



Data, Information, Confidentiality and the Legal Landscape

Presented by
Prof. Joanne Irene Gabrynowicz
to
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University of Mississippi School of Law

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Sources of Privacy Law



- **The Constitution**
 - 4th, 5th and 14th Amendments
 - Due process
 - Federal and state
- **Common Law**
 - Tort
 - Informational privacy
- **Statutes**
 - HIPPA, FERPA, 1974 Privacy Act, Federal Torts Claim Act, Patriot Act, Fair Credit Reporting Act, Wiretapping Statute, etc.
- **Regulations**



The Constitution



- **4th Amendment**

- Protects "right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures"

- **14th Amendment**

- "Penumbra" rights

- Protects privacy of intimate activities

- Right to raise family, consensual sex, etc.

- "Rational basis"

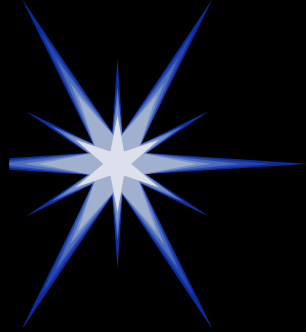


Common Law



- **Developed in 1890s**
 - **"The Right to Privacy"**
 - Warren and Brandeis, 1890 *Harvard Law Review*
- **Freedom from intrusion into fundamental, personal, intimate aspects of lives**
- **Tort of Privacy**
 - **Personal privacy**
 - **Intrusion upon seclusion**
 - **Highly offensive to ordinary, reasonable, prudent person**
 - **Publicity of private facts in an offensive manner**
 - **"Ms. X has syphilis", e.g.**
 - **False light invasion of privacy**
 - **Misappropriation of name or likeness for commercial gain**





Informational Privacy

- **Newer, related to personal privacy**
- **Right to determine**
 - **What personal information is being collected**
 - **How personal information is being used**
- **Case - by - case determination**
- **Preference for legislative rather than judicial protection**



Privacy Statutes



- Apply to local, state and federal governments
- Initially, inapplicable to private sector
 - Changing trend: HIPAA, e.g.
- No single federal law protects privacy of personal information in public and private databases
- Statutes address specific interests, e.g.
 - Financial, educational, computers, credit, health
 - Generally, have exceptions for law enforcement officials and national security
 - Few, if any, generic privacy protection laws
- Legislative reactions to information misuse
 - Publication of video rental record, e.g.





1996 Health Insurance Portability and Accountability Act (HIPAA)



- **Protected health information (PHI)**
 - Individually identifiable health information
 - Information can be "de-identified"
- **NASA is not a "covered entity" i.e.,**
 - Health plan, health care clearinghouse, health care provider who transmits PHI electronically
- **Conceivably could be a "business associate"**
 - Entity who assists or performs function involving PHI with/for "covered entity"





1996 Health Insurance Portability and Accountability Act (HIPAA)



Research Exception

- Covered entity may use or disclose PHI, regardless of the funding source
- IF approved by
 - Board
 - Institutional review board
 - Privacy board



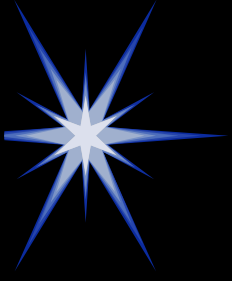


1996 Health Insurance Portability and Accountability Act (HIPAA)



- **Sources of health information e.g.,**
 - Medical records, epidemiological databases, disease registries, hospital discharge records, government compilations of vital and health statistics, demographics, etc.
- **Research**
 - "Systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge"

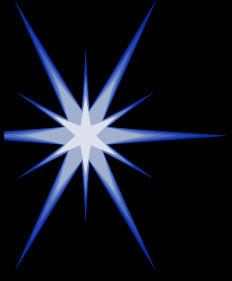




1974 Privacy Act

- **Safeguards against invasion of privacy by misuse of records by Federal agencies**
- **Allows citizen or lawful alien to**
 - **Learn how records are collected, maintained, used, and disseminated**
 - **Seek amendment of inaccurate, incomplete, untimely, or irrelevant information**





1974 Privacy Act

"Record"



- Any item, collection, or grouping of information
- About an individual
- Maintained by an agency
 - Education, financial transactions, medical history, and criminal or employment history, etc.
- And contains name or identifying number, symbol, or particular e.g., finger or voice print or photograph



1974 Privacy Act



- **"System of records"**

- Group of any records
- Under control of any agency
- From which information is retrieved by name or identifying particular

- **"Statistical record"**

- Record in a system of records
- Maintained for statistical research or reporting only
- Not used in whole or in part in making any determination about an identifiable individual



1974 Privacy Act



- **"Matching program"**
 - Compares two or more records/systems
 - With non-Federal records
 - To determine eligibility for or indebtedness to a Federal benefits program
- **Excludes**
 - Aggregate statistical data without personal identifiers
 - Matches that support any research or statistical project the data of which may not be used to determine rights and/or benefits of specific individuals
 - No case law
 - Only one state attorney general opinion which also refers the requesters to the federal agencies





NASA Regulations Pursuant to 1974 Privacy Act

- **Covers**
 - FOIA requests
 - Personnel-type, administrative records
- **Doesn't cover**
 - Research
 - Information about research subjects
 - Information about individuals in geospatial data



Absent Specific Legislation Make a Good Faith Effort

Consider Privacy Related Questions

- **Do images/data contain**
 - Identifiable persons and/or discrete groups
 - Enough information, if put together, can lead to individual and/ or group identities
- **Is an "individual" imaged?**
 - Natural or juridical
- **Do images/data reveal information on private signs, markers, buildings unintended for public view?**





Absent Specific Legislation Make a Good Faith Effort



Consider Privacy Related Questions

- **Err on the side of privacy**
- **Public access data combined with other?**
- **What do combined or correlated data reveal?**
- **Access only the data you absolutely need**



Absent Specific Legislation Make a Good Faith Effort

Consider Emerging Concepts

- **Fair information policies**
 - Is there a sense of legitimate expectation of privacy
- **Privacy protection policies**
 - In-house
 - Self-imposed
- **Privacy advocates/officers**
 - In-house
 - Departmental, program and/or agency wide



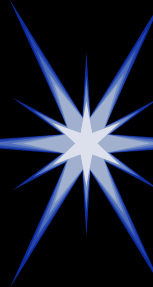


Code of Fair Information Practice

The 5 Basic Principles

- **There must be**
 - 1 no data record-keeping systems whose very existence is secret .**
 - 2 a way for an individual to find out what information about him/her is in a record and how it is used.**
 - 3 a way for an individual to prevent information about him/her obtained for one purpose from being used or made available for other purposes without his/her consent.**

**Records, Computers, and the Rights of Citizens,
Report of the Secretary's Advisory Committee on Automated Data Systems
commissioned by the Department of Health, Education and Welfare**



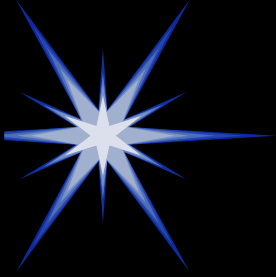
Code of Fair Information Practice

The 5 Basic Principles



- 4 There must be a way for an individual to correct or amend a record of identifiable information about him/her.**
- 5 Any organization creating, maintaining, using or disseminating records of identifiable personal data must assure the reliability of the data for their intended use and must take reasonable precautions to prevent misuse of the data.**

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Questions? Comments?

Special thanks to:

Prof. Paul Secunda

Dr. Jacqueline Serrao

University of Mississippi School of Law

NRSSLC

