

Genetics Privacy

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.

Genetics privacy is the protection of genetic information from unauthorized disclosure to third parties, such as family members, employers, insurers, law enforcement, and the government. Genetic information can include DNA test results, biochemical tests, and diagnoses made from physical examinations or family histories.

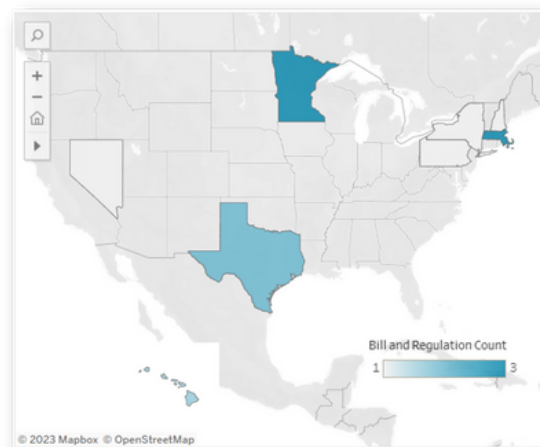
Proposed and Enacted Legislation and Regulation

Updated Weekly

28 Pieces of legislation and regulation are currently proposed and enacted related to genetics privacy.

The proposed legislative efforts include:

- the disclosure of information collected by genetic material testing entities (PA HB 812);
- the disclosure of individually identifiable health information of a newborn child obtained through newborn screening (HI SB 1471);
- limiting the purposes for which genetic testing may be conducted on DNA samples for newborn screening (NJ A 4642)



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

Medicaid Policies

Updated Annually Each Fall

State Medicaid programs do not specifically state policies related to genetics privacy. However, there may be broad policies protecting all consumer health data. Check your state's general Medicaid policies by visiting your program's website.



geneticpolicy.nccrcg.org



@geneticpolicy

Policy Statements

Updated as needed

23 Policy statements related to genetics privacy 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 genetic privacy. These statements range from general policies on consumer protections to specific policies on how research should be conducted.

<https://geneticpolicy.nccrcg.org/policy-area/genetic-privacy/>