

## Direct-to-Consumer (DTC) Genetic Testing

The Genetics Policy Hub (GPH), a program of the National Coordinating Center for the Regional Genetics Networks, is a policy education website where you can explore state-based policies, ranging from Medicaid to policies being proposed by state governments to federal policies, ranging from proposed legislation to policy statements written by professional organizations. This policy overview highlights the data within GPH related to genetics privacy. This document is for informational purposes only, and specific questions about the information presented should be directed to the government agencies or organizations discussed. If you have questions about our methodology or feedback on what should be added to GPH, please get in touch with [geneticpolicy@nccrcg.org](mailto:geneticpolicy@nccrcg.org).

Direct-to-Consumer (DTC) genetic testing are tests that are ordered directly from the laboratory by the individual being tested, often without the input of a medical provider. These tests can be risk assessments (i.e., determines an individual's risk of developing disease, but cannot determine if the individual has the disease), diagnostic, or carrier testing (i.e., tries to determine the risk of having a baby with a specific disease). The level of support the genetic testing laboratory offers in helping the patient understand their results vary widely.

## Enacted and Proposed Legislation and Regulation

Updated Weekly

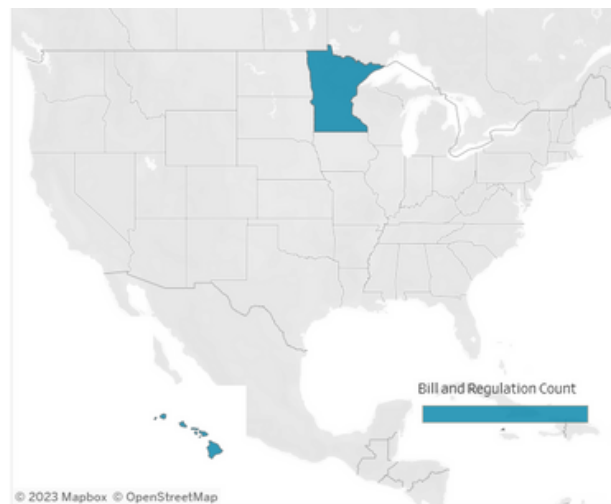
**3** pieces of legislation are enacted or proposed related to direct-to-consumer genetic testing.

The enacted legislation:

- TN HB 1310, TX HB 2545: requires direct-to-consumer genetic testing companies to obtain consent and provide information regarding the collection, use, and disclosure of the consumer's genetic data

The proposed legislation:

- MN SF 1138/MN HF 1520: would require direct-to-consumer genetic testing companies to provide disclosure notices and obtain consent




<https://geneticpolicy.nccrcg.org/legislative-policies/>

## Medicaid Policies

Updated Annually Each Fall

State Medicaid programs do not specifically state policies related to direct-to-consumer genetic testing. However, there may be broad policies protecting use of genetic data. Check your state's general Medicaid policies by visiting your program's website.

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Updated as needed

**8** Policy statements related to direct-to-consumer genetic testing from professional organizations

Professional organizations write policy statements to communicate what they believe is best for their community. Many professional organizations in the genetic system have written policy statements about direct-to-consumer genetic testing. These statements range from general policies on consumer protections to specific policies on how research should be conducted.

<https://geneticpolicy.nccrcg.org/policy-area/direct-to-consumer-testing/>