Within the past 3 years, 26 bills across 16 states were introduced to protect genetic privacy for direct-to-consumer genetic testing (Table). There were 11 states that adopted these bills, often with near-unanimous bipartisan support. Many of the bills carry a broad, sweeping title full of promise—the Genetic Information Privacy Act. However, the public should not be fooled. Even though the bills do offer sensible and important protections, they miss the mark at fully addressing many genetic privacy concerns held by the public and many in the medical and research fields. There are, however, some glimmers of hope that should serve as models for future efforts.

Privacy for Genetic Data
With entrenched public concerns about the privacy of genetic data, it is no wonder that legislators are taking up this important issue. But why now? Much of the current legislative effort is driven by a model law developed by the Coalition for Genetic Data Protection. The Coalition’s membership includes just 2 companies, 23andMe and Ancestry. Given that the Coalition is proposing regulation for its own industry, it is not surprising that these laws do not provide protections that fully address public concerns.

The contours of the model law are based on a 2018 report by the Future of Privacy Forum, an advisory partner of the Coalition. The model law seeks to codify legal principles including transparency, consent, and security for consumer genetic testing services. Thus, a key component of the model law framework is to bolster rules regarding consumer consent. Under the model act, companies must provide clear notices of their privacy practices that are written in plain language, and must obtain express consent from consumers for numerous practices, including the collection, sharing, and continued storage of their genomic data, as well as other activities, such as marketing. Consumers must be able to revoke their consent and have their biospecimens destroyed. Companies also are required to establish strong security protections to minimize risk of unintended disclosure.

The model law also narrowly constrains 2 types of disclosures. First, the legislation requires companies to establish “valid legal processes” for sharing consumer data to law enforcement without express consent. However, the term valid legal process is not defined in the model law. Second, the model legislation states that direct-to-consumer companies cannot disclose genetic information to life, long-term care, or disability insurers without the consumer’s consent.

Although these changes may seem transformative, they miss the mark on robust protections. Having transparent privacy practices and seeking robust consent for the sharing of data are clearly an unalloyed good. However, the paradigm of consumer education and consent rests on notions of privacy self-management in that consumers are expected to understand (through company disclosures) how their data are collected and shared and then make informed choices about whether to participate in the service. Yet it is well-known that people rarely read privacy notifications, meaning that any consent to privacy practices they provide is not truly informed. For example, a recent study found that only 44% of people were aware that a company’s privacy policy can allow sharing of personal data. Misunderstandings of health data protections are even worse. Only 18% of people were aware that health-related apps are not barred from selling collected data to third parties.

The enacted legislation does not robustly address the fact that third parties, particularly law enforcement and insurers, can still access and use consumer genetic data.

Disclosure of Direct-to-Consumer Genetic Data to Third Parties
In addition, the model statute does not go far enough in its regulation of disclosures. Past practices of direct-to-consumer companies sharing data with law enforcement for criminal investigations and familial searches prompted concern among the public. The model act would seemingly curtail this practice through its requirement of a valid legal process. Although the term valid legal process was not defined in the model law, it could perhaps require a warrant or court order before the sharing of information can occur. However, it does nothing to directly regulate when and how law enforcement can access consumer data.

For example, in one well-known example, law enforcement partners signed into databases as ordinary consumers to gain access to genetic data. Thus, by focusing only on the actions of the direct-to-consumer companies and not law enforcement itself, the model law only goes so far toward protecting consumer privacy. For state legislatures truly interested in bolstering privacy...
protections, a recently passed Maryland law offers a more robust model. Key elements of Maryland's law include judicial supervision of use of genealogy testing for forensic purposes, affirmative consumer consent for use of data, and protections for third parties believed to be related to a suspect.

The insurance regulations in the model law also fall short. Under the Genetic Information Nondiscrimination Act, federal law prohibits genetic discrimination by health insurers and employers, but does not cover other insurers. For this reason, the model law seeks to ostensibly bolster consumer privacy by prohibiting direct-to-consumer companies from disclosing consumer genetic information to life, long-term care, or disability insurers unless they have consumer consent. This provision is likely an attempt to quell fears of genetic discrimination. However, this feeble attempt to address the gap in the federal Genetic Information Nondiscrimination Act will do little to nothing to truly protect consumers because it does nothing to stop insurers from requiring consumers to consent to sharing in order to obtain insurance or from requiring consumers to directly share relevant genetic test results.

Similar to the law enforcement example, there are more robust models available. In 2020, Florida became the first state to ban life, long-term care, and disability insurers from discriminating on the basis of genetic information. Yet, Florida is just the tip of the iceberg. Since 2021, there have been 29 bills introduced across 16 states that relate to genetics and insurance underwriting (Table). The proposed bills often get strong pushback from the life insurance industry and only a handful are enacted. Those bills that do pass rarely fully ban underwriting on the basis of genetic testing. Florida’s law, however, provides a model for states wishing to provide stronger protections for consumers.

**Conclusion**

Although a groundswell of states passing a Genetic Information Privacy Act seems like a consumer win, the sweeping name should not obscure the fact that most of the laws passed at the state level only add minimal protections focused on consumer consent, transparency, and internal data handling. The enacted legislation does not robustly address the fact that third parties, particularly law enforcement and insurers, can still access and use consumer genetic data.

Most notably, Ancestry and 23andMe have stated that the model law protections align with their current data practices. Even though the bills may help improve privacy practices for smaller direct-to-consumer companies, these new protections are unlikely to move the needle on increased privacy protections because the largest industry players are already complying. More can and should be done.

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**ARTICLE INFORMATION**

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**Table. State Legislative Trends Regarding Genetic Privacy for Direct-to-Consumer Genetic Testing and Genetic Antidiscrimination for Insurance**

<table>
<thead>
<tr>
<th>Legislative activity</th>
<th>Year range</th>
<th>No. of states</th>
<th>State</th>
<th>Genetic privacy for direct-to-consumer genetic testing</th>
<th>Genetic antidiscrimination for insurancea</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2021-2023</td>
<td>16</td>
<td>Arizona, California, Hawaii, Kentucky, Maryland, Minnesota, Montana, Nebraska, Pennsylvania, South Dakota, Texas, Utah, Vermont, Virginia, West Virginia, Wyoming</td>
<td>16</td>
<td>Connecticut, Florida, Georgia, Illinois, Indiana, Louisiana, Maine, Maryland, Michigan, New York, North Carolina, Pennsylvania, South Carolina, Tennessee, Texas, Vermont</td>
</tr>
<tr>
<td>Enacted legislation</td>
<td>2021-2023</td>
<td>11</td>
<td>Arizona, California, Kentucky, Maryland, Minnesota, Montana, South Dakota, Texas, Utah, Virginia, Wyoming</td>
<td>3</td>
<td>Connecticut, Louisiana, Tennessee</td>
</tr>
</tbody>
</table>

a Types of insurance could include life, health, long-term care, and disability.

b This was the first state to ban life, long-term care, and disability insurers from discriminating on the basis of genetic information in 2020.

c There is variability in the specific provisions and protections.