



THE NATIONAL ACADEMIES

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National Academies Studies on Privacy and Confidentiality

Here is a synopsis of relevant work at the Academies on privacy and confidentiality and access to research data. Included are past studies of the Committee on National Statistics (CNSTAT), some recent reports, some ongoing studies, and one under consideration.

Past studies

CNSTAT has been engaged in issues of confidentiality protection and data access almost since its inception. It has produced a number of reports that have been helpful in guiding data practices not only among federal statistics agencies but also among researchers and agencies that conduct or fund research.

Privacy and Confidentiality as Factors in Survey Response (1979)

Sharing Research Data (1985)

Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics (1993). George Duncan, Chair.

Improving Access to and Confidentiality of Research Data: Report of a Workshop (2000). Norman Bradburn, Chair.

Describes the tradeoffs between confidentiality and data access, ethical and legal requirements, alternative approaches, and current practices.

Protecting Participants and Facilitating Social and Behavioral Sciences Research (2003). Joint with the National Academies Board on Behavioral, Cognitive, and Sensory Sciences. Cora Marrett, Chair.

Discusses confidentiality protection and data access considerations for Institutional Review Boards; includes paper by George Duncan on confidentiality protection techniques to facilitate data access.

Expanding Access to Research Data: Reconciling Risks and Opportunities (2005). Eleanor Singer, Chair.

“. . . no one way is optimal for all data users of all purposes. . . . statistical agencies must provide both unrestricted access to anonymized public-use files and



restricted access to detailed, individually identifiable confidential data for researchers under carefully specified conditions.”

“ . . . licensing agreements should be expanded.”

“ . . . users, like agencies, should be held accountable for safeguarding the confidentiality of micro-data files to which they are granted access.”

“ . . . laws, enforcement, and penalties are not enough. . . . What is needed in addition . . . is a system of norms and values concerning the ethical use of such data.”

Improving Business Statistics Through Interagency Data Sharing: Summary of a Workshop (2006)

To help the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA) achieve its full potential through responsible data sharing among statistics agencies, in particular for data that have been commingled with IRS data.

Recent studies

Three recent Academies studies address privacy and confidentiality:

Putting People on the Map: Protecting Confidentiality with Linked Social-Spatial Data (2007). Myron Gutmann, Chair. National Academies Committee on the Human Dimensions of Global Change.

“The linkage of spatial and social information, like the growing linkage of socioeconomic characteristics with biomarkers (biological data on individuals) has the potential to revolutionize social science and to significantly advance policy making.”

“Because technical strategies will not be sufficient in the foreseeable future for resolving the conflicting demands for data access, data quality, and confidentiality, institutional approaches will be required to balance those demands.” (Establishing tiers of risk and access, developing data sharing protocols, allocating authority for decisions on access to appropriate and informed decision makers)

Engaging Privacy and Information Technology in a Digital Age (2007). National Academies Computer Sciences and Telecommunications Board.

The report discusses meanings of privacy and how they have changed; tools to protect privacy, including actions that individuals and information collectors can take and technologies for encryption and for screening out identifying characteristics; and guidance to facilitate a thoughtful debate on privacy. The report describes some privacy



rights of individuals and what firms and organizations can do to protect the privacy of personal information they collect.

Understanding Business Dynamics: An Integrated Data System for America's Future (2007). John Haltiwanger and Lisa Lynch, Co-chairs. Committee on National Statistics.

Focuses on strategies to improve the coverage and depth of business data, the report also addresses “shifting the legal and organizational environment to accommodate data sharing and confidentiality protection.”

Ongoing studies

Protecting Individual Privacy in the Struggle Against Terrorists: A Framework for Assessment. Committee on Technical and Privacy Dimensions of Information for Terrorism Prevention and Other National Goals. Committee on Law and Justice, Committee on National Statistics, and Computer Science and Telecommunications Board.

At the request of the Department of Homeland Security, the National Research Council convened the Committee on Technology and Privacy Dimensions of Information for Terrorism Prevention and other National Goals. The committee is examining the nexus between terrorism prevention and privacy, including implications of surveillance, data mining, and information fusion technologies. As part of its work, the Committee is developing a framework for assessing fundamental questions that national security programs should address when collecting, accessing, or analyzing data derived from personal information. The Committee's report is expected to be released in the fall of 2008.

HIPAA. A committee of the Institute of Medicine (IOM) is being convened to investigate the effects of the privacy provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) on health research. The committee will consider how the HIPAA Privacy Rule is interpreted and implemented, as well as how it relates to the Common Rule, which institutional review boards apply, regarding informed consent for human subjects research.

Workshop on Protecting Student Records and Facilitating Education Research. The 1974 Family Educational Rights and Privacy Act (FERPA) provides for privacy rights and confidentiality of data for people enrolled in schools that receive federal funds. Although FERPA appears to permit research access to identifiable longitudinal records on students and school characteristics, its current legal interpretation is more narrow, causing many state education agencies to be wary of providing education records for research purposes. As a result, much research critical to improving instruction has come to a halt. CNSTAT and the Academies Center for Education, in collaboration with the American Educational Research Association, are convening a workshop to discuss and help to resolve many of the issues in providing research access to the information while protecting privacy and confidentiality. The workshop is scheduled for 24-25 April 2008 at the National Academies.

Workshop on Collecting, Storing, Protecting, and Accessing Biological Data. CNSTAT and the Committee on Population (CPOP) are working with the National Institute on Aging to



explore privacy and confidentiality issues in collecting biological and genetic information in longitudinal surveys. The effort will build upon the CPOP reports, *Cells and Surveys: Should Biological Measures Be Included in Social Science Research?* (2001) and *Biosocial Surveys* (2008). The workshop is scheduled for 17-18 November 2008 at the National Academies.

Under consideration

Privacy and confidentiality principles. How issues of privacy and confidentiality should be addressed in an era of burgeoning massive databases of personal information is the Gordian knot of the digital age. CNSTAT is considering a study to develop and test principles to govern a broad variety of data systems that may be useful for research purposes.

A panel would develop a set of principles for privacy and confidentiality of personal information together with an exposition of the fundamental reasons underlying them and guidance on their application. This brief statement of principles would be for privacy and confidentiality what the Belmont Report was for research involving human subjects.

The panel would seek wide input in developing the principles. It would apply them in specific cases, for example education data, to show how to make the principles operational and to test them. The panel would also develop guidance to the research community on applying the principles and best practices for protecting privacy and confidentiality.

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