

H.639

Introduced by Representatives Scheu of Middlebury, Arsenault of Williston,

Birong of Vergennes, Bishop of Colchester, Bluemle of

Burlington, Cina of Burlington, Dodge of Essex, Greer of

Bennington, Gregoire of Fairfield, Holcombe of Norwich,

Howard of Rutland City, James of Manchester, Kleppner of

Burlington, Masland of Thetford, McCann of Montpelier,

McGill of Bridport, Morrow of Weston, Mrowicki of Putney,

Noyes of Wolcott, Ode of Burlington, Page of Newport City,

Pouech of Hinesburg, Priestley of Bradford, Rachelson of

Burlington, Satcowitz of Randolph, Stevens of Waterbury,

Sweeney of Shelburne, and Tomlinson of Winooski

Referred to Committee on

Date:

Subject: Commerce and trade; consumer protection; genetic data privacy

Statement of purpose of bill as introduced: This bill proposes to require direct-

to-consumer genetic testing companies and related providers to protect the

genetic data information of Vermonters. The bill requires companies to limit

data sharing, allows consumers to access their own data, and otherwise

provides other genetic data privacy protections to consumers.

1 An act relating to genetic data privacy

2 It is hereby enacted by the General Assembly of the State of Vermont:

3 Sec. 1. 9 V.S.A. chapter 61A is added to read:

4 CHAPTER 61A. DATA PRIVACY

5 Subchapter 1. Genetic Information Privacy

6 § 2411. SHORT TITLE AND DEFINITIONS

7 (a) This subchapter shall be known, and may be cited, as the “Genetic
8 Information Privacy Act.”

9 (b) As used in this subchapter:

10 (1) “Affirmative authorization” means an action that demonstrates an
11 intentional decision by a consumer.

12 (2) “Biological sample” means any material part of the human,
13 discharge therefrom, or derivative thereof, such as tissue, blood, urine, or
14 saliva, known to contain deoxyribonucleic acid (DNA).

15 (3) “Consumer” means an individual who is a Vermont resident.

16 (4) “Dark pattern” means a user interface designed or manipulated with
17 the substantial effect of subverting or impairing user autonomy, decision
18 making, or choice.

19 (5) “Direct-to-consumer genetic testing company” means an entity that:

20 (A) sells, markets, interprets, or otherwise offers consumer-initiated
21 genetic testing products or services directly to consumers;

1 (B) analyzes genetic data obtained from a consumer, except to the
2 extent that the analysis is performed by a person licensed in the healing arts for
3 diagnosis or treatment of a medical condition; or

4 (C) collects, uses, maintains, or discloses genetic data that is:

5 (i) collected or derived from a direct-to-consumer genetic testing
6 product or service; or

7 (ii) directly provided by a consumer.

8 (6) “Disclose,” “disclosing,” or “disclosure” means to solicit, sell,
9 assign, transfer, give, provide, or trade, whether or not for valuable
10 consideration.

11 (7) “Express consent” means a consumer’s affirmative authorization to
12 grant permission in response to a clear, meaningful, and prominent notice
13 regarding the collection, use, maintenance, or disclosure of genetic data for a
14 specific purpose. Express consent cannot be inferred from inaction.
15 Agreement obtained through the use of dark patterns does not constitute
16 express consent.

17 (8)(A) “Genetic data” means any data, regardless of its format, that
18 results from the analysis of a biological sample from a consumer, or from
19 another element enabling equivalent information to be obtained, and concerns
20 genetic material. Genetic material includes deoxyribonucleic acids (DNA),
21 ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations or

1 modifications to DNA or RNA, single nucleotide polymorphisms (SNPs),
2 uninterpreted data that results from the analysis of the biological sample, and
3 any information extrapolated, derived, or inferred therefrom.

4 (B) “Genetic data” does not include deidentified data. For purposes
5 of this subdivision (B), “deidentified data” means data that cannot be used to
6 infer information about, or otherwise be linked to, a particular individual,
7 provided that the business that possesses the information:

8 (i) takes reasonable measures to ensure that the information cannot
9 be associated with a consumer or household;

10 (ii) publicly commits to maintain and use the information only in
11 deidentified form and not to attempt to reidentify the information, except that
12 the business may periodically attempt to reidentify the information solely for
13 the purpose of determining whether its deidentification processes satisfy the
14 requirements of this subdivision (B), on the express condition that the business
15 does not use or disclose any information reidentified in this process and
16 destroys the reidentified information upon completion of that periodic
17 assessment; and

18 (iii) contractually obligates any recipients of the information to
19 take reasonable measures to ensure that the information cannot be associated
20 with a consumer or household and to commit to maintaining and using the
21 information only in deidentified form and not to reidentify the information.

1 (C) “Genetic data” does not include data or a biological sample to the
2 extent that data or a biological sample is collected, used, maintained, and
3 disclosed:

4 (i) exclusively for scientific research conducted by an investigator
5 with an institution that holds an assurance with the U.S. Department of Health
6 and Human Services pursuant to 45 C.F.R. Part 46; or

7 (ii) in compliance with all applicable federal and State laws and
8 regulations for the protection of human subjects in research, including the:

9 (I) Common Rule, 45 C.F.R. Part 46;

10 (II) U.S. Food and Drug Administration regulations pursuant to
11 21 C.F.R. Parts 50 and 56; and

12 (III) Family Educational Rights and Privacy Act, 20 U.S.C.
13 § 1232g.

14 (9) “Genetic testing” means any laboratory test of a biological sample
15 from a consumer for the purpose of determining information concerning
16 genetic material contained within the biological sample, or any information
17 extrapolated, derived, or inferred therefrom.

18 (10) “Person” means an individual, partnership, corporation, association,
19 business, business trust, or legal representative of an organization.

1 (11)(A) “Publicly available information” means information that is
2 made available through federal, state, or local government records or to the
3 general public from widely distributed media.

4 (B) “Publicly available information” does not include:

5 (i) biometric data collected by a business about a consumer
6 without the consumer’s knowledge;

7 (ii) information that is collated and combined to create a consumer
8 profile that is made available to a user of a publicly available website either in
9 exchange for payment or free of charge;

10 (iii) information that is made available for sale;

11 (iv) an inference that is generated from the information described
12 in subdivision (ii) or (iii) of this subdivision (11)(B);

13 (v) any obscene visual depiction, as defined in 18 U.S.C. § 1460;

14 (vi) personal data that is created through the combination of
15 personal data with publicly available information;

16 (vii) genetic data, unless otherwise made publicly available by the
17 consumer to whom the information pertains;

18 (viii) information provided by a consumer on a website or online
19 service made available to all members of the public, for free or for a fee, where
20 the consumer has maintained a reasonable expectation of privacy in the
21 information, such as by restricting the information to a specific audience; or

1 (ix) intimate images, authentic or computer generated, known to
2 be nonconsensual.

3 (12) “Service provider” means a sole proprietorship, partnership, limited
4 liability company, corporation, association, or other legal entity that is
5 involved in the collection, transportation, and analysis of the consumer’s
6 biological sample or extracted genetic material:

7 (A) on behalf of the direct-to-consumer genetic testing company;

8 (B) on behalf of any other company that collects, uses, maintains, or
9 discloses genetic data collected or derived from a direct-to-consumer genetic
10 testing product or service; or

11 (C) that is directly provided by a consumer.

12 § 2412. REQUIREMENTS

13 (a) Privacy terms and consent. To safeguard the privacy, confidentiality,
14 security, and integrity of a consumer’s genetic data, a direct-to-consumer
15 genetic testing company shall:

16 (1) provide clear and complete information regarding the company’s
17 policies and procedures for the collection, use, maintenance, and disclosure, as
18 applicable, of genetic data by making available to a consumer all of the
19 following:

1 (A) a summary of its privacy practices, written in plain language, that
2 includes information about the company's collection, use, maintenance, and
3 disclosure, as applicable, of genetic data;

4 (B) a prominent and easily accessible privacy notice that includes, at
5 a minimum, complete information about the company's data collection,
6 consent, use, access, disclosure, maintenance, transfer, security, and retention
7 and deletion practices; and

8 (C) a notice that the consumer's deidentified genetic or phenotypic
9 information may be shared with or disclosed to third parties for research
10 purposes in accordance with 45 C.F.R. Part 46; and

11 (2) obtain a consumer's express consent for the collection, use, and
12 disclosure of the consumer's genetic data, including, at a minimum, separate
13 and express consent for each of the following:

14 (A) the use of the genetic data collected through the genetic testing
15 product or service offered to the consumer, including:

16 (i) who has access to genetic data;

17 (ii) how genetic data may be shared; and

18 (iii) the specific purposes for which the data will be collected,
19 used, and disclosed;

20 (B) the storage of a consumer's biological sample after the initial
21 testing requested by the consumer has been fulfilled;

1 (C) each use of genetic data or the biological sample beyond the
2 primary purpose of the genetic testing or service and inherent contextual uses;

3 (D) each transfer or disclosure of the consumer's genetic data or
4 biological sample to a third party other than a service provider, including the
5 name of the third party to which the consumer's genetic data or biological
6 sample will be transferred or disclosed and the intended purpose of said
7 transfer, except that a company shall not require a consumer to expressly
8 consent to the actions in this subdivision (D) in order to receive the services
9 ordered from the company by the consumer; and

10 (E) the marketing or facilitation of marketing to a consumer based on
11 the consumer's genetic data or the marketing or facilitation of marketing by a
12 third party based upon the consumer having ordered, purchased, received, or
13 used a genetic testing product or service.

14 (b) Marketing exception.

15 (1) Subdivision (a)(2)(E) of this section does not require a direct-to-
16 consumer genetic testing company to obtain a consumer's express consent to
17 market to the consumer on the company's own website or mobile application
18 based upon the consumer having ordered, purchased, received, or used a
19 genetic testing product or service from that company if the content of the
20 advertisement does not depend upon any information specific to that consumer.

1 Nothing in this subdivision alters, limits, or negates the requirements of any
2 other antidiscrimination law or targeted advertising law.

3 (2) Any advertisement of a third-party product or service presented to a
4 consumer pursuant to subdivision (1) of this subsection or subdivision
5 (a)(2)(E) of this section shall be prominently labeled as advertising content and
6 be accompanied by the name of any third party that has contributed to the
7 placement of the advertising. If applicable, the advertisement also shall clearly
8 indicate that the advertised product or service, and any associated claims, have
9 not been vetted or endorsed by the direct-to-consumer genetic testing
10 company.

11 (c) Revoking consent.

12 (1) A direct-to-consumer genetic testing company that is subject to the
13 requirements in subdivision (a)(2) of this section shall provide effective
14 mechanisms, without any unnecessary steps, for a consumer to revoke consent
15 after it is given, at least one of which utilizes the primary medium through
16 which the company communicates with consumers.

17 (2) If a consumer revokes consent pursuant to subdivision (1) of this
18 subsection, the direct-to-consumer genetic testing company shall:

19 (A) honor the consumer's consent revocation as soon as practicable,
20 but not later than 30 days after the individual revokes consent; and

1 (B) if the revocation is related to the storage or use of a consumer's
2 biological sample, destroy the consumer's biological sample not later than 30
3 days after receipt of the revocation of consent.

4 (d) Data security and access.

5 (1) A direct-to-consumer genetic testing company shall:

6 (A) implement and maintain reasonable security procedures and
7 practices to protect a consumer's genetic data against unauthorized access,
8 destruction, use, modification, or disclosure; and

9 (B) develop procedures and practices to enable a consumer to easily:

10 (i) access the consumer's genetic data;

11 (ii) delete the consumer's account and genetic data, except for
12 genetic data that is required to be retained by the company to comply with
13 applicable legal and regulatory requirements; and

14 (iii) request to have and have the consumer's biological sample
15 destroyed.

16 (2) Genetic data and biometric samples of consumers shall not be stored
17 within the territorial boundaries of any country currently sanctioned in any way
18 by the U.S. Office of Foreign Assets Control or designated as a foreign
19 adversary under 15 C.F.R. § 7.4(a).

20 (3) Genetic data or biometric data of consumers shall only be transferred
21 or stored outside the United States with the express consent of the consumer.

1 (e) Contracts. A contract between a direct-to-consumer genetic testing
2 company and a service provider shall prohibit the service provider from:

3 (1) retaining, using, or disclosing the biological sample, genetic data, or
4 any information regarding the identity of the consumer, including whether that
5 consumer has solicited or received genetic testing, for a commercial purpose
6 other than providing the services specified in the contract with the business;
7 and

8 (2) associating or combining the biological sample, genetic data, or any
9 information regarding the identity of the consumer, including whether that
10 consumer has solicited or received genetic testing, with information the service
11 provider has received from or on behalf of another person or persons, or has
12 collected from its own interaction with consumers or as required by law.

13 (f) Discrimination. A person or public entity shall not discriminate against
14 a consumer because the consumer exercised any of the consumer's rights under
15 this subchapter by:

16 (1) denying goods, services, or benefits to the consumer;
17 (2) charging different prices or rates for goods or services, including
18 through the use of discounts or other incentives, or imposing penalties;

19 (3) providing a different level or quality of goods, services, or benefits
20 to the consumer;

1 (4) suggesting that the consumer will receive a different price or rate for
2 goods, services, or benefits, or a different level or quality of goods, services, or
3 benefits; and

4 (5) considering the consumer's exercise of rights under this subchapter
5 as a basis for suspicion of criminal wrongdoing or unlawful conduct.

6 (g) Nondisclosure. Notwithstanding any other provision in this section, a
7 direct-to-consumer genetic testing company shall not disclose a consumer's
8 genetic data to any entity that is responsible for administering or making
9 decisions regarding health insurance, life insurance, long-term care insurance,
10 disability insurance, or employment, or to any entity that provides advice to an
11 entity that is responsible for performing those functions.

12 § 2413. ENFORCEMENT

13 (a) A direct-to-consumer genetic testing company or service provider that
14 violates this subchapter or rules adopted pursuant to this subchapter commits
15 an unfair and deceptive act in commerce in violation of section 2453 of this
16 title.

17 (b) The Attorney General shall have the same authority under this
18 subchapter to make rules, conduct civil investigations, bring civil actions, and
19 enter into assurances of discontinuance against any person as provided under
20 chapter 63 of this title.

1 § 2414. APPLICABILITY

2 (a) The provisions of this subchapter shall not reduce a direct-to-consumer
3 genetic testing company's duties, obligations, requirements, or standards under
4 any applicable State and federal laws for the protection of privacy and security.

5 (b) In the event of a conflict between the provisions of this subchapter and
6 any other law, the provisions of the law that afford the greatest protection for
7 the right of privacy for consumers shall control.

8 (c) This subchapter shall not apply to any of the following:

9 (1) protected health information that is collected, maintained, used, or
10 disclosed by a covered entity or business associate governed by the privacy,
11 security, and breach notification rules issued by the U.S. Department of Health
12 and Human Services, 45 C.F.R. Parts 160 and 164, established pursuant to the
13 Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-
14 191, and the Health Information Technology for Economic and Clinical Health
15 Act, Pub. L. No. 111-5;

16 (2) a covered entity governed by the privacy, security, and breach
17 notification rules issued by the U.S. Department of Health and Human
18 Services, 45 C.F.R. Parts 160 and 164, established pursuant to the Health
19 Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191,
20 and the Health Information Technology for Economic and Clinical Health Act,
21 Title XIII of the American Recovery and Reinvestment Act of 2009, Pub. L.

1 No. 111-5, to the extent that the provider or covered entity maintains, uses, and
2 discloses genetic information in the same manner as medical information or
3 protected health information, as described in subdivision (1) of this subsection;

4 (3) a business associate of a covered entity governed by the privacy,
5 security, and data breach notification rules issued by the U.S. Department of
6 Health and Human Services, 45 C.F.R. Parts 160 and 164, established pursuant
7 to the Health Insurance Portability and Accountability Act of 1996, Pub. L.
8 No. 104-191, and the Health Information Technology for Economic and
9 Clinical Health Act, Title XIII of the American Recovery and Reinvestment
10 Act of 2009, Pub. L. No. 111-5, to the extent that the business associate
11 maintains, uses, and discloses genetic information in the same manner as
12 medical information or protected health information, as described in
13 subdivision (1) of this subsection;

14 (4) scientific research or educational activities conducted by a public or
15 private nonprofit postsecondary educational institution that holds an assurance
16 with the U.S. Department of Health and Human Services pursuant to 45 C.F.R.
17 Part 46, to the extent that the scientific research and educational activities
18 conducted by that institution comply with all applicable federal and State laws
19 and regulations for the protection of human subjects in research, including the
20 Common Rule pursuant to 45 C.F.R. Part 46, U.S. Food and Drug

1 Administration regulations pursuant to 21 C.F.R. Parts 50 and 56, and the
2 Family Educational Rights and Privacy Act, 20 U.S.C. § 1232g;

3 (5) tests conducted exclusively to diagnose whether an individual has a
4 specific disease, to the extent that all persons involved in the conduct of the
5 test maintain, use, and disclose genetic information in the same manner as
6 medical information or protected health information, as described in
7 subdivision (1) of this subsection; and

8 (6) genetic data used or maintained by an employer, or disclosed by an
9 employee to an employer, to the extent that the use, maintenance, or disclosure
10 of that data is necessary to comply with a local, State, or federal workplace
11 health and safety ordinance, law, or regulation.

12 (d) Nothing in this subchapter shall be construed to affect access to
13 publicly available information.

14 Sec. 2. EFFECTIVE DATE

15 This act shall take effect on July 1, 2026.