

“Medical Privacy in a Broader Privacy Context”

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Overview

- Actions as Chief Counselor for Privacy
- Are they picking on doctors?
- What has changed with medical records
- The HIPAA privacy rule

I. Actions as Chief Counselor, 1999 to early 2001

- HIPAA medical privacy: WH coordinator
- Genetic Discrimination Executive Order
- Gramm-Leach-Bliley: before, after, regs
- Internet privacy; encryption; safe harbor; federal websites and databases; computer security; public records; and so on
- Presidential Privacy Archives, at www.privacy2000.org

II. Are They Picking on Doctors: Some U.S. Privacy Laws

- Fair Credit Reporting Act, 1970
- Privacy Act, 1974 (federal agencies)
- Family Educational Rights and Privacy Act,
. 1974
- Right to Financial Privacy Act, 1978
- [medical legislation proposed, 1970s]
- Cable Communications Policy Act, 1984
- Electronic Communications Privacy Act,
1984

U.S. Privacy Laws (cont.)

- Video Privacy Protection Act, 1988
- Employee Polygraph Protection Act, 1988
- Telephone Consumer Protection Act, 1991
- Driver's Privacy Protection Act, 1994, 1999
- Telecommunications Act, 1996
- HIPAA, 1996
- Children's On-Line Privacy Protection Act, 1998
- Gramm-Leach-Bliley Act, 1999 (financial)

II. What has changed for medical records?

- From paper to electronic records
- More actors see the data
- How to create patient trust?

Paper to Electronic

- History of mostly paper records
- Recently enter some records electronically for payment and other purposes
- Soon will be mostly electronic records

How is Electronic Different?

- Much more permanent storage
- Much easier to link databases
- Often, much more detailed information
 - “Digital Angel” reports vital signs remotely
- Thus, more people see more data for longer

More Actors See the Data

- History of paper records in the general practitioner's office
- Medical subspecialties
 - More doctors and nurses see it
- HMOs and insurers
 - “Managed” care uses data intensively

More Actors See the Data

- Oversight, audit, accreditation
- Outsourcing (back office), joint ventures
- Research
- Many of these activities are across state lines, so limited effect of state confidentiality laws

Do Consumers Trust the Change?

- 90 percent of Americans say they have “lost all control” over their personal information
- WSJ poll 9/99: “erosion of personal privacy” as greatest fear for the new century
- 1 in 6 Americans have misreported to a doctor due to privacy concern

IV. HIPAA Medical Privacy

- In light of these changes:
 - Key points from the March comments
 - The politics of HIPAA and privacy
 - Re-discovering why the rule makes sense

Key points from March

- Overwhelming procedural burden if repeal
 - 52,000 + 24,000 + many more comments
 - Perhaps 100 to 200 distinct policy issues
 - Each decision must be made and then justified on the basis of the record
 - If repeal, likely no medical privacy protection in place until 2004 and likely much later

Key points from March

- The link between administrative simplification and privacy
 - Clear statutory and policy basis for expanding electronic flows *and* protecting privacy
- A strong lawsuit if repeal
 - Statutory deadline of rule by 2000
 - Link with administrative simplification
 - Legal and political impact if “unlawful”

Key points from March

- Statements by President Bush to “guarantee the privacy of medical records”
- My March recommendation: permit the December rule to go into effect while announcing a speedy process for clarifying a few key issues where changes are lawful and appropriate
- That’s what happened (though I differ on which issues to change)

- Political consensus that need legal protection of medical records
- If had “repealed” the rule, then straight line from arsenic to global warming to guaranteeing the right of companies to
- Likely result in lawsuit that was “unlawful” to repeal the rule

HIPAA and Privacy Politics

- Reports that President Bush sincerely believes in privacy protection
- So, decision to keep the December rule
- Significant possibility, after the HIPAA decision, that there will be some additional political activity on privacy by this Administration, beyond medical area
- Query: is the HIPAA rule good politics but bad policy?

Rediscovering why the medical privacy rule makes sense

- The rule is not radical -- it reinstates state medical confidentiality law for an era where records are shared nationally & electronically
- Basic structure:
 - Information flows quite freely for treatment, payment, and health care operations
 - Patient consent needed for other transfers
 - Rules for balancing interests for research, public health, law enforcement, etc.

Business Associates

- Imagine a hospital that hires a computer firm to handle its entire back office
- Without coverage for business associates, then all those hospital records are totally unprotected
- So, need business associates rule with contractual understandings

Scope of rule

- Proposed rule scope for electronic records and information contained elsewhere in electronic form; asked for comments
- Oral: should your statements to psychiatrist be covered?
- Written: coverage for a written HIV test?
- So, rule only makes with broader scope, and that's lawful

Required new information flows?

- None.
- 2 exceptions:
 - Patient access
 - For specific privacy enforcement actions
- So, no reduction in privacy from the rule

Accounting

- Industry concern that will be hard to log when patient records are disclosed for other than treatment, payment, & operations
- But, says MIS community, this sort of accounting is a standard feature in the patient management systems coming on the market

Preemption

- Statute was clear -- HHS had no discretion
- For civil & consumer rights, tradition is to allow states to provide greater protections
- Can you create a consensus process in California & other states?

Consent

- Proposed rule: no consent for treatment, payment, health care operations
- AMA and others argued that patient autonomy and medical ethics require patient consent; final rule takes this view
- One issue to fix: prescription records and prior consent

Summary on HIPAA

- Substance held up to scrutiny
- Many of the criticisms were not valid: see “Myths and Realities about HIPAA” at www.healthprivacy.org
- HIPAA will be a major source of practical experience at building confidentiality into computer systems

Concluding Thoughts

- As medical care shifts to electronic records, privacy & security need to be built in
- The most sensitive data deserves the greatest protection, and people consider medical the most sensitive
- After 25 years of debate, is time to institutionalize good medical privacy practices
- In closing, a common-sense test:

President Clinton, at Aspen Institute:

“Do you have privacy policies you can be proud of? Do you have privacy policies you would be glad to have reported in the media?”

If so, your policies are far more likely to survive, and help your organization prosper, in the information age.

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