



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Confidentiality Subject Aid

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Description

A short guide to some key resources and readings on the topic of confidentiality.

Body

That which is done or communicated in trust is confidential. Confidential information is information entrusted to another. The implication is that, for some reason, such as personal privacy or competitive advantage, the person entrusting this information does not wish others to know. Thus confidential information is information to be shared only with a very limited group who are involved with furthering certain ends which the one entrusting the information wants served, such as the treatment of a disease, or development and manufacture of a new product. Most professions recognize some duty to keep a client's information confidential, although such a duty has limits when the confidential information concerns a danger to others.

Subject Overviews

American Speech Hearing Association. 2013. "Confidentiality". Accessed 12 July 2016. <http://www.asha.org/practice/ethics/confidentiality/>

Though written specifically for members of the American Speech Hearing Association, this document provides an excellent overview of what confidentiality entails when working with personal data in practice and research and how to handle this data in medical settings, schools, and the classroom.

Bok, Sissela. 1983. "The Limits of Confidentiality." *Hastings Center Report*. 13(1): 24-31.

This older but excellent article discusses the concept of confidentiality as it relates to all professions, from doctors to lawyers to researchers, and discusses difficult decisions that have to be made when faced with the need to disclose confidential information.

National Bioethics Advisory Commission. (2006) Chapter 5: [Ensuring Voluntary Informed Consent and Protecting Privacy and Confidentiality](#) from *Report on Ethical and Policy Issues in Research Involving Human Participants. Vol. 1 Report and Recommendations*. Washington, D.C.: National Bioethics Advisory Commission.

All research, whether clinical, epidemiological, health services, or social science, involves issues related to protecting privacy and confidentiality. In fact, in some research the invasion of privacy or breaches in confidentiality are the only research-related risks to which participants might be exposed. Privacy and confidentiality, however, tend to be poorly understood concepts, often mistakenly used interchangeably and either ignored or inappropriately handled by investigators and institutional review boards.

Kaiser, Karen. 2009. "[Protecting Respondent Confidentiality in Qualitative Research](#)". *Qualitative Health Research*. 19(11): 1632-1641.

For qualitative researchers, maintaining respondent confidentiality while presenting rich, detailed accounts of social life presents unique challenges. These challenges are not adequately addressed in the literature on research ethics and research methods. Using an example from a study of breast cancer survivors, the author argues that by carefully considering the audience for one's research and by re-envisioning the informed consent process, qualitative researchers can avoid confidentiality dilemmas that might otherwise lead them not to report rich, detailed data.

Policy and Guidance

National Institutes of Health. 2015. "Protecting Personal Health Information in Research: Understanding the HIPPA Privacy Rule." Accessed 12 July 2016. https://privacyruleandresearch.nih.gov/pr_02.asp

The Health Insurance Portability and Accountability Act of 1996 protects personal health information and attempts to balance a person's interest of keeping his or her health information confidential with other social benefits, such as health care and research. Along with providing access to the full HIPAA rule, this online booklet also seeks to help researchers handle personal health data according to these regulations.

National Human Research Protections Advisory Committee. 2002. *Recommendations on Confidentiality and Research Data Protections*. Washington, D.C.: National Human Research Protections Advisory Committee. Accessed 17 July 2016. https://cyfar.org/sites/default/files/Confidentiality_0.pdf

Research in the biomedical and social sciences encompasses a broad array of topical areas, designs, and degrees of risk. Many studies pose minimal risk to research subjects. Some studies, however, are inaccurately perceived as conveying minimal risk. In such studies, disclosure of identifiable data may present a significant risk to the subject as a result of the sensitive nature of the topic, variety of social interactions, or possible financial or legal implications of the activity being studied. In such research, especially in the social and behavioral sciences, protecting the confidentiality of data collected from or about private individuals is often the key element in minimizing risk. This report summarizes major confidentiality issues and outlines ways that researchers can minimize risks to research participants and their personal data.

The National Academies of Science, Engineering and Medicine. 2007. *Ethical Considerations for Research Involving Prisoners*. Washington, D.C.: National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK19882/>

Because prisoners face restrictions on liberty and autonomy, have limited privacy, and often receive inadequate health care, they require specific protections when involved in research, particularly in today's correctional

settings. Given these issues, the Department of Health and Human Services' Office for Human Research Protections commissioned the Institute of Medicine to review the ethical considerations regarding research involving prisoners. The resulting analysis contained in this book emphasizes five broad actions to provide prisoners involved in research with critically important protections: expand the definition of 'prisoner'; ensure universally and consistently applied standards of protection; shift from a category-based to a risk-benefit approach to research review; update the ethical framework to include collaborative responsibility; and enhance systematic oversight of research involving prisoners.

The National Academies of Science, Engineering and Medicine. 2004. *The Ethical Conduct of Clinical Research Involving Children*. Washington, D.C.: National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK25557/>

In recent decades, advances in biomedical research have helped save or lengthen the lives of children around the world. With improved therapies, child and adolescent mortality rates have decreased significantly in the last half century. This report provides background and makes recommendations regarding (1) the regulation of clinical research involving children; (2) the evaluation of the risks and benefits to children; (3) the use of informed consent; (4) the use of payments related to research participation; (5) the enforcement of regulations on this area of research; and (6) the roles and responsibilities of those involved.

The National Academies of Science Engineering and Medicine. 2014. *Emerging and Readily Available Technologies and National Security: A Framework for Addressing Ethical, Legal, and Societal Issues*. Washington, D.C.: National Academies Press. <https://www.nap.edu/catalog/18512/emerging-and-readily-available-technologies-and-national-security-a-framework>

Emerging and Readily Available Technologies and National Security addresses topics such as the ethics of using autonomous weapons that may be available in the future; the propriety of enhancing the physical or cognitive capabilities of soldiers with drugs or implants or prosthetics; and what limits, if any, should be placed on the nature and extent of economic damage that cyber weapons can cause. This report explores three areas with respect to emerging and rapidly

available technologies: the conduct of research; research applications; and unanticipated, unforeseen, or inadvertent ethical, legal, and societal issues. The report articulates a framework for policy makers, institutions, and individual researchers to think about issues as they relate to these technologies of military relevance and makes recommendations for how each of these groups should approach these considerations in its research activities. Emerging and Readily Available Technologies and National Security makes an essential contribution to incorporate the full consideration of ethical, legal, and societal issues in situations where rapid technological change may outpace our ability to foresee consequences.

The National Academies of Science, Engineering and Medicine. 2016. *Doing Global Science: A Guide to Responsible Conduct in the Global Research Enterprise*. Princeton, NJ: Princeton University Press.

<https://www.interacademies.org/publication/doing-global-science-guide-responsible-conduct-global-research-enterprise>

This concise introductory guide explains the values that should inform the responsible conduct of scientific research in today's global setting. Featuring accessible discussions and ample real-world scenarios, *Doing Global Science* covers proper conduct, fraud and bias, the researcher's responsibilities to society, communication with the public, and much more. The book places special emphasis on the international and highly networked environment in which modern research is done, presenting science as an enterprise that is being transformed by globalization, interdisciplinary research projects, team science, and information technologies.

National Research Council. 2000. *Improving Access to and Confidentiality of Research Data: Report of a Workshop*. Washington D.C.: National Academies Press. <https://www.nap.edu/catalog/9958/improving-access-to-and-confidentiality-of-research-data-report-of>

The workshop summarized in this report was convened by the Committee on National Statistics (CNSTAT) to promote discussion about methods for advancing the often conflicting goals of exploiting the research potential of microdata and maintaining acceptable levels of confidentiality.

National Research Council. 2007. *Putting People on the Map: Protecting confidentiality with linked social-spatial data*. Washington, D.C.: National Academies Press, 2007. <http://www.nap.edu/catalog/11865/putting-people-on-the-map-protecting-confidentiality-with-linked-social>

Precise, accurate spatial information linked to social and behavioral data is revolutionizing social science by opening new questions for investigation and improving understanding of human behavior in its environmental context. At the same time, precise spatial data make it more likely that individuals can be identified, breaching the promise of confidentiality made when the data were collected. Because norms of science and government agencies favor open access to all scientific data, the tension between the benefits of open access and the risks associated with potential breach of confidentiality pose significant challenges to researchers, research sponsors, scientific institutions, and data archivists. *Putting People on the Map* finds that several technical approaches for making data available while limiting risk have potential, but none is adequate on its own or in combination. This book offers recommendations for education, training, research, and practice to researchers, professional societies, federal agencies, institutional review boards, and data stewards.

Bibliography

Online Ethics Center for Engineering and Science. 2016. "[Human Subjects and Informed Consent](#)." In Online Ethics Center for Engineering and Science. Last updated July 2016.

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