Division of Legislative Services

ISSUE BRIEF

Genetic Privacy and Protection

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Overview

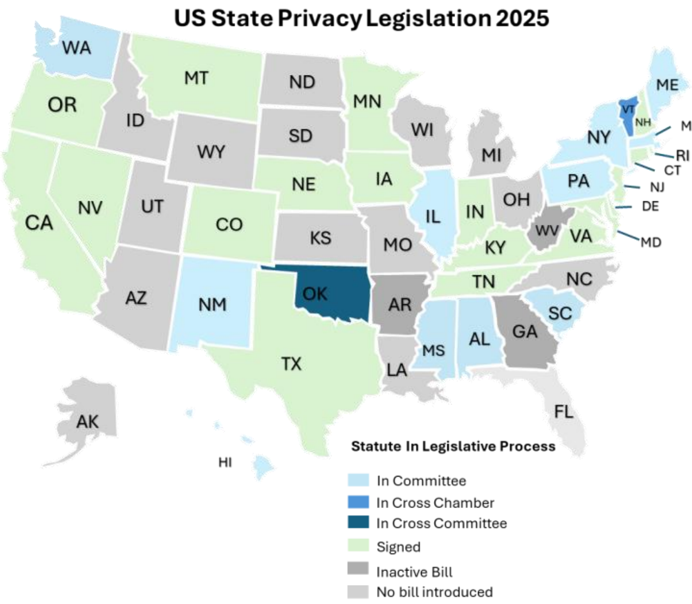
Genetic testing companies like Ancestry and 23andMe have become increasingly popular, with the genetic testing market projected to increase to $2 billion in 2025. Customers enjoy the convenience of an at-home DNA testing kit and the features an accompanying app brings to inform them of their genetics. However, the collection and storage of millions of genetic information and the absence of legal guidelines regulating the use of this information brings into question customer privacy and protection laws. Currently, the U.S. has no federal privacy law and only 20 states have their own privacy laws. More importantly, the state privacy laws often do not apply to direct-to-consumer genetic testing companies.

Federal laws exist to protect people from genetic discrimination under the Genetic Information Nondiscrimination Act (GINA) by prohibiting requiring genetic testing and placing restrictions on the collection of genetic information in some cases. However, GINA only applies to employers and health insurers; its reach does not extend to life insurance companies, direct-to-consumer genetic testing companies, or other non-health entities. GINA also does not "explicitly protect" epigenetic information. The legal limits of GINA and the absence of direct regulation of DNA testing companies has left millions of consumer genomic data vulnerable to breaches and undisclosed sale of their private information.

In 2024, a data breach left nearly 7 million 23andme customers vulnerable. In light of the breach, affected customers filed a class action lawsuit alleging illegal access and sale of personal, genetic, and ancestry information. 23andme settled for a $30 million payout to customers whose information was stolen. Six months later, the company filed for bankruptcy, continuing to leave user data at risk. On May 19th, biotechnology company Regeneron Pharmaceuticals announced it plans to buy 23andme. While the deal is pending, several state attorney generals (AGs) are warning their constituents to delete their data. North Carolina and Texas Attorney Generals have expressed their concern as DNA testing companies collect and store genetic information. This warning extends to relatives of users as well, as even a user's family member has cause to worry about their genetic privacy.

While Delaware has enacted legislation to protect genetic privacy in recent years, experts caution that genetic information privacy laws should not rely on consumers to "self-manage" their data privacy and instead should enact more robust, all-encompassing laws. For example, California has a genetic privacy law, a general data protection law, and a state version of the GINA law. Genetic privacy professor Anya Prince suggests other states follow suit to best protect their citizens.

Genetic Privacy Laws by State



Tennessee SB 1295. Requires genetic testing companies that are direct-to-consumer to obtain initial and separate express consent for use or disclosure of the consumer's genetic data. Companies must provide a process for the consumer to access, delete, and destroy their genetic data and biological sample, among other requirements.

Indiana HB 1521. Requires provider to disclose specified information to any individual who submits biological material for testing. Prohibits provider from taking specified actions regarding biological material or the resulting data.

Virginia SB 1087. Establishes requirements for direct-to-consumer genetic testing companies, including express consent requirements and prohibitions on disclosure of genetic data by direct-to-consumer companies.

Maryland HB 1007. Prohibits life and disability insurance carriers from discriminating against individuals and requires written consent before providing access to sensitive information or mandating genetic testing to access insurance coverage.

Recent Delaware Legislation

- **HB 286**, 152nd GA. Amends the Delaware Code to prohibit genetics-based discrimination (genetic characteristics, genetic information, or the result of any genetic test) in life insurance.
  - **HS 1 to HB 286.** Requires written consent of the individual before providing genetic information to a life insurance company.
- **HB 154**, 152nd GA. Delaware Personal Data Privacy Act. Establishes a consumer's personal data rights and applies to entities who controlled or processed the personal data of at least 35,000 consumers. Provides the Department of Justice with enforcement authority regarding the Act.
  - "Personal data rights" includes genetic and biometric data, citizenship status, religious beliefs

Current Events

- Two U.S. Senators introduced the Genomic Data Protection Act in December 2024. The Act draws inspiration from state privacy laws. It was referred to Committee and died there but has the potential to be re-introduced this session.
- The outcome of a court hearing and ombudsman report regarding Regeneron's plan to buy 23andme will be available by the end of June 2025.

Additional Resources

- An NCSL article regarding investigative genetic genealogy and state laws that address privacy and justice implications.
- This AP News article that details Regeneron Pharmaceuticals' potential buyout of 23andme.
- The Future for Privacy Forum identifies states that use its best practices for consumer genetic testing services.