

NCVHS Workshop on Data Linkages to Improve Health Outcomes

Maximizing the Benefits from Linked Data: Access for Research and Related Issues

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Some Laws Affecting the Sharing of Linked Data

- Agency statutes for collecting the information
 - defining appropriate uses, confidentiality
 - (e.g. NDNH)
- Privacy Act
- Paperwork Reduction Act
 - “promote sharing of information collected for statistical purposes consistent with privacy rights and confidentiality pledges”
- CIPSEA



What is CIPSEA?

- Confidential Information Protection (Subtitle A)
- Purposes:
 - strengthen and foster public trust in pledges of confidentiality
 - prohibit disclosure in identifiable form
 - control access to and uses made of statistical information
 - ensure that information is used exclusively for statistical purposes



What is CIPSEA?

- Statistical Efficiency (Subtitle B)
- Purposes:
 - reduce paperwork burden on businesses
 - improve comparability of economic statistics
 - increase understanding of the economy



Why was CIPSEA necessary?

- More than 70 Federal agencies or organizational units with a patchwork of legislative protections
- Many attempts to strengthen and standardize statutory protections for confidentiality of individually identifiable data



What are the Benefits of CIPSEA?

- Uniform protection across agencies
- Coverage of all data collected for statistical purposes under a pledge of confidentiality
- Strong penalty for disclosure: \$250,000 fine and/or five years in prison
- Exemption from FOIA requests



Key Distinctions in CIPSEA

- Statistical versus nonstatistical agencies
 - different requirements and privileges for statistical agencies
 - only statistical agencies can designate agents to perform exclusively statistical activities
 - statistical agencies are those whose activities are predominantly the collection, compilation, processing, or analysis of information for statistical purposes.



Key Distinctions in CIPSEA

- statistical versus non-statistical purposes
 - statistical purpose means the description, estimation, or analysis of the characteristics of groups, without identifying the individuals or organizations that comprise such groups
 - nonstatistical purpose means a use in identifiable form that affects the rights, privileges, or benefits of a respondent



What Requirements does CIPSEA impose on Agencies?

- Inform the public
 - inform respondents about the uses of the information they provide
 - pledge to keep the information confidential using “CIPSEA pledge”
- Safeguard the information
 - Honor the pledge made to respondents



What kinds of data sharing does CIPSEA enable?

- What information is covered?
 - business data
- What agencies are affected?
 - three designated statistical agencies only: BEA, BLS, and Census
- CIPSEA does not alter existing laws that may permit other data sharing among Federal agencies



What are the implications of CIPSEA?

- For Federal Agencies protecting confidential statistical information
 - offers new protections for agencies that did not have strong legislative protection
 - does not restrict or diminish existing protections



What are the implications of CIPSEA?

- For Federal Agencies providing access to confidential statistical information
 - permits statistical agencies to designate agents to perform exclusively statistical activities
 - requires policies and procedures for access and control
 - responsibilities for information security and employee training



What are the implications of CIPSEA?

- For Researchers seeking access to confidential statistical information
 - no “right of access”
 - must honor safeguards
 - share responsibility

