

Confidentiality, Privacy, and the Ethics of Social Data

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January 2007

Outline

- Overview of human rights and social science
- Brief history of human subjects abuses and confidentiality breaches
- Statutory protections and authorizations
- Informed consent
- Institutional review boards

Privacy and Public Policy

- The right to privacy
- The public demand for information
- Balancing these concerns

Unethical Medical and Social Research

- Examples that have received much attention
- The Tuskegee Syphilis Study
- Eugenics

Breaches of Confidentiality with Statistical Data

- Illegal uses of statistical data
- The French Census of 1941
- [Japanese Internment In WWII](#)

Basic Public Policy

- The Privacy Act
- The Confidential Information and Statistical Efficiency Act
- URLs on course web site

Statutes Affecting Census and Census Research Data Centers

- Title 13 (Census Bureau data)
- Title 26 (Internal Revenue Service data)
- Title 44 (CIPSEA)

Mandatory v. Voluntary Censuses and Surveys

- Mandatory: response compelled by law
- Voluntary: respondent may refuse all or items

Informed Consent

- What will be asked/collected?
- Current uses
- Potential future uses

Institutional Review Boards

- Human subjects
- Ethical treatment of subjects
- Protection of confidentiality
- Secondary data analysis