

Privacy and Surveillance Subject Aid

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Description

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

Body

It is common to distinguish four species of privacy: physical, informational, decisional, and psychological/mental privacy. In addition, philosopher and legal theorist Anita Allen (2003) distinguishes dispositional privacy. Physical privacy is a restriction on the ability of others to experience a person through one or more of the five senses. Informational privacy is a restriction of access to and control of facts about the person that are unknown or unknowable. Decisional privacy is the exclusion of others from decisions, such as health care decisions or marital decisions, made by the person and his group of intimates. Psychological/mental privacy relates to the restriction on others' ability to access and manipulate ones thoughts and personal identity. Finally, dispositional privacy is a restriction on the ability of others to know a person's states of mind.

Claims to privacy find moral justification in a recognition that people need to have control over some matters that intimately relate to them in order to function as people and be responsible for their own actions. Foremost among these are rights to one's own body. If, for example, people were permitted to drug one another at will, that would effectively undercut the rest of moral life.

Just what a person is expected to do in order to respect another's privacy varies with culture. For example, expectations that people will knock on the door before entering certain areas assumes the existence of both doors and of expectations about the amount of so-called "private space" to which a person is entitled. In some contemporary cultures, parents oversee their children's affairs much more closely than in others. In traditional Chinese families, for example, it is expected that parents will do such things as read the mail addressed to their adolescent children as part of their responsible oversight of their children, whereas in Anglo-American culture such acts would be viewed as intrusions on the adolescent's privacy.

Questions of privacy have become particularly prominent as computers and other technological innovations have made it possible to collect, assemble, and transmit quantities of information in ways that previously were impossible. Once the questions of appropriate levels of privacy protection have been established, the question of how that level of privacy can be practically ensured is a matter of security.

See also Kenneth E. Himma, and Hermann T. Tavani. 2008. "Chapter 6: Information Privacy: Concepts, Theories and Controversies" in *The Handbook of Information and Computer Ethics*. Hoboken, N.J: Wiley. Pp. 131-164.

Subject Overviews

Allen, Anita. 2015. "Privacy and Medicine", In *The Stanford Encyclopedia* of *Philosophy* edited by Edward N. Zalta. Accessed 18 July 2016. http://plato.stanford.edu/archives/fall2015/entries/privacy-medicine/.

Gives an excellent overview of the importance of privacy in medical care and research, including major concepts and laws protecting personal information in these settings.

Madden, Mary and Lee Rainie. 2015. "American Attitudes About Privacy, Security, and Surveillance." Pew Research Center. Access 18 July 2016.

http://www.pewinternet.org/2015/05/20/americans-attitudes-aboutprivacy-security-and-surveillance/.

This report provides a glimpse of current American citizens' views about privacy and surveillance, especially in regard to the use of this data by government agencies and other organizations.

Markkula Center for Applied Ethics, 2017. *Focus Area: Internet Ethics*? https://www.scu.edu/ethics/internet-ethics-blog/

An excellent online resource that regularly includes presentations on topics of privacy and surveillance, including many of the privacy-related controversies surrounding debate about the legislation in EU nations on The Right to Erasure (formerly known as the Right to be Forgotten).

National Research Council of the National Academies. 2007. Engaging Privacy and Information Technology in a Digital Age. Washington, D.C.: National Academy Press. <u>http://www.nap.edu/catalog/11896/engaging-</u> privacy-and-information-technology-in-a-digital-age

Privacy is a growing concern in the United States and around the world. The spread of the Internet and the seemingly boundless options for collecting, saving, sharing, and comparing information is cause for consumer concern. Online practices of business and government agencies may present new ways to compromise privacy, and e-commerce and technologies that make a wide range of personal information available to anyone with a Web browser only begins to hint at the possibilities for inappropriate or unwarranted intrusion into our personal lives. "Engaging Privacy and Information Technology in a Digital Age" presents a comprehensive and multidisciplinary examination of privacy in the information age.

Nissenbaum, Helen. 2006. "<u>Protecting Privacy in an Information Age: The</u> <u>Problem of Privacy in Public</u>." *Online Ethics Center for Engineering and Science.* Accessed 18 July 2016.

This essay argues that information and communications technology, by facilitating surveillance, vastly enhancing the collection, storage, and analysis of information, and enabling profiling, data mining and aggregation, has significantly altered the meaning of public information.

Moor, James H. 1997. "<u>Towards a Theory of Privacy in the Information Age</u> ." *Computers and Society* 27(3): 27-32.

This essay discusses how the ability of computers to manipulate information makes information raises important questions about the need for privacy in our society, and offers a theory that argues privacy is an expression of the core value of security, and since people have a basic right to be protected, we as a society must also include privacy protection as a core value of our society.

Tavani, Herman T. 2008. "Informational Privacy: Concepts, Theories, and Controversies." In *The Handbook of Information and Computer Ethics*. Edited by K. E. Himma and H. T. Tavani. Hoboken, NJ: John Wiley and Sons, pp. 131-164.

An excellent overview the provides an introduction to key concepts, theories and controversies affecting informational privacy. This includes an overview to privacy in general, and the four distinct kinds of privacy that exist (physical, informational, decisional, and psychological/mental) and finally considers four distinct categories that affect informational privacy: consumer privacy (and the threat from cookies technology), medical/healthcare privacy (and the threat from data-mining technology/big data), employee/workplace privacy (and the threat from surveillance technologies) and location privacies (and the threat from RFID technology).

van den Hoven, Jeroen, Martijn Blaauw, Wolter Pieters and Martijn Warnier. 2014. "Privacy and Information Technology." In *The Stanford Encyclopedia of Philosophy* edited by Edward N. Zalta. Accessed 18 July 2016. <u>http://plato.stanford.edu/archives/win2014/entries/it-privacy/</u>.

Human beings value their privacy and the protection of their personal sphere of life. They value some control over who knows what about them. They certainly do not want their personal information to be accessible to just anyone at any time, but recent advances in information technology threaten privacy, have reduced the amount of control over personal data, and open up the possibility of a range of negative consequences as a result of access to personal data.

Policy and Guidance

National Academies of Science, Engineering and Medicine. *Challenges and Opportunities in Using Residual Newborn Screening Samples for Translational Research: Workshop Summary.* Washington D.C.: National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK52737/

Newborn screening samples are used to test more than 4 million infants each year for life-threatening diseases that are treatable if found at birth. These specimens also represent a potentially invaluable resource for public health and biomedical research. The IOM held a workshop to examine issues surrounding the use of residual specimens for translational research.

National Academies of Science, Engineering and Medicine. 2010. Conducting Biosocial Surveys: Collecting, Storing, Accessing, and Protecting Biospecimens and Biodata. Washington D.C.: National Academies Press. <u>https://www.nap.edu/catalog/12942/conductingbiosocial-surveys-collecting-storing-accessing-and-protectingbiospecimens-and</u>

Recent years have seen a growing tendency for social scientists to collect biological specimens such as blood, urine, and saliva as part of large-scale household surveys. By combining biological and social data, scientists are opening up new fields of inquiry and, for the first time, are able to address many new questions and connections. But including biospecimens in social surveys also adds a great deal of complexity and cost to the investigator's task. Along with the usual concerns about informed consent, privacy issues, and the best ways to collect, store, and share data, researchers now face a variety of issues that are much less familiar or that appear in a new light.

National Academies of Science, Engineering and Medicine. 2009. *Ensuring the Integrity, Accessibility, and Stewardship of Research Data in the Digital Age*. Washington D.C.: National Academies Press.

https://www.nap.edu/catalog/12615/ensuring-the-integrity-accessibilityand-stewardship-of-research-data-in-the-digital-age

As digital technologies are expanding the power and reach of research, they are also raising complex issues. These include complications in ensuring the validity of research data; standards that do not keep pace with the high rate of innovation; restrictions on data sharing that reduce the ability of researchers to verify results and build on previous research; and huge increases in the amount of data being generated, creating severe challenges in preserving that data for long-term use. "Ensuring the Integrity, Accessibility, and Stewardship of Research Data in the Digital Age" examines the consequences of the changes affecting research data with respect to three issues — integrity, accessibility, and stewardship — and finds a need for a new approach to the design and the management of research projects. The report recommends that all researchers receive appropriate training in the management of research data, and calls on researchers to make all research data, methods, and other information underlying results publicly accessible in a timely manner. The book also sees the stewardship of research data as a critical long-term task for the research enterprise and its stakeholders.

The National Academies of Science, Engineering and Medicine. 2007. *Applications of Toxicogenomic Technologies to Predictive Toxicology and Risk Assessment*. Washington D.C.: National Academies Press. <u>https://www.nap.edu/catalog/12037/applications-of-toxicogenomic-</u> technologies-to-predictive-toxicology-and-risk-assessment

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The National Academies of Science, Engineering and Medicine. 2002. *Research Ethics in Complex Humanitarian Emergencies: Summary of a Workshop.* Washington D.C.: National Academies Press. <u>https://www.nap.edu/catalog/10481/research-ethics-in-complex-</u> <u>humanitarian-emergencies-summary-of-a-workshop</u>

Situations involving conflict and forced migration have become increasingly commonplace in today's world. The need to understand the causes, consequences, and characteristics of these situations is creating a burgeoning field of research. But given the nature of complex emergency settings, traditional research guidelines may be inappropriate. The research and policy community has recognized this problem and has begun to address issues surrounding the ethics of doing research in emergency settings and among conflict-affected and displaced populations. The Roundtable on the Demography of Forced Migration, under the aegis of the Committee on Population of the National Research Council, held a workshop to examine some of these issues. This report to the Roundtable summarizes the workshop presentations and discussion.

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Bibliography

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Topics

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