GENETIC INFORMATION DISCRIMINATION AND PROTECTIONS

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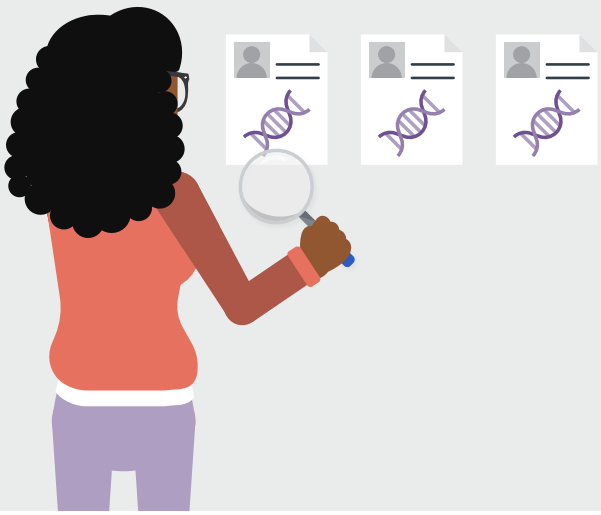
In the United States, there are several federal and state laws designed to protect individuals against their genetic information being used against them. It is important to understand what protections are in place and what areas are not yet regulated. As genetic testing becomes increasingly available, we expect to see news laws and regulations enacted in the coming years.

GINA (Genetic Information Non-Discrimination Act)

Genetic discrimination occurs when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder (Donald & Sanders, 2008; GINA,2008).

The Genetic Information Non-discrimination Act (GINA) is a federal law and **protects individuals in the United States from employment discrimination on the basis of their genetic data, but does not apply to life insurance, long-term care (LTC) insurance or disability insurance.** GINA also does not include protection for members of the U.S. military, Veterans Administration, Indian Health Service and federal employees (Donald & Sanders, 2008).

When ordered by a healthcare provider, or obtained through direct to consumer (DTC) testing and shared with the clinician as part of a medical history, genetic information may be added to a patient's electronic health record. It is common practice for insurance companies offering life, LTC or disability insurance to gain access to a customer's medical records as a condition of providing the insurance. In contrast to employers and health insurance providers, there is no federal US legislation prohibiting purveyors of life, LTC or disability insurance from using that genetic data in evaluating an application, whether to charge a higher rate or deny coverage outright (Tenenbaum & Goodman 2017).



GINA has two parts:

Title I - which prohibits genetic discrimination in **health insurance.**

Title II - which prohibits genetic discrimination in **employment.**

Title I

Title I makes it illegal for health insurance providers to use or require genetic information to make decisions about a person's insurance eligibility or coverage. This part of the law went into effect on May 21, 2009. Under GINA, genetic information is defined as "any individual, information about (i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual " (GINA, 2008).

This means that health insurance companies cannot use the results of a direct-to-consumer genetic test (or any other genetic test) to deny coverage or require you to pay higher premiums.

Title II

Title II makes it illegal for employers to use a person's genetic information when making decisions about hiring, promotion, and several other terms of employment. This part of the law went into effect on November 21, 2009. GINA asserts that people with genetic dispositions to disease must be given an equal opportunity to earn an income like anyone else. Under this law, it is also illegal to engage in workplace harassment or create a hostile work environment on the basis of an individual's genetic information (GINA, 2008).

However, GINA does not apply when an employer has fewer than 15 employees.

As mentioned, GINA does not apply to other forms of insurance, such as disability insurance, LTC insurance, or life insurance. Companies that offer these policies have the right to request medical information, including the results of any genetic testing, when making decisions about coverage and rates. Some of these companies request information about genetic testing as part of their application process, but others do not. It is unclear whether genetic information, including the results of DTC genetic testing, will become a standard part of the risk assessment that insurance companies undertake when making coverage decisions. Any information in your medical records is accessible by insurance companies when you apply for a policy and grant them access to your records (Song,2018). According to the American Council of Life Insurers (ACLI) if an insurer asks about genetic tests on a life insurance application it would only be interested in an at-home test if your results came back with a recommendation that you contact your doctor about a particular result. And even then, an insurer would want the result confirmed through a doctor-ordered genetic test. The type of genetic tests that insurers are interested in are those ordered by medical providers. Typically, genetic testing is done by doctors only when a patient has a family history of a disease or as a diagnostic tool, not just because someone wants to find out if he or she is predisposed to certain conditions (Klitzman, Appelbaum, Chung, 2014).

If you already have a life insurance policy, the results of any genetic tests you take won't affect your existing coverage. That means your insurer cannot drop you if you take a test that shows that, for example, you're predisposed to a certain type of cancer.

When applying for life insurance, genetic test results could even work in an individual's favor in some instances. The insurance company will ask about your family's medical history on the application for coverage. If you report on your application that, for example, your mother had breast cancer before the age of 50, your "mortality risk" would be considered higher. However, if you took a genetic test and the markers for breast cancer were negative, your family history may be forgiven (Huddleston & Danise, 2021).

Positive results from a genetic test can further work in your favor if you've taken steps to reduce the risk of developing disease. For example, if you're at risk of developing colon cancer and have had regular colonoscopies to find any sign of the disease early, the insurer may consider it positive that you're taking action. It could be a bigger strike against you if you hadn't taken any steps to stay on top of your health after receiving positive genetic test results (Huddleston & Danise, 2021; Song, 2018).

Relatively few genetic-related disorders have demonstrable importance for medical underwriting in life insurance because they must have the following six characteristics:

1. They must be **adult-onset.** A person having a disorder with childhood onset, such as type 1 diabetes, will be symptomatic by the time of a typical application for life insurance.

2. They must have a **high penetrance**, which means a significant likelihood that a gene variant will be expressed.

3. They must have a **high absolute risk**, meaning there is a substantial risk that an individual with a risk-conferring genotype will get the disorder.

4. They must have a **high relative risk**, meaning that individuals with the risk-conferring genotype are significantly more likely to express the particular condition than other individuals.

5. There must be a **high mortality rate for the condition** and a **lack of effective treatment**, especially if the disease is not detected early.

6. There must be a **lack of family history of the disorder**, because if there were a family history then genetic test results would be less valuable. The lack of family history for a life insurance applicant with a positive genetic test is most likely to occur when a young adult applies for life insurance before the applicant's parent, the carrier of an autosomal dominant allele, has begun to exhibit symptoms or the affected parent has died of other causes before reaching the age when the genetic-related condition would manifest.

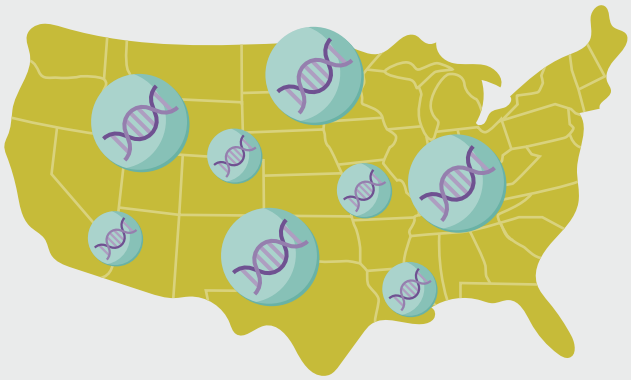
Individual states' laws

A number of individual states have passed their own laws regarding genetic discrimination, including Connecticut, Michigan, Ohio, California and Oregon (National Conference of State Legislatures, 2008; Parkma,2015).

California's GINA of 2011 (**CalGINA**) adds 'genetic information' to the list of protected classes for a number of different areas of law, including life and disability insurance. CalGINA prohibits genetic discrimination in emergency medical services, housing, mortgage lending, education, and other state funded programs (Wagner,2011; Singh,2019). **Oregon's law** covers LTC, disability and life insurance, referring generally to 'any policy of insurance' (Tenenbaum & Goodman 2017).

3X4 Genetics recommends you investigate your individual state's laws and protections for further information about how genetic testing may affect you in particular.

But there hasn't been much political momentum lately to expand GINA protection nationally. In the US, no federal legislation directly addresses use of genetic information by life insurers and state laws are variable: a few bar use of genetic test results (e.g., Vermont), others prohibit decisions based on genetic information regarding specific conditions (e.g., sickle-cell trait, in North Carolina)), and some merely require informed consent for genetic testing (e.g., New York) or that underwriting decisions reflect actual risk (e.g., Wisconsin). While some states have relatively robust protections, most have none (Klitzman, Appelbaum, Chung 2014).



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