



Biology & Society

Are Laws Protecting Genetic Privacy Necessary?

The rapid development of new tools and techniques to analyze DNA makes it possible to test for alleles related to thousands of medical conditions. In theory, the results of genetic testing should benefit everyone. Accurate genetic data helps physicians select the proper treatments for patients. It may allow people with genes that place them at risk of certain conditions to minimize those risks.

At issue, however, is individual privacy. Once a test is done, who has access to the data, and how can they use it? Could employers refuse to hire people who might drive up their medical costs? Might insurance companies refuse to renew the policies of individuals with genes for certain disorders? These are not hypothetical questions. In 2005, managers of a professional basketball team asked one of its players to be tested for a gene linked to heart ailments. When he refused, they traded the player to another team. Dr. Francis Collins, director of the National Human Genome Research Institute, worries that “the public is afraid of taking advantage of genetic testing.” Is he correct? Should genetic data be protected by law, or should it be open to public view?

The Viewpoints

Genetic Privacy Does Not Need Legal Protection

Other laws already protect individuals from discrimination on the basis of medical disability. Employers and insurance companies are nonetheless allowed to ask individuals if they smoke, use alcohol, or have a history of medical problems. Having this information allows employers to make intelligent choices about whom to hire. It also helps insurance companies maintain lower rates for their healthiest clients. Free access to genetic data should be a public right.



Many commercial laboratories test human DNA for genetic disorders.

Genetic Privacy Should Be Protected by Law

The Genetic Information Nondiscrimination Act (GINA) went into effect in 2009, and it provides important protections to personal privacy. Individuals may not take advantage of today’s advances in genetic medicine if they fear their personal information might be used to deny them employment or insurance. We need such laws to realize the full benefits of modern medicine and to protect otherwise healthy individuals from genetic discrimination.

Research and Decide

- 1. Analyze the Viewpoints** To make an informed decision, learn more about genetic testing by consulting library or Internet resources. Then, list the key arguments expressed by the proponents and critics of both points of view. Find out if laws preventing genetic discrimination have been proposed or passed in your state.
- 2. Form an Opinion** Should access and use of genetic data be regulated? Weigh both sides of the issue. Who will benefit from the sharing of genetic data? Will anyone suffer? Do some arguments outweigh others? If so, which ones? Explain your answers.