
OLR Bill Analysis

sHB 5128

AN ACT CONCERNING DIRECT-TO-CONSUMER GENETIC TESTING.

SUMMARY

This bill gives consumers a property right and exclusive control over:

1. their biological samples (material from a person's body known to contain DNA including tissue, blood, urine, and saliva) that are given to or used by a direct-to-consumer genetic testing company and
2. results from genetic testing by these companies on their DNA.

This includes the right of control over the collection, use, retention, maintenance, disclosure, and destruction of a consumer's biological sample and results. The bill requires direct-to-consumer genetic testing companies to conduct their business and affairs consistent with these rights.

Additionally, the bill requires these companies to (1) disclose certain policies and procedures to consumers and (2) get a consumer's consent for various uses of their genetic data. The bill prohibits companies from disclosing the results of genetic testing on a consumer's DNA to anyone other than the consumer unless the consumer expressly consents to the disclosure, or it is disclosed to someone under a court order, warrant, or subpoena.

The bill also requires companies to have security procedures and certain processes to let consumers take certain actions.

Violations of the bill's provisions are deemed an unfair or deceptive trade practice under the Connecticut Unfair Trade Practices Act (CUTPA) (see BACKGROUND).

EFFECTIVE DATE: October 1, 2026

SCOPE OF THE BILL

Direct-to-Consumer Genetic Testing Companies

The bill applies to “direct-to-consumer genetic testing companies,” which are individuals or entities that, in the ordinary course of business in Connecticut, offer genetic testing directly to a consumer or collect, use, or analyze genetic data given by a consumer. The term does not include a licensed health care services provider who, within the provider’s scope of practice, orders genetic testing for a medical purpose.

Genetic Testing

The bill defines “genetic testing” as (1) a lab test of a person’s complete DNA sequence or a DNA region, chromosome, gene, or gene product to determine the presence or absence of a genetic characteristic and (2) an interpretation of genetic data.

Genetic Data

The bill applies to “genetic data,” which is data in any format about an individual’s genetic characteristics. It includes:

1. raw sequence data that results from sequencing all or part of a person’s DNA;
2. genotypic (a person’s unique sequence of DNA) or phenotypic (a person’s observable characteristics) information from analyzing raw sequence data; and
3. information that (a) is about a person’s health condition, (b) the person gives the company, or (c) the company analyzes related to raw sequence data and uses for scientific research or product development.

It does not include de-identified data, which is data that cannot reasonably be used to infer information about, or be linked to, an individual as long as the company that has the data (1) takes administrative and technical steps to make sure it cannot be associated

with an individual, (2) publicly commits to have and use it only in de-identified form and does not reidentify it, and (3) contractually obligates any recipient of the data to do the same.

POLICY DISCLOSURES

The bill requires companies to:

1. disclose their policies and procedures on the collection, use, and disclosure of genetic data before taking a consumer's biological sample, genetic data, or payment; and
2. prominently display a privacy notice on their websites with their policies and procedures on the collection, use, access, disclosure, transfer, security, retention, and deletion of a consumer's data and consent.

CONSENT REQUIREMENTS

Collecting, Using, or Disclosing Genetic Data

The bill requires companies to get a consumer's express consent to collect, use, or disclose the consumer's genetic data. Before doing so, companies must disclose to the consumer:

1. their policies and procedures on using consumers' genetic data they collect;
2. each person who may access the results of genetic testing they perform, including vendors or service providers; and
3. how the company may disclose the consumer's genetic data.

Express consent under the bill requires the consumer to affirmatively respond to a clear, meaningful, and prominent notice about collecting, using, retaining, or disclosing the consumer's genetic data for a specific purpose.

Transferring Genetic Data, Using It for Other Purposes, and Retaining Samples

The bill requires a company to get a separate express consent before:

1. disclosing or transferring genetic data to anyone other than a vendor or service provider,
2. using the genetic data for any purpose other than the primary purpose the company gave to the consumer, or
3. retaining a consumer's biological sample after completing genetic testing.

Research Purposes

The bill requires a company to get the consumer's informed consent in compliance with federal regulations on human subjects to disclose or transfer genetic data to a third party for research purposes or research done under the company's control for publication or generalized knowledge.

PROHIBITED DISCLOSURES

The bill prohibits a company from disclosing a consumer's genetic data to:

1. the consumer's employer;
2. someone who in the ordinary course of business offers health, life, or long-term care insurance or provides information to an insurer, health care center, or fraternal benefit society for underwriting or rating risks; or
3. a third party the company knows or reasonably should know intends to use it for marketing, including targeted advertising.

SECURITY AND COMPANY PROCEDURES

The bill requires companies to have reasonable security measures to protect consumers' biological samples and genetic data from unauthorized access, destruction, use, modification, or disclosure. It also requires companies to have procedures that allow consumers to:

1. access their genetic data;
2. require the company to delete their genetic data or destroy, and

confirm destruction of, their biological samples; and

3. revoke consent for using their genetic data for research, including by a third party.

BACKGROUND

Connecticut Unfair Trade Practices Act (CUTPA)

By law, CUTPA prohibits businesses from engaging in unfair and deceptive acts or practices. It allows the Department of Consumer Protection commissioner, under specified procedures, to issue regulations defining an unfair trade practice, investigate complaints, issue cease and desist orders, order restitution in cases involving less than \$10,000, impose civil penalties of up to \$5,000, enter into consent agreements, ask the attorney general to seek injunctive relief, and accept voluntary statements of compliance. It also allows individuals to sue. Courts may issue restraining orders; award actual and punitive damages, costs, and reasonable attorney's fees; and impose civil penalties of up to \$5,000 for willful violations and up to \$25,000 for a restraining order violation.

COMMITTEE ACTION

General Law Committee

Joint Favorable Substitute

Yea 20 Nay 0 (03/11/2026)