



March 25, 2020

The Honorable Hannah-Beth Jackson
California Senate Judiciary Committee
State Capitol
Room 2187
Sacramento, CA 95814

Re: SB 980 (Umberg, Privacy: DNA testing companies)—Support

Dear Senator Jackson,

Consumer Reports¹ writes in support of SB 980. For over 80 years, Consumer Reports has worked with consumers for truth, transparency, and fairness in the marketplace. We are strong proponents of public policy that bolsters consumers' privacy and their individual right to choose who accesses their data and for what purposes. It is within this framework that we support this bill, because it would strengthen privacy protections to uniquely sensitive personal information collected by direct-to-consumer (DTC) genetic testing companies. This bill will ensure that genetic information remains confidential by providing detailed requirements to allow for authorization to disclose the information to specific recipients, and appropriately limits the ways in which companies can use this information.

With increasing developments of at-home healthcare solutions, testing, and products, it is important to ensure that our laws protect consumers in the rapidly changing market. Currently, no federal law directly addresses consumer privacy issues resulting from DTC genetic testing. While the California Consumer Privacy Act gives consumers the right to opt out of the sale of this information, this protection kicks in only after the consumer takes action. As a result, by default, DTC genetic testing companies can do whatever they want with consumers' most personal information.

¹ Consumer Reports is an independent, nonprofit membership organization that works side by side with consumers to create a fairer, safer, and healthier world. For over 80 years, CR has provided evidence-based product testing and ratings, rigorous research, hard-hitting investigative journalism, public education, and steadfast policy action on behalf of consumers' interests. Unconstrained by advertising, CR has exposed landmark public health and safety issues and strives to be a catalyst for pro-consumer changes in the marketplace. From championing responsible auto safety standards, to winning food and water protections, to enhancing healthcare quality, to fighting back against predatory lenders in the financial markets, Consumer Reports has always been on the front lines, raising the voices of consumers.

Inappropriate use of this highly sensitive data can deeply affect consumers. For example, access to life, disability, and long-term care insurance can be impacted by the results of genetic testing.² Genetic information gathered by DTC genetic companies can be shared with or sold to third parties, with no disclosure to the consumer. Further, in a survey of DTC genetic testing companies, 71% percent of companies could use consumer information internally for purposes other than providing the results to consumers.³ By curbing unauthorized disclosure and curbing secondary uses of this sensitive data, this bill would extend important privacy protections to consumers. We urge your support.

Respectfully submitted,



Maureen Mahoney
Policy Analyst
Consumer Reports

Cc: The Honorable Thomas Umberg
Members, Senate Judiciary Committee
Christian Kurpiewski, Committee Counsel

² Catherine Roberts, *Should You Give the Gift of a Genetic Testing Kit?*, CONSUMER REPORTS (Dec. 16, 2019), <https://www.consumerreports.org/genetic-testing/should-you-give-the-gift-of-a-genetic-testing-kit/>.

³ James W. Hazel and Christopher Slobogin, *Who Knows What, and When: A Survey of the Privacy Policies Proffered by U.S. Direct-to-Consumer Genetic Testing Companies*, 28 CORNELL J.L. & PUB POL'Y at 52 (2018).