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September 17, 2021

The Honorable Gavin Newsom
Governor, State of California
1303 10th Street, Suite 1173
Sacramento, CA 95814

Signature Requested: SB 41 (Umberg), Privacy: genetic testing companies

Dear Governor Newsom,

The undersigned consumer and privacy groups respectfully request your signature on SB 41. We are strong proponents of public policy that bolsters consumers' privacy and their control over who accesses their data and for what purposes. It is within this framework that we support this bill, which will strengthen privacy protections for uniquely sensitive personal information collected by direct-to-consumer (DTC) genetic testing companies. This bill will ensure that genetic information remains confidential by requiring consent before disclosure of this information to third parties and limiting the ways in which companies can use this information without customer consent.

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. About one in five US consumers has taken a DTC genetic test,

many of whom likely assume that their data is covered by strong health privacy protections.¹ Genetic testing *in a healthcare setting* is covered by the Health Insurance Portability and Accountability Act (HIPAA)² and the Confidentiality of Medical Information Act (CMIA), both of which prohibit most disclosure of covered data without consent. But currently, no federal law directly addresses consumer privacy issues resulting from *direct-to-consumer* genetic testing, nor does CMIA.³ While the California Consumer Privacy Act gives consumers the right to opt out of the sale of this information,⁴ this protection kicks in only after consumers know they have the right to stop this sharing and take action.⁵ By default, DTC genetic testing companies can share this sensitive information with third parties. And unlike passwords, which can be changed if shared, a person's genetic information cannot be altered and therefore the sharing cannot be undone.

Importantly, the bill has a strong definition of consent, including a clear prohibition on deceptive interfaces known as “dark patterns,” to make sure that consumers have a meaningful choice over how their data is used. Subverting consumer intent online has become a real problem, and it's important to address, particularly since genetic data is so sensitive. 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 forced users through confusing consent dialogs to ostensibly obtain consent to share and collect data for any

¹ Catherine Roberts, *Read This Before You Buy A Genetic Testing Kit*, CONSUMER REPORTS (Feb. 2, 2021), <https://www.consumerreports.org/genetic-testing/genetic-testing-kit-read-this-before-you-buy/>.

² Although consumers may rely on HIPAA to protect their health privacy, the results of DTC genetic testing are rarely protected under HIPAA because they must be maintained by a healthcare provider, health plan, or healthcare data clearinghouse. See 45 C.F.R § 160.103, 45 C.F.R § 164.501.

³ Cal. Civ. Code § 56.05(j). Medical information is defined as “any individually identifiable information, in electronic or physical form, in possession of or derived from a provider of health care, health care service plan, pharmaceutical company, or contractor regarding a patient's medical history, mental or physical condition, or treatment.” Therefore, results of a DTC genetic test are not protected by CMIA.

⁴ Cal. Civ. Code § 1798.140(o)(1).

⁵ Cal. Civ. Code § 1798.120(a). For more information about relevant federal and state privacy laws with respect to these companies, please see *Direct-to-Consumer Genetic Testing: The Law Must Protect Consumers' Genetic Privacy*, CONSUMER REPORTS, Appendix (July 2020), <https://advocacy.consumerreports.org/wp-content/uploads/2020/07/DTC-Genetic-Testing-White-Paper-4.pdf>.

number of undisclosed purposes.⁶ And researchers increasingly have been paying attention to manipulative dark patterns as well. 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.⁷

The bill also requires DTC genetic testing companies to keep sensitive genetic information secure from unauthorized access, which is particularly important in light of security breaches at genetic testing companies in recent years,⁸ including a recent security breach involving customer genetic data at GEDMatch in July of last year.⁹ DNA data is not currently covered by California's data security requirement.¹⁰ Although Section 5 of the Federal Trade Commission Act requires some level of data protection,¹¹ such protection is unclear and underenforced.

Inappropriate use of this highly sensitive data can deeply affect consumers. Aside from consumers' inherent interest in keeping this information private, access to long-term care insurance can be impacted by the results of genetic testing, for example.¹² Further, in a survey of DTC genetic testing companies, 71% percent of companies' privacy policies allow consumer information to be used internally for purposes other than providing the results to consumers.¹³ Not

⁶ *Deceived by Design: How Tech Companies Use Dark Patterns to Discourage Us from Exercising Our Rights to Privacy*, NORWEGIAN CONSUMER COUNCIL (Jun. 27, 2018), <https://fil.forbrukerradet.no/wp-content/uploads/2018/06/2018-06-27-deceived-by-design-final.pdf>.

⁷ Mathur, Arunesh and Acar, Gunes and Friedman, Michael and Lucherini, Elena and Mayer, Jonathan and Chetty, Marshini and Narayanan, Arvind, *Dark Patterns at Scale: Findings from a Crawl of 11K Shopping Websites*, PROC. ACM HUM.-COMPUT. INTERACT. (2019), <https://webtransparency.cs.princeton.edu/dark-patterns/>.

⁸ Makena Kelly, *MyHeritage Breach Leaks Millions of Account Details*, THE VERGE (June 5, 2018), <https://www.theverge.com/2018/6/5/17430146/dna-myheritage-ancestry-accounts-compromised-hack-breach>; Zach Whittaker, *DNA Testing Site Veritas Genetics Confirms Data Breach*, TechCrunch (Nov. 7, 2019), <https://techcrunch.com/2019/11/07/veritas-genetics-data-breach/>.

⁹ Zach Whittaker, *GEDMatch Confirms Data Breach After Users' Profile Data Made Available to Police*, TECHCRUNCH (July 22, 2020), <https://techcrunch.com/2020/07/22/gedmatch-investigating-dna-profile-law-enforcement/>.

¹⁰ Cal. Civ. Code § 1798.81.5.

¹¹ 15 U.S.C § 45.

¹² Cal. Ins. Code § 10233.2. Under the prohibited provisions governing long-term insurance, prohibiting the use of genetic information is not mentioned, and neither genetic testing nor genetic information is referenced.

¹³ 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

surprisingly, consumers strongly value protections over this data: over 60,000 consumers have signed a national petition calling on lawmakers to ensure that this data is kept private and secure.¹⁴

The bill includes important provisions to ensure the provisions will not impact public health efforts to track disease outbreaks. While the Department of Public Health has raised late concerns that the bill could potentially interfere with their ability to request samples from consumers to track hypothetical future diseases in the community, the exemption in the bill for “Tests conducted exclusively to diagnose whether an individual has a specific disease”—language that was carefully worked out with stakeholders, including the Department of Public Health, over the past year—fully accommodates this public health tracking. If concerns remain, adjustments can be made in a budget or omnibus bill next year to address this hypothetical situation. The bill’s very real protections should not be torpedoed this year with a veto of the bill, particularly in light of the path forward for enacting a simple fix next year if the language already in the bill proves inadequate.

This bill would extend important privacy protections to consumers. We urge you to sign this bill to ensure that consumers have the privacy protections that they deserve.

Respectfully submitted,

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Emory Roane, Policy Counsel, Privacy Rights Clearinghouse

CORNELL J. L. & PUB. POL’Y 35 at 52 (2018).

¹⁴ Consumer Reports, Protect your DNA! (last visited Sept. 17, 2021), <https://action.consumerreports.org/privacy20200722petition?INTKEY=IA207CP>

cc: The Honorable Thomas J. Umberg
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