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American Statistical Association's Privacy, Confidentiality, and Data Security web site

I. Privacy, Confidentiality, and Data Dissemination Guidelines for Government Agencies and International Organizations

Government Agencies and International Organizations collect, compile, process, store and disseminate many kinds of data for persons, households, companies, establishments, and other organizations. These activities are governed by statutes, regulations, and policies designed to limit invasion of privacy and protect the confidentiality of the data. This section provides information about general privacy and confidentiality protection guidelines for government and international agencies, and guidelines that are specific to individual agencies and contractors.

A. General Guidelines

148 - [Office of Management and Budget, "Order Providing for the Confidentiality of Statistical Information," Federal Register, Vol. 62, No. 124 \(June 1997\): 35044-55.](#)

content (R),(D)

sponsor (G)

Privacy and confidentiality policies regarding federally-collected statistics for individuals and organizations.

265 - ["Statistical Policy Working Paper 22 - Report on Statistical Disclosure Limitation Methodology." \(1994\)](#)

content (D), (R)

sponsor (G)

V. Topics in Education

VI. Topics in Finance

VII. Ethics, Principles, and Standards

VIII. Legal and Regulatory Sites

IX. Training Opportunities

Keyword Search:

Extremely useful for newcomers to this field. Opening chapters are especially valuable for those interested in a non-technical treatment of essential concepts and techniques. Following a description of federal agency practices as of the early 1990's, more technical discussions of disclosure limitation methodology for both tabular data and microdata files are provided. The report concludes with a list of recommendations and a research "agenda". Contains extensive annotated bibliography.

150 - *Principles and Practices for A Federal Statistical Agency*, 2nd ed. (2001, Margaret E. Martin, Miron L. Straf, and Constance F. Citro Editors; Committee on National Statistics, National Research Council)

content (R), (D)

sponsor (G)

On-line full text version of a publication of recommended principles and practices for federal statistical agencies. Topics covered include protecting the confidentiality and respecting the privacy of data providers.

151 - *Improving Access to and Confidentiality of Research Data: A Report of a Workshop, 2000*. (Christopher Mackie and Norman Bradburn, Editors; Committee on National Statistics, National Research Council)

content (R), (D)

sponsor (G)

Summary of a workshop convened to discuss "methods for advancing the often conflicting goals of exploiting the research potential of microdata and maintaining acceptable levels of confidentiality."

152 - *Confidentiality, Disclosure and Data Access: Theory and Practical Application for Statistical Agencies* (2002, P. Doyle, J. Lane, J. Theeuwes, and L. Zayatz, Elsevier Science)

content (D)

sponsor (G)

This link provides a description of the publication, as well as its table of contents and ordering information.

B. United States Federal Agencies and States

1. Government-wide in Applicability

[250 - Privacy Act of 1974 \(as of May 2002, U.S. Department of Justice\)](#)

[content \(R\)](#)

[sponsor \(G\)](#)

The site provides guidelines as to which data may and may not be disclosed under the terms of the Privacy Act.

[\(table of contents of Act\)](#)

[\(text of Act\)](#)

[251 - 1977 Assessment of the 1974 Privacy Act \(Privacy Protection Study Commission\)](#)

[content \(D\)](#)

[sponsor \(G\)](#)

This is the commission's evaluation of the effectiveness of the above 1974 Act.

[252 - Confidential Information Protection and Statistical Efficiency Act of 2002 \(CIPSEA\) as Title V in E-Government Act of 2002 \(Enrolled as Agreed to or Passed by Both House and Senate\)](#)

[\[H.R.2458.ENR\]](#)

[content \(R\)](#)

[sponsor \(G\)](#)

An act providing strong confidentiality protection for Federal statistical agencies collecting data for statistical purposes under pledges of confidentiality. Provides for data sharing among selected Federal agencies.

2. Individual Executive Branch Departments

a. Commerce

[153 - U.S. Census Bureau, Center for Economic Studies \(CES\) Privacy and Policy Statements' "Protection of Confidentiality Information,"](#)

[content \(R\)](#)

[sponsor \(G\)](#)

A statement of Title 13, sections 9 and 214.

[154 - U.S. Census, Statistical Research Division's "Privacy and Confidentiality Research and the U.S. Census Bureau:](#)

[Recommendations Based on a](#)

[Review of the Literature," Research Report Series, Survey Methodology #2002-01 \(2002, Thomas Mayer\)](#)
content (D), (R)
sponsor (G)

"This paper explores a number of issues regarding privacy concerns and attitudes, confidentiality beliefs, and their relationship to the functions of the U.S. Census Bureau."

155 - [U.S. Census' Statistical Disclosure Control \(SDC\)](#)
content (R), (D)
sponsor (G)

"This page provides links and conventional references to much of the research sponsored by the U.S. Census Bureau in the areas of statistical disclosure control, confidentiality, and disclosure limitation."

b. Education

220 - [National Center for Education Statistics, Statistical Standard 4-2, "Maintaining Confidentiality"](#)
content (D)
sponsor (G)

The purpose of this standard is "to protect the confidentiality of NCES data that contain information about individuals (individually identifiable information). For this reason, staff must be cognizant of the requirements of the law and must monitor the confidentiality of individually identifiable information in their daily activities and in the release of information to the public."

221 - [National Center for Education Statistics, \(NCES\) Statistical Standards](#)
content (D)
sponsor (G)

Includes standards on documentation and dissemination of data.

222 - Protecting the Privacy of Student Records: Guidelines for Education Agencies (1997, Oona Cheung, Barbara Clements, and Ellen Pechman, U.S. Department of Education, National Center for Education Statistics.)

content (D)

sponsor (G)

This document addresses the need for the members of the educational community to understand their legal responsibilities and to develop procedures to maintain the privacy of student records.

156 - U.S. Department of Education, "Protection of Human Subjects in Research",

content (R),(D)

sponsor (G)

A set of links in the following categories: General Information; Regulations Governing the Protection of Human Subjects in Research; Guidance and Educational Materials, and Assurance Information and Other.

157 - National Center for Education Statistics, Restricted Use Data Procedures Manual

content (R), (D)

sponsor (G)

An on-line manual reviewing laws, licensing procedures, data security, and on-site inspections.

c. Energy

158 - U. S. Department of Energy's "Human Subjects Regulations, Orders, Policy Statements, and Legislation,"

content (R), (D)

sponsor (G)

An index of links to Dept of Energy documents.

159 - Energy Information Administration's Standards for

[Statistical Activities, U.S. Department of Energy](#)

content (R), (D)

sponsor (G)

Two EIA standards of particular interest are: 2002-21- Data Protection and Accessibility, and 2002-22

Non-disclosure of Company Identifiable Data in Aggregate Cells.

Also of note are the Supplemental materials for Standard 2002-22, "Guidelines for Implementation of a Disclosure Limitation Rule," which explains in how to apply the pq rule.

d. Health and Human Services

160 - [Department of Health and Human Services, Standards for Privacy of Individually Identifiable Health Information Federal Register Federal Register/ Vol. 65, No. 250/Thursday, December 28, 2000](#)

content (R)

sponsor (G)

See especially pp. 82708-82712 for a detailed discussion of the HIPAA Privacy Rule standard for statistical de-identification. Statisticians made important contributions to this regulation.

161 - [National Institutes of Health, Notice for the Required Education in the Protection of Human Research Participants](#)

content (R), (D)

sponsor (G)

"Beginning on October 1, 2000, the NIH will require education on the protection of human research participants for all investigators submitting NIH applications for grants or proposals for contracts or receiving new or non-competing awards for research involving human subjects."

164 - [National Center for Health Statistics, NCHS Public-use Data Files and Documentation](#)

content (R),(D)

sponsor (G)

The site's information is specific to NCHS datasets. Links of interest include "How NCHS Protects Your Privacy" and "NCHS Research Data Center".

e. Justice

165 - [U.S. Department of Justice's "Summary of Human Subject Protection Issues Related to Large Sample Surveys," \(June 2001\)](#)

content (R) (D)

sponsor (G)

This site discusses ways of ensuring ethical compliance with the Common Rule in the conduct of large sample surveys.

[\(text version of the Report\)](#)

[\(pdf version of the Report\)](#)

f. Labor

239 - [U.S. Department of Labor, Bureau of Labor Statistics, "Bureau of Labor Statistics Data Integrity Guidelines"](#)

content (R), (D)

sponsor (G)

"The following guidelines must be followed by all Bureau of Labor Statistics (BLS) program offices and BLS employees to ensure the integrity of information maintained and disseminated by the BLS. Office of Management and Budget (OMB) information quality guidelines define 'Integrity' as the security of information-protection of the information from unauthorized access or revision, to ensure that the information is not compromised through corruption or falsification."

Topic areas include: the Confidential nature of BLS records, Data collection, Procedures for safeguarding confidential

information, Dissemination of news and data releases, and Data security.

g. Treasury

240 - [U.S. Bureau of the Treasury, Office of Tax Policy, Report to The Congress on Scope and Use of Taxpayer Confidentiality Provisions; Volume I: Study of General Provisions, October 2000](#)

content (R), (D)

sponsor (G)

"Section 3802 of the Internal Revenue Service Restructuring and Reform Act of 1998 ("RRA 1998") requires the Secretary of the Treasury and the Joint Committee on Taxation (the "JCT") to conduct separate studies of the scope and use of provisions regarding taxpayer confidentiality and to report the findings of such study, together with any recommendations deemed appropriate to Congress. The staff of the Joint Committee on Taxation (the "JCT staff") published its report on January 28, 2000.

3. Independent Agencies

166 - [National Science Foundation's "Computer Tapes Containing Microdata,"](#)

content (D), (R)

sponsor (G)

Describes the agency's procedures for protecting the confidentiality of individual information in connection with the release of files containing microdata to researchers.

167 - [Federal Reserve Board's Survey of Consumer Finance's Working Papers](#)

A listing of publications on statistical methods.

Content (D), sponsor (G)

Direct links of interest include:

["Disclosure Review and the 1998](#)

[Survey of Consumer Finances,"](#)
(2000, Fries, Gerhard and Barry
Johnson)

Content (D), sponsor (G)

A case study of the procedures that were used to limit disclosure risk in the release of tabular and microdata from an important federal survey.

["Multiple Imputation in the Survey of Consumer Finances,"](#) (1998,
Kennickell, Arthur)

Content (D), sponsor (G)

A paper closely related to Fries and Johnson's paper. The paper discusses how the author applies multiple imputation methodology as a data simulation technique for limiting disclosure in the Survey of Consumer Finances. The paper is contained in two PDF files: Part I contains the text of the paper and Part II contains additional figures, such as tables/graphics.

(Part I: Paper)

(Part II: Additional Figures)

["Multiple Imputation and Disclosure Protection: The Case of the 1995 Survey of Consumer Finances"](#)

(1997, Kennickell, Arthur)

Content (D), sponsor (G)

Paper preceding Kennickell's 1998 work, its content is further developed in the latter paper.

4. Legislative Branch Offices

a. General Accounting Office

236 - [U.S. General Accounting Office's "Find GAO Reports Page."](#)
content (R), (D)

sponsor (G)

This feature allows a search by GAO report number, full text, date, "titles, abstracts, agency/organization names, or subject terms." It is updated as new reports are added. Topics recommended as searches

include: privacy, confidentiality, and disclosure. Results of privacy/confidentiality/disclosure searches covered issues ranging from: personal health, medical record privacy, computer use, tax data, Lyme disease, Internet pharmacies, consumer health care, finance and the Securities Exchange Commission. Search results offer both abstracts and full-text of GAO reports.

[237 - U.S. General Accounting Office's Report: "Human Subjects Research: HHS Takes Steps to Strengthen Protections but Concerns Remain, GAO, May 2001," "GAO-01-775T](#)

[content \(R\)](#)

[sponsor \(G\)](#)

Abstract: "At the federal level the Department of Health and Human Services (HHS) is seeking to better protect human subjects in biomedical research by enhancing the visibility of its human subjects protection activities, improving its monitoring of compliance with relevant regulations by institutions and investigators, and strengthening enforcement of those regulations. HHS has also issued new guidance and is collecting information to improve oversight and monitoring at the institutional level. HHS activities directed at the investigator level consist largely of educational efforts to heighten investigators' awareness of and compliance with ethical policies and practices in conducting research. Overall, HHS' actions appear promising, but GAO has some concerns about the pace and scope of HHS' efforts to ensure the safety and protection of participants in clinical trials."

[238 - U.S. General Accounting Office's Report: "Record Linkage and Privacy--Issues in Creating New Federal Research and Statistical Information, GAO, April 2001,"](#)

[GAO-01-126SP](#)

[content \(R\), \(D\)](#)

[sponsor \(G\)](#)

Abstract: "This study focuses on privacy issues related to record-linkage--a computer-based process that combines multiple sources of existing data. Federally sponsored linkage projects conducted for research and statistical purposes have many potential benefits, such as informing policy debates; tracking program outcomes; helping local government or business planning; or contributing knowledge that, in some cases, might help millions of people. Despite these benefits, concerns about personal privacy are relevant because linkages often involve data on identifiable persons. GAO describes (1) how record linkage can create new research and statistical information, (2) why linkage heightens certain privacy issues, and (3) how data stewardship might be enhanced."

5. Federal Contractors

168 - [University of North Carolina, Carolina Population Center, National Longitudinal Study of Adolescent Health, Add Health Data, "Datasets" page](#)

[content \(D\)](#)

[sponsor \(A\), \(G\)](#)

The site's information is specific to the above dataset. Links of particular interest include "Deductive Disclosure, and "Public Use and Restricted Use Data".

169 - [University of Michigan, Inter-university Consortium for Political and Social Research, "Private Use or Restricted Use Data Collections" of the National Archive of Criminal Justice Data](#)

[content \(R\),\(D\)](#)

[sponsor \(G\),\(A\)](#)

Data use restriction measures specific to Archive of Justice Datasets.

270 - [University of Michigan, Inter-](#)

[university Consortium for Political and Social Research, "Disclosure Limitation at ICPSR." \(JoAnne McFarland O'Rourke, Fall 2003 Bulletin of ICPSR, Volume XXIV, No.1.\)](#)

content (R), (D)

sponsor (G), (A)

"Disclosure analysis often involves trial and error in determining the most appropriate methods for reducing disclosure risk and must include an analysis of the impact on the data: What is lost and gained by the methods pro-posed? Which analytic capabilities are diminished? Which are preserved? How will the information lost affect data interpretation? Can the lost information be released in some other way? . . . Disclosure analysis is perhaps more easily understood with examples of specific applications. ICPSR has conducted two full disclosure analyses within the Substance Abuse and Mental Health Data Archive (SAMHDA) . . ."

6. U.S. States

[171 - Hawaii's Office of Information Practices](#)

content (R), (D)

sponsor (G)

The site covers a wide range of privacy and confidentiality (P&C) issues such as laws for medical data and public records, a "guidance" section providing information in a question and answer format, and "other links" to additional state and national P&C websites.

[172 - Massachusetts Health Data Consortium's Privacy Resource Center](#)

content (R),(D)

sponsor (Prof)

This homepage has links to the Privacy Resource Data Center, Conferences, Data Products and Research

Direct Link:

[Massachusetts Health Data Consortium's Privacy Resource Center](#)

Content (R), (D), sponsor (Prof)

The resource center provides links to many online resources including research papers, articles, presentations, books, legislation and conferences. The site has a specific link to its HIPAA Privacy Resource Center (a Part of the Privacy Officers' Forum).

173 - [Missouri Department of Health's and Senior Services, "Confidentiality Data Release Rules."](#)(Garland Land, Director of the Center for Health Information Management and Epidemiology)
content (D)

sponsor (G)

A power point presentation addressing issues of sample size, stability of rates, public release tapes and risk from interactive systems.

NOTE: This file requires a PowerPoint viewer.

174 - [Washington \(State's\) Department of Health's "Data Guidelines for Working With Small Numbers"](#)

content (D)

sponsor (G)

Guidelines are provided for those working with tabular and/or microdata for small populations. Detailed information about reducing disclosure risk and a glossary of terms are included in a question-and-answer format.

C. Federal Privacy Commissioner of Canada

170 - [Federal Privacy Commissioner of Canada's Homepage.](#)

content (D), (R)

sponsor (G)

The site contains links to a broad range privacy related information such as: recent speeches and findings, a resource center for individual and business data, linked publications, provincial/territorial links and fact sheets. An FAQ section is provided along with an interactive Privacy Quiz.

D. United Kingdom's Office for National Statistics

223 - [United Kingdom's Office for National Statistics, Code of Practice, 2002](#)

content (R)

sponsor (G)

The "key principles and standards" for official statisticians. The third Protocol on Professional Competence directly relates to ethical issues.

224 - [United Kingdom's Office for National Statistics, Draft Protocol on Quality Management, 2003](#)

content (R)

sponsor (G)

A draft of the protocol appears on the site for public consultation, along with a response form.

E. United Nations' Statistics Division

225 - [United Nations Statistical Commission, "The Fundamental Principles of Official Statistics" \(April 1994\)](#)

content (R)

sponsor (Prof)

An internationally approved statement of the basic norms which government statistical services are expected to follow in their work.

226 - [United Nations' Statistics Division, "Good practices in official statistics."](#)

content (R)

sponsor (Prof)

The work is an extension and elaboration of the Fundamental Principles of Official Statistics. It provided a brief explication of each of the ten fundamental principles, along with direct links to extracts of individual national practices with respect to relevant key concepts. Of particular relevance are Principles 6, and to a lesser extent 2, 5, and 7.

227 - [United Nations' Statistics Division, "Search the good practices database."](#)

content (R)

sponsor (Prof)

A search engine for finding national practice with respect to these individual concepts by country. Searches for all countries and/or all concepts are also possible. Concepts are listed along with the Principle number in which they are found.

For example, "confidentiality" and "privacy" are cited in the annotations to Principles 6 and 7; "access to microdata" and "statistics legislation" are identified cited under Principle 6; and "minimize reporting burden" and "access to administrative records" are identified and cited under 7.

260 - [United Nations Statistics Division, Handbook of Statistical Organization, Third Edition: The Operation and Organization of a Statistical Agency \(December 2001\)](#)

content (R), (D)

sponsor ([Prof](#))

"The Handbook of Statistical Organization, Third Edition: The Operation and Organization of a Statistical Agency deals with the fundamentals of national systems of official statistics: general principles, data collection and respondent policies, principles of organization and management, and dissemination guidelines. Key chapters discuss: the structure of statistical systems, coordination tools, the chief statistician, users and their needs, developing a progress plan, managing staff, managing information technology, interacting with respondents, getting information to the users, and confidentiality and disclosure. The intended audience for the Handbook are both chief statisticians (and their colleagues) and those charged with oversight of the official statistics function."

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