connecting for Health as an example
 - Customer-centered records

The Better Choice

- With the second option – A NHIN to Be Proud Of – the patients are not treated as the political enemies
 - The risk of political backlash is less
 - The quality of the NHIN for actual patients is higher
- That, I think, should be our goal
- Thank you

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