Confidentiality, Privacy, and the Ethics of Social Data

John M. Abowd
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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