



March 3, 2021

The Honorable Thomas J. Umberg, Chair
California Senate Judiciary Committee
State Capitol, Room 2187
Sacramento, CA 95814

Re: SB 41 (Umberg), Privacy: genetic testing companies

Dear Chair Umberg,

Consumer Reports¹ writes in support of SB 41. 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 control over who accesses their data and for what purposes. It is within this framework that we support this bill, because it would strengthen privacy protections for uniquely sensitive personal information collected by direct-to-consumer (DTC) genetic testing companies. This bill will help ensure that genetic information remains confidential by requiring consent before disclosure of this information to third parties, and by limiting 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. 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.² Genetic testing *in a healthcare setting* is covered

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.

² 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/>.

by the Health Insurance Portability and Accountability Act (HIPAA)³ 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.⁴ While the California Consumer Privacy Act gives consumers the right to opt out of the sale of this information,⁵ this protection kicks in only after the consumer takes action.⁶ As a result, by default, DTC genetic testing companies could legally share this information with third parties.

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 number of undisclosed purposes.⁷ 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.⁸

Use of these dark patterns is already illegal under Unfair and Deceptive Acts and Practices (UDAP) law, but that hasn't been adequate to protect consumers from these deceptive interfaces. For example, last year, the Federal Trade Commission (FTC) sued Age of Learning, an online education service for children, for its deceptive interface that led consumers to believe they were signing up for one year of service, when in fact, by default, they were charged each year.⁹

³ Although consumers may rely on HIPAA to protect their health privacy, the results of DTC genetic testing is rarely protected under HIPAA because it 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.

⁴ 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 the CMIA.

⁵ Cal. Civ. Code § 1798.140(o)(1).

⁶ 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>.

⁷ *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>.

⁸ Mathur et al., *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/>.

⁹ Fed. Trade Comm'n v. Age of Learning, Inc., Complaint for Permanent Injunction and Other Equitable Relief, Case No. 2:20-cv-7996. U.S. District Court Central District of California at 4-6 (Sept. 1, 2020),

Attorney General Karl Racine of the District of Columbia filed suit against Instacart for using a deceptive interface that made a service fee look like a tip.¹⁰ In 2019, the FTC alleged that Match.com tricked consumers into subscribing by sending them misleading advertisements that claimed that someone wanted to date them—even though many of those communications were from fake profiles.¹¹ Similarly, in late 2016, the FTC took action against Ashley Madison for using fake profiles to trick consumers into upgrading their membership.¹² The FTC filed suit against Facebook in 2011 for forcing consumers to use a deceptive interface to get them to provide so-called “consent” to share more data.¹³ Despite these enforcement actions, the use of dark patterns remains all too common. Given how widespread these interfaces are, it’s important to explicitly clarify that they are illegal, and expand the AG’s authority to act.

The bill also requires DTC genetic testing companies to keep genetic information secure from unauthorized access, which is particularly important in light of security breaches at genetic testing companies in recent years,¹⁴ including a recent security breach involving customer genetic data at GEDMatch in July of last year.¹⁵ DNA data is not currently covered by California’s data security requirement.¹⁶ Although Section 5 of the Federal Trade Commission Act requires some level of data protection, such protection is unclear and underenforced.¹⁷

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

<https://www.ftc.gov/system/files/documents/cases/1723086abcmousecomplaint.pdf>. According to the FTC, this is a UDAP violation, *See* ¶ 57.

¹⁰ District of Columbia v. Mapbear, Inc. d/b/a Instacart, Complaint for Violations of the Consumer Protection Procedures Act and Sales Tax Law, Superior Court of the District of Columbia at ¶ 2 (Aug. 2020), <https://oag.dc.gov/sites/default/files/2020-08/Instacart-Complaint.pdf>. The AG alleged that “Instacart’s misrepresentations and omissions regarding its service fee constitute deceptive and unfair trade practices that violated D.C. Code § 28-3904.” *See* ¶ 86.

¹¹ Fed. Trade Comm’n v. Match Group, Inc., Complaint for Permanent Injunction, Civil Penalties, and Other Relief, Case No. 3:19-cv-02281, U.S. District Court, Northern District of Texas, Dallas Division at 2 (Sept. 25, 2019), https://www.ftc.gov/system/files/documents/cases/match_-_complaint.pdf. According to the FTC, this is a Section 5 violation. *See* p. 20-21.

¹² Fed. Trade Comm’n v. Ruby Corp. et al, Complaint for Permanent Injunction and Other Equitable Relief, Case 1:16-cv-02438, United States Circuit Court for the District of Columbia at 6 (Dec. 14, 2016), (<https://www.ftc.gov/system/files/documents/cases/161214ashleymadisoncmplt1.pdf>). According to the FTC, this is a Section 5 violation. *See* p. 13-14.

¹³ Fed. Trade Comm’n, In the Matter of Facebook Inc. at 5-6 (2011) <https://www.ftc.gov/sites/default/files/documents/cases/2011/11/111129facebookcmpt.pdf>. According to the FTC, this is a Section 5 violation. *See* p. 19.

¹⁴ 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/>.

¹⁵ 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/>.

¹⁶ Cal. Civ. Code § 1798.81.5.

¹⁷ 15 U.S.C § 45.

insurance can be impacted by the results of genetic testing.¹⁸ 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, including to develop new products and services.¹⁹ Not surprisingly, consumers strongly value protections over this data: over 60,000 consumers have signed our national petition calling on lawmakers to ensure that this data is kept private and secure.²⁰

This bill would extend important privacy protections to consumers, and we thank you for your leadership in pursuing this important legislation. As the bill continues to move through the legislative process, we encourage you to tighten the exemption for companies with state public health testing contracts so that they are prevented from engaging in secondary use and disclosure of this information. We look forward to working with you to ensure that consumers have the strongest possible privacy protections with respect to this data.

Sincerely,

Maureen Mahoney
Senior Policy Analyst
Consumer Reports

cc: Members, California Senate Judiciary Committee

¹⁸ 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.

¹⁹ 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 35 at 52 (2018).

²⁰ Consumer Reports, Protect your DNA! (last visited March 3, 2021), <https://action.consumerreports.org/privacy20200722petition?INTKEY=IA207CP>