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Standards for Privacy of Individually
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Rule**

To Privacy," 4 Harv.L.Rev. 193. More than a century later, privacy continues to play an important role in Americans' lives. In their book, *The Right to Privacy*, (Alfred A. Knopf, New York, 1995) Ellen Alderman and Caroline Kennedy describe the importance of privacy in this way:

Privacy covers many things. It protects the solitude necessary for creative thought. It allows us the independence that is part of raising a family. It protects our right to be secure in our own homes and possessions, assured that the government cannot come barging in. Privacy also encompasses our right to self-determination and to define who we are. Although we live in a world of noisy self-confession, privacy allows us to keep certain facts to ourselves if we so choose. The right to privacy, it seems, is what makes us civilized.

Or, as Cavoukian and Tapscott observed the right of privacy is: "the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated." See A. Cavoukian, D. Tapscott, "Who Knows: Safeguarding Your Privacy in a Networked World," Random House (1995).

Increasing Public Concern About Loss of Privacy

Today, it is virtually impossible for any person to be truly "let alone." The average American is inundated with requests for information from potential employers, retail shops, telephone marketing firms, electronic marketers, banks, insurance companies, hospitals, physicians, health plans, and others. In a 1998 national survey, 88 percent of consumers said they were "concerned" by the amount of information being requested, including 55 percent who said they were "very concerned." See *Privacy and American Business, 1998 Privacy Concerns & Consumer Choice Survey* (<http://www.pandab.org>). These worries are not just theoretical. Consumers who use the Internet to make purchases or request "free" information often are asked for personal and financial information. Companies making such requests routinely promise to protect the confidentiality of that information. Yet several firms have tried to sell this information to other companies even after promising not to do so.

Americans' concern about the privacy of their health information is part of a broader anxiety about their lack of privacy in an array of areas. A series of national public opinion polls conducted by Louis Harris & Associates documents a rising level of public concern about privacy, growing from 64 percent in

1978 to 82 percent in 1995. Over 80 percent of persons surveyed in 1999 agreed with the statement that they had "lost all control over their personal information." See Harris Equifax, *Health Information Privacy Study* (1993) (<http://www.epic.org/privacy/medical/polls.html>). A Wall Street Journal/ABC poll on September 16, 1999 asked Americans what concerned them most in the coming century. "Loss of personal privacy" was the first or second concern of 29 percent of respondents. All other issues, such as terrorism, world war, and global warming had scores of 23 percent or less.

This growing concern stems from several trends, including the growing use of interconnected electronic media for business and personal activities, our increasing ability to know an individual's genetic make-up, and, in health care, the increasing complexity of the system. Each of these trends brings the potential for tremendous benefits to individuals and society generally. At the same time, each also brings new potential for invasions of our privacy.

Increasing Use of Interconnected Electronic Information Systems

Until recently, health information was recorded and maintained on paper and stored in the offices of community-based physicians, nurses, hospitals, and other health care professionals and institutions. In some ways, this imperfect system of record keeping created a false sense of privacy among patients, providers, and others. Patients' health information has never remained completely confidential. Until recently, however, a breach of confidentiality involved a physical exchange of paper records or a verbal exchange of information. Today, however, more and more health care providers, plans, and others are utilizing electronic means of storing and transmitting health information. In 1996, the health care industry invested an estimated \$10 billion to \$15 billion on information technology. See National Research Council, Computer Science and Telecommunications Board, "For the Record: Protecting Electronic Health Information," (1997). **The electronic information revolution is transforming the recording of health information so that the disclosure of information may require only a push of a button. In a matter of seconds, a person's most profoundly private information can be shared with hundreds, thousands, even millions of individuals and organizations at a time.** While the majority of medical records still are in paper form, information from those

records is often copied and transmitted through electronic means.

This ease of information collection, organization, retention, and exchange made possible by the advances in computer and other electronic technology affords many benefits to individuals and to the health care industry. Use of electronic information has helped to speed the delivery of effective care and the processing of billions of dollars worth of health care claims. Greater use of electronic data has also increased our ability to identify and treat those who are at risk for disease, conduct vital research, detect fraud and abuse, and measure and improve the quality of care delivered in the U.S. The National Research Council recently reported that "the Internet has great potential to improve Americans' health by enhancing communications and improving access to information for care providers, patients, health plan administrators, public health officials, biomedical researchers, and other health professionals." See "Networking Health: Prescriptions for the Internet," National Academy of Sciences (2000).

At the same time, these advances have reduced or eliminated many of the financial and logistical obstacles that previously served to protect the confidentiality of health information and the privacy interests of individuals. And they have made our information available to many more people. The shift from paper to electronic records, with the accompanying greater flows of sensitive health information, thus strengthens the arguments for giving legal protection to the right to privacy in health information. In an earlier period where it was far more expensive to access and use medical records, the risk of harm to individuals was relatively low. In the potential near future, when technology makes it almost free to send lifetime medical records over the Internet, the risks may grow rapidly. It may become cost-effective, for instance, for companies to offer services that allow purchasers to obtain details of a person's physical and mental treatments. In addition to legitimate possible uses for such services, malicious or inquisitive persons may download medical records for purposes ranging from identity theft to embarrassment to prurient interest in the life of a celebrity or neighbor. The comments to the proposed privacy rule indicate that many persons believe that they have a right to live in society without having these details of their lives laid open to unknown and possibly hostile eyes. These technological changes, in short, may provide a reason for institutionalizing