



consumer action



September 4, 2020

The Honorable Gavin Newsom
California State Capitol, Suite 1173
Sacramento, California 95814

Re: SB 980 (Umberg)
REQUEST FOR SIGNATURE

Dear Governor Newsom:

We write to respectfully request your signature on SB 980 (Umberg) which would strengthen privacy protections for highly sensitive genetic information collected by direct-to-consumer (DTC) genetic testing companies like 23andme and AncestryDNA.

This bill would enact basic rules for consumer protection by requiring that companies provide information regarding the company's policies and procedures, and obtaining a consumer's consent for the collection, use, and disclosure of the consumer's genetic data.

Genetic data is especially intimate because it is a unique and immutable personal identifier, potentially contains medical information, and has implications not only for the individual but for the individual's relatives who have not chosen to take these tests. All results from genetic testing should be private by default, yet DTC companies currently can and do use consumer data for purposes other than providing results to consumers – including company-sponsored research, and selling consumer data to third parties without consumer knowledge or consent. SB 980 would put sensible safeguards around this highly private data to ensure consumers have control over their genetic information.

Neither state nor federal law adequately protect Californians in the rapidly changing market of at-home healthcare solutions, testing, and products. No federal law directly addresses consumer privacy issues resulting from DTC genetic testing. While the California Consumer Privacy Act gives consumers a limited opportunity to request to opt out of the future sale of this information, DTC genetic testing companies by default can legally sell this very sensitive information to third parties unless each individual consumer is aware of and takes the unnecessarily cumbersome steps to limit this sharing – assuming the consumer can find out who has received their genetic information from the DTC company. Even these steps do not affect the personal information that has already been sold, and nothing prevents sharing of information that occurs without a formal "sale." SB 980 will ensure that sensitive genetic information remains confidential by default and appropriately limits the ways in which companies can use this information.

Inappropriate use of this highly sensitive data can deeply affect consumers. Genomic data can be used to uniquely identify an individual and never expires, making it impossible for consumers to fully undo inappropriate sharing of this information as they might do for other personal information. The highly distinguishable and stable aspects of genetic information also make it incredibly valuable to marketers, data brokers, and insurers. Access to long-term care insurance, for example, can be impacted by the results of genetic testing. SB 980 would ensure that Californians have better control over who has access to their sensitive genetic information, including ensuring that people and companies administering insurance may not access DTC genetic testing results.

Equally important, DTC companies would not be allowed to employ user interfaces that make it difficult for users to make choices that protect the privacy of their genetic data, otherwise known as “dark patterns.” Dark patterns are user interface design choices that benefit an online service by coercing, steering, or deceiving users into making unintended and potentially harmful decisions.¹ Because they mislead users into making choices that are not in their interest, and deprive them of their agency, dark patterns are generally considered unethical.² Sites often make it much easier to agree to a potential transaction than to say no, relying on consumers’ limited attention span and the habit of clicking “OK.” In response to Europe’s recent GDPR privacy law, many websites force users through confusing consent dialogs³ to ostensibly obtain consent to share and collect data for any number of undisclosed purposes. A 2019 Princeton University study of 11,000 shopping sites found more than 1,800 examples of dark patterns, many of which clearly crossed the line into illegal deception.⁴

SB 980 relies on accepted standards for the treatment of dark patterns. The bill’s definition of dark patterns, for example, closely mirrors language in the bipartisan DETOUR Act in Congress that makes it unlawful for a large online operator to “design, modify, or manipulate a user interface with the purpose or substantial effect of obscuring, subverting, or impairing user autonomy, decision-making, or choice to obtain consent or user data.”⁵

While the exploitation of dark patterns is not limited to DTC genetic testing, it is important to address it in this context because genetic data is so sensitive and has implications not only for the consumer but also their blood relatives. By explicitly prohibiting the use of “dark patterns” to obtain consent, SB 980 protects against inappropriate manipulation of consumer choice that could result in the consumer’s unintended exposure of their genetic data, test results or other sensitive personal information. By including an explicit prohibition against dark pattern use by DTCs, SB

¹ <https://arxiv.org/pdf/1907.07032.pdf>.

² <https://fil.forbrukerradet.no/wp-content/uploads/2018/06/2018-06-27-deceived-by-design-final.pdf>.

³ <https://www.forbrukerradet.no/side/facebook-and-google-manipulate-users-into-sharing-personal-data/>.

⁴ <https://arxiv.org/pdf/1907.07032.pdf>.

⁵ <https://www.congress.gov/bill/116th-congress/senate-bill/1084/text>.

980 ensures that consumers have real choice about whether to share their genetic data.

The bill has only negligible state costs; it does not allow for a private right of action, ensuring that litigation will be extremely limited, nor does it require the Attorney General or any other public prosecutor to develop regulations or to institute any enforcement action. If any discretionary compliance efforts are undertaken because DTC companies choose to flout the law, the bill provides for recovery of any public costs of prosecution.

By curbing unauthorized disclosure and secondary uses of this highly sensitive data and ensuring genetic information cannot be used inappropriately, this bill would provide common-sense privacy protections to consumers. For these reasons, we respectfully request your signature on SB 980.

Sincerely,

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cc: Senator Tom Umberg