

# “Medical Privacy in a Broader Perspective”

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# Overview

- Free flow of information
- Administration privacy policy
- Some costs and benefits of health privacy
- Concluding thoughts

# I. “Free flow of information”

- A noble goal, but what does it mean?
  - Security -- free flow to hackers?
  - Intellectual property -- free flow to pirates?
  - Privacy -- free flow to intruders?
- Moral:
  - *Many* wonderful flows
  - *Not all* flows are wonderful



# “Free flow of medical data”

- HIPAA and administrative simplification -- *many* new flows
- Enormous benefits from new flows: electronic records “can save lives -- by helping doctors make quicker and better-informed decisions, by helping to prevent drug interactions, by giving patients in rural areas the benefit of specialist care hundreds of miles away” President Clinton 10/31/99

# “Free flow of medical data”

- “Today with a click of a mouse, personal health information can easily -- and legally -- be passed around without patients’ consent ... to people who are not doctors ... for reasons that have nothing to do with patient care. A recent survey showed that more than a third of all Fortune 500 companies check medical records before they hire or promote. One large employer in Pa. had no trouble obtaining detailed information on the prescription drugs taken by its workers -- easily discovering that an employee was HIV positive.”

# “Free flow of information”

## ■ Security is needed

- Encryption and other security measures
- Security regs pending

## ■ Privacy is needed

- Will have some flows, but not all flows



## II. Administration Privacy Policy

- Support self-regulation generally
- Sensitive categories deserve legal protection
  - Medical & Genetic
  - Financial
  - Children's Online
  - SSNs
- Government should lead by example

# Internet Privacy

- Quantity of policies
  - 15% to 66% to 88% from 1998 to 2000
- Quality of policies
  - Seek continued improvement
- Incentives for good action by companies
- Codes for specific sectors, such as online profiling
- Concern about “free riders” with no policies



# Safe Harbor

- Now approved by E.U.
- Self-regulation as a core achievement
- Lawful basis for trans-Atlantic data flows
- Streamlined registration
- We encourage you to join the Safe Harbor

# Medical Records Privacy

- HIPAA 1996 called for legislation by 8/99
- President announced proposed regs 10/99
- Over 53,000 submissions of comments
- SOTU promise to make the regs final this year

# Genetic Discrimination

- Mapping of Human Genome
- February 8 Executive Order
  - Prohibits federal agencies from using genetic information in hiring or promotion
- Call for legislation
  - Extend protections to private sector
  - Apply to purchase of health insurance



# Financial Privacy

- Financial Modernization enacted in 1999
  - Notice of uses
  - Choice to 3d parties
  - Security
  - Enforcement

# Financial Privacy (cont.)

- Clinton-Gore Plan announced in April
  - Choice for affiliates, too
  - Opt in for especially sensitive data, including medical
  - Access and other provisions
- Legislation:
  - House Banking passed opt in for medical
  - Life and other insurers that are not covered entities

# Other Privacy Legislation

- Children's Online Privacy Protection Act of 1998
  - FTC rules took effect 4/2000
  - Key is “verifiable parental consent”
- Identity Theft law in 1998
- Pretext Calling law in 1999
- “Opt in” for motor vehicle records for marketing in 1999



# Government-held Information

- Government to lead by example -- clear policies at all agency web sites
- Improve government computer security -- reduces unauthorized access to files
- With Federal CIO Council, develop “privacy impact assessments” for new IT systems

# Summary on privacy legislation

- Significant level of legislative activity
- Significant level of public concern
  - WSJ poll in 9/99
- Seek balance among multiple goals
  - Good medical care and good privacy
  - Privacy and use of information for economic growth, education, research, and other goals
  - *Which* uses of data are net beneficial, upon thoughtful consideration

# III. The Costs and Benefits of Health Privacy?

## ■ Benefits:

- Correct market failures
- Protect “rights” in privacy
- Address public concerns

## ■ Costs:

- Potentially great, so address burden directly



# Market failures

- The RIA: “Basis for the Proposed Action”
- Information costs -- hard to know what “they” do with “your” information
- Bargaining costs -- what if you want privacy?
- Third-party issues; patient often not interacting with data user
- “Free & efficient” market in health data?

# Rights arguments

- Whalen v. Roe and possible constitutional basis for right to privacy in medical info
- The most intimate facts about a person's body
- Mental health -- even more intimate?
- Do individuals deserve a say in how the data is used?

# Public concerns

- WSJ, 9/99
- 1 in 6 adults have taken steps to shield medical information from providers
- 3 groups:
  - privacy purists
  - those who don't care
  - privacy pragmatists -- but more “pure” on medical



# Harms if lack of faith in privacy

- If no confidence in privacy, may not go to provider
- If go to provider, then may not report accurately
  - Foregone treatment
  - Inaccurate treatment, e.g., drug interactions when doctor does not know of other prescriptions

# Costs of medical privacy regs

- A goal: focus Administration efforts on provisions that effectively protect privacy; stay vigilant on burden
- Some examples on burden:
  - Scalability -- size of covered entity
  - De-identification -- free use once de-identify
  - Clearinghouse exceptions where appropriate
    - Notice and access

## V. The process from here

- Final rules this year -- pledge in SOTU
- Effective date 2 years later
- Seek legislation to address imperfections in the regulatory authority



# Steps for you to consider

- Consider Privacy Impact Assessments for your organization
- Privacy point person for the organization
- Professional groups and industry leaders should use the two years wisely

# Concluding thoughts

- *Many* flows are good, but not all flows are good
- The Administration has sought balance in this area
- Take advantage of new technologies to promote individual care, public health, research, and other goals
- 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 succeed, in the information age.**