

# Introduction to Health Privacy

by  
Health Privacy Project  
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**The Health Privacy Project is dedicated to raising public awareness of the importance of ensuring health privacy in order to improve health care access and quality, for individuals and their communities.**

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Welcome to the Health Privacy Project's Primer on Privacy. This introductory slide show describes:

- Threats to patient privacy;
- The role privacy plays in assuring access to health care and high quality care; and
- Current legal protections for health information.

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## Privacy and Health Care

- Medical information is among the most sensitive and personal information collected and shared
- Privacy is central to the doctor-patient relationship

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**Surprisingly, there is no comprehensive federal health privacy law.**

**People's medical records are less protected than their credit reports or video rental records.**

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## **State Health Privacy Laws**

- There is a patchwork of state health privacy laws. Some laws cover:
  - specific individuals or organizations; or
  - specific medical conditions
- BUT state laws vary widely and few address health privacy concerns in a comprehensive fashion.

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## New Urgency Exists for Privacy Rules

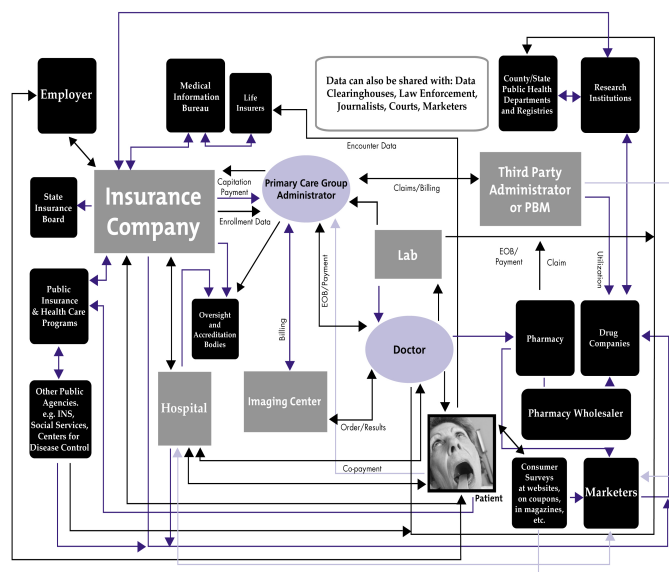
- Rise in managed care
- New information and communications technology
- Concerns raised by mapping of the human genome
- Increased demand for health data
- Commercial use of health data

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### Do You Know Where Your Medical Information Goes?

#### Sample Data Flow

Based on a presentation developed by the California HealthCare Foundation



Please note that the explanations are meant to be illustrative. They are not comprehensive.

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## **Secondary Users of Health Care Information**

- Drug Marketers
- Public Assistance Programs
- Law Enforcement Agencies
- Courts
- Private Database Companies such as Medical Information Bureau

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## **Increased Access Equals Increased Risk of Misuse**

- Access by those who are not bound by ethical or legal standards
- Access motivated by profit
- Access motivated by curiosity

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## Increased Reliance on Computerization of Health Information

- Computers can offer a higher degree of security
- But breaches in security can have much greater consequences

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## Lack of Trust

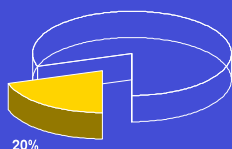


Only a third of U.S. adults say they trust health plans and government programs to maintain confidentiality all or most of the time.

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California HealthCare Foundation, national poll, January 1999

## Fear is Justified: Improper Disclosures



One in five American adults believe that a health care provider, insurance plan, government agency, or employer has improperly disclosed personal medical information. Half of these people say it resulted in personal embarrassment or harm.

•Health Privacy Project 1999, California HealthCare Foundation, national poll, January 1999

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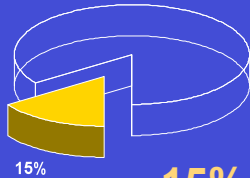
## Fear is Justified: Access by Employers

In a recent survey of Fortune 500 companies, only 38% responded that they do not use or disclose employee health information for employment decisions.

(Report prepared for Rep. Henry A. Waxman by Minority Staff Special Investigations Division  
Committee on Government Reform, U.S. House of Representatives April 6, 2000)

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## Consumer Anxiety



**15%** of American adults say they have done something out of the ordinary to keep medical information confidential.

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California HealthCare Foundation, national poll, January 1999

## Privacy-protective Behaviors

- Paying out-of-pocket
- Doctor-hopping
- Giving inaccurate or incomplete information
- Asking a doctor not to write down certain health information or to record a less serious or embarrassing condition
- Avoiding care altogether

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## Impact on Individual

- Patient risks undetected and untreated conditions;
- Doctor's ability to diagnose and treat patients is jeopardized without access to complete and accurate information; and
- Future treatment may be compromised if the doctor misrepresents patient information so as to encourage disclosure.

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## Impact on Community

Without full patient participation up-front, the information collected will be unreliable for users downstream. Ultimately, health care initiatives that depend on complete and accurate information may be undermined.

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## **Privacy is Essential to Health Care**

**Protecting patient privacy:**

- Ensures access to care; and
- Improves the quality of care for individuals and their communities.

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## **Good News**

**The Secretary of the U.S. Department of Health and Human Services issued the final federal health privacy regulation in December 2000.**

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## Bad News

The regulation provides only a partial solution. Under the regulation many record holders are not covered.

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The question remains:

**“When all is said and done, will our health care records be used to heal us or reveal us?”**

(Donna Shalala, U.S. Secretary of Health and Human Services)

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## For More Information

Please visit other areas on our Web site to learn more about:

- Details on the federal health privacy regulation;
- The laws in your state;
- Internet privacy;
- Financial health information privacy; and
- Much more.

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