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Updates on Developments in Data Privacy and Cybersecurity

Utah and South Dakota Enact Genetic Privacy Laws as Other States Advance Bills

By Libbie Canter, Elizabeth Brim & Clare Mathias on April 3, 2026

At the state level, genetic privacy remains a fast-moving topic, and states continue to introduce and advance bills regulating genetic data.

Several proposals that we covered in more detail earlier this year have progressed since our last update, including:

- **Utah** enacted **HB 182**, which regulates “foreign adversaries” access to genetic sequencing information. The final version of the bill delayed the effective date until January 1, 2028 (previously May 5, 2027) and added an exemption to the storage-related provisions for genetic sequencing data gathered as part of a clinical trial (i) from clinical trial subjects outside of the U.S. or (ii) when the storage, transfer, or remote access to the data is permitted under the DOJ Data Security Program.
- **South Dakota** enacted **SB 49**, which regulates the practices of direct-to-consumer (“DTC”) genetic testing companies. The law takes effect July 1, 2026.
- The **Wisconsin** legislature passed **AB 673**, which would regulate foreign adversaries access to genomic sequencing information. However, the Wisconsin governor **vetoed** the bill on March 27, 2026, **citing** potential unintended consequences that the bill may have on medical and research activities in Wisconsin, such as multi-institution or international research collaborations or industry partnerships.

Additionally, several states have proposed new bills, including:

- **West Virginia** introduced **HB 5034**, which is a multi-faceted bill that would regulate foreign adversaries' access to genetic data and also includes additional DTC-like provisions that would apply to entities that collect, use, or analyze genetic data.
 - The foreign adversary provisions would apply to medical facilities, research facilities, companies, entities, or nonprofit organizations and would prohibit the use of genome sequencers or software produced by certain companies based in, owned by, or controlled by a "foreign adversary," defined by **15 C.F.R. Section 791.4**. The bill would also prohibit these entities from storing genome sequencing data or providing access to it within the boundaries of a foreign adversary, except as part of a clinical trial or biomedical research study subject to or conducted in accordance with the DOJ Data Security Program. The bill would also prohibit the sale of genomic sequencing data in bankruptcy or reorganization to a foreign adversary or certain companies based in, owned by, or controlled by a foreign adversary. The bill would also require entities to annually certify compliance with the provisions of the bill to the state attorney general.
 - The DTC-like provisions would apply to entities that offer "consumer genetic testing products or services directly to a consumer" or that "collect[], use[], or analyze[] genetic data." The bill would prohibit the collection or processing of genomic information without a consumer's "express consent," and require separate express consent to transfer the data to a third party or use the data beyond the service's primary purpose. HB 5034 would grant consumers the right to access, delete, and direct the destruction of their genomic information and biological samples. Additionally, these provisions would (i) prohibit the storage of genetic data or biometric samples of West Virginia residents collected in the state within the territorial boundaries of any country sanctioned by the U.S. office of foreign asset control or designated as a foreign adversary and (ii) require consent of the resident to transfer or store such data outside of the U.S.
 - The bill contains exceptions for (i) "an entity when it is engaged only in collecting, using, or analyzing genetic data or biological samples in the context of research as defined in 45 CFR 164.501 conducted with the express consent of an individual and in accordance with" human subject research frameworks

and (ii) PHI that is collected by a covered entity or business associate “if separate informed consent related to the collection, use, and dissemination of genetic data is obtained and the [entity] follows the policies under this article.”

The bill does not contain an express exemption for de-identified data.

- The West Virginia Attorney General can bring enforcement actions under the bill, with damages of \$2,500 for each violation. HB 5034 also contains a private right of action.
- **Connecticut** introduced **HB 5128**, which would regulate DTC genetic testing companies. The Connecticut Attorney General specifically called for the legislature to enact such a law in its 2025 Connecticut Data Privacy Act **Enforcement Report**. The bill defines “direct-to-consumer genetic testing companies” as an entity that “offers genetic testing directly to a consumer” or that “collects, uses or analyzes genetic data that a consumer has provided.” The bill also establishes that a consumer has a property right in their biological sample and genetic test results derived from the consumer’s DNA. HB 5128 requires companies to disclose their genetic data handling practices to consumers and to obtain consumers’ “express consent” for genetic data collection, use, disclosure, and retention, along with secondary uses, third-party transfers, and post-testing sample retention. The bill would grant consumers the right to access, delete, require destruction, and revoke consent for their genetic data. The bill includes exceptions for disclosures pursuant to court order and for de-identified data, but does not include an exemption for research conducted in accordance with human subject research frameworks or for entities or data subject to HIPAA. Violations are deemed unfair or deceptive trade practices enforceable by the Connecticut Attorney General. The bill would take effect on October 1, 2026.
- **Rhode Island** introduced **H 7639**, which largely mirrors **S 2203**, which we summarized in our **last update**. Like S 2203, H 7639 regulates DTC genetic testing companies.
- **Illinois** introduced **SB 2994**, which would amend the Genetic Information Privacy Act to also regulate “neurotechnology.” The bill defines neurotechnology to include “devices capable of recording, interpreting, and altering the response of an

individual's central or peripheral nervous system to its internal or external environment." If enacted, Illinois would follow **several other states** in enacting protections for neural data and/or provisions to regulate neurotechnology. The amendment would take effect January 1, 2027.

- **California** introduced **AB 1727**, which would amend **California's genetic privacy law** to include criminal penalties. Specifically, the bill would make it a misdemeanor for a person to "willfully sell[] or transfer[] genetic data" without "express consent." The misdemeanor would be punishable by up to a year of imprisonment, a fine of up to \$1,000, or both. Currently, the statute assesses a civil penalty of up to \$1,000 for a negligent violation, and a civil penalty of between \$1,000 and \$10,000 for a willful violation, which this amendment would not change.

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