



# **PRIVACY and PROGRESS in Whole Genome Sequencing**

*Presidential Commission for the Study of Bioethical Issues*

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# PRIVACY and PROGRESS in Whole Genome Sequencing

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## **PRIVACY and PROGRESS in Whole Genome Sequencing** Presidential Commission for the Study of Bioethical Issues

Over the course of less than a decade, whole genome sequencing has progressed from being one of our nation's boldest scientific aspirations to becoming a readily available technique for determining the complete sequence of an individual's deoxyribonucleic acid (DNA)—that person's unique genetic blueprint. With this tremendous advance comes the accumulation of vast quantities of whole genome sequence data and complex questions of how—across a multitude of clinical, research, and social environments—to protect the privacy of those whose genomes have been sequenced. Collections of whole genome sequence data have already been key to important medical breakthroughs, and they hold enormous promise to advance clinical care and general health moving forward. To realize this promise of great public good ethically, individual interests in privacy must be respected and secured. Large-scale collections of genomic data raise serious concerns for the individuals participating. One of the greatest of these concerns centers around privacy: whether and how personal, sensitive, or intimate knowledge and use of that knowledge about an individual can be limited or restricted (by means that include guarantees of confidentiality, anonymity, or secure data protection). Because whole genome sequence data provide important insights into the medical and related life prospects of individuals as well as their relatives—who most likely did not consent to the sequencing procedure—these privacy concerns extend beyond those of the individual participating in whole genome sequencing. These concerns are compounded by the fact that whole genome sequence data gathered now may well reveal important information, entirely unanticipated and unplanned for, only after years of scientific progress. Another privacy concern associated with whole genome sequencing is the potential for unauthorized access to and misuse of information. For example, in many states someone could legally pick up a discarded coffee cup and send a saliva sample to a commercial sequencing entity in an attempt to discover an individual's predisposition to neurodegenerative disease. The information might then be misused, for example, by a contentious spouse as evidence of unfitness to parent in a custody case. Or, the information might be publicized by a malicious stranger or acquaintance without the individual's knowledge or consent in a social networking space, which could adversely affect that individual's chance of finding a spouse, achieving standing in a community, or pursuing a desired career path.

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