

Know Your Genetic Privacy Rights

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Your genes contain information that literally defines who you are. Scientists are eagerly exploring new benefits of that data, while policymakers are taking steps to ensure it is not misused. What are the risks associated with genetic privacy? What are your rights?

Recently, the Council for Responsible Genetics published a "Genetic Privacy Manual." The [online guide](#) [1] is a comprehensive source of information for consumers about the use of genetic information in fields ranging from human health and reproduction to the criminal justice system. The guide delves into the science of genetic testing and summarizes legal protections such as the relatively new Genetic Information Nondiscrimination Act (GINA).

Developments in human genetic technology, including those in the area of predictive genetic testing are promoted as holding great potential for improving health and economic growth. However, these developments also warrant concern about the privacy of genetic information and the potential uses to which such information may be put. Two emerging closely-related issues have created particular disquiet: genetic privacy and genetic discrimination; that is, the protection of individual genetic information and the differential treatment of individuals on the basis of actual or presumed genetic differences." - [CRG's Genetic Privacy Manual](#) [1]

As the Genetic Privacy Manual points out, there are huge potential benefits from genetic research, both to individuals and to the wider scope of medical science. But the innovative possibilities should not blind the industry to the very real risks to consumer rights that the technology poses. As markets for secondary uses for genetic information grow, consumers will have to stay very aware of how their genetic profiles are being acquired and shared.

Check out the [Council for Responsible Genetics' homepage](#) [2] for more information on how new genetic technologies and research may affect your rights.

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