II

118TH CONGRESS
2D SESSION

S. 5433

To provide consumers with the right to delete their genomic data, and for other purposes.

IN THE SENATE OF THE UNITED STATES

DECEMBER 5, 2024

Mr. CASSIDY (for himself and Mr. PETERS) introduced the following bill; which was read twice and referred to the Committee on Commerce, Science, and Transportation

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A BILL

To provide consumers with the right to delete their genomic data, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Genomic Data Protection Act''.

SEC. 2. CONSUMER RIGHTS REGARDING GENOMIC DATA.

(a) REQUIREMENTS.—

(1) CONSUMER CONTROLS.—A direct-to-consumer genomic testing company shall develop procedures and provide an effective mechanism (including

an option that is through the primary medium by which the company communicates with the consumer) to allow a consumer to—

(A) access the genomic data of the consumer; and

(B) subject to paragraph (4)—

(i) delete the account of the consumer, including any genomic data associated with such account; and

(ii) request the destruction of any biological sample of the consumer.

(2) NOTIFICATION.—

(A) CONSUMER CONTROLS AND USE OF DEIDENTIFIED GENOMIC DATA.—A direct-to-consumer genomic testing company shall make available, in a clear and conspicuous, not misleading, and easy-to-read manner a notice that—

(i) provides a detailed and accurate representation of the rights set forth in subparagraphs (A) and (B) of paragraph (1); and

(ii) discloses that the deidentified genomic data of a consumer may be shared or disclosed to conduct medical or scientific

research, consistent with the privacy regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d–2 note).

(B) PURCHASE OF COMPANY OR GENOMIC DATA.—In the event that a direct-to-consumer genomic testing company (or the genomic data of such company) is purchased or otherwise acquired by another entity, the direct-to-consumer genomic testing company shall send to each consumer, not fewer than 30 days prior to the date on which the purchase or acquisition is complete, a notice that includes—

(i) the identity of the entity purchasing or otherwise acquiring the company; and

(ii) a detailed and accurate representation of the rights set forth in subparagraphs (A) and (B) of paragraph (1).

(3) PROCESSING OF DELETION OR DESTRUCTION REQUESTS.—With respect to a consumer's request to delete the genomic data or to destroy the biological sample of the consumer, a direct-to-consumer genomic testing company shall—

(A) fulfill such request not later than 30 days after the date on which the consumer makes such request; and

(B) notify the consumer of such deletion or destruction not later than 30 days after the deletion or destruction.

(4) EXCEPTIONS.—A direct-to-consumer genomic testing company shall not permit a consumer to exercise a right described in paragraph (1)(B) if the company determines that the exercise of the right would require the deletion of information—

(A) subject to a warrant, lawfully executed subpoena, or other court order; or

(B) the company is required to retain in order to comply with any other applicable legal or regulatory requirement.

(b) ENFORCEMENT.—

(1) UNFAIR OR DECEPTIVE ACTS OR PRACTICES.—A violation of this section or a regulation promulgated thereunder shall be treated as a violation of a rule defining an unfair or deceptive act or practice under section 18(a)(1)(B) of the Federal Trade Commission Act (15 U.S.C. 57a(a)(1)(B)).

(2) POWERS OF THE COMMISSION.—

(A) IN GENERAL.—The Commission shall enforce this section in the same manner, by the same means, and with the same jurisdiction, powers, and duties as though all applicable terms and provisions of the Federal Trade Commission Act (15 U.S.C. 41 et seq.) were incorporated into and made a part of this section.

(B) PRIVILEGES AND IMMUNITIES.—Any person who violates this section or a regulation promulgated thereunder shall be subject to the penalties and entitled to the privileges and immunities provided in the Federal Trade Commission Act (15 U.S.C. 41 et seq.).

(C) AUTHORITY PRESERVED.—Nothing in this section shall be construed to limit the authority of the Commission under any other provision of law.

(D) RULEMAKING.—Not later than 1 year after the date of enactment of this section, the Commission shall promulgate in accordance with section 553 of title 5, United States Code, such rules as may be necessary to carry out this section.

(c) DEFINITIONS.—In this section:

(1) BIOLOGICAL SAMPLE.—The term ''biological sample'' means any material part of the human, discharge therefrom, or derivative thereof, such as tissue, blood, urine, or saliva, known to contain deoxyribonucleic acid (DNA).

(2) COMMISSION.—The term ''Commission'' means the Federal Trade Commission.

(3) CONSUMER.—The term ''consumer'' means an individual that obtains a genomic testing product or service from a direct-to-consumer genomic testing company.

(4) DIRECT-TO-CONSUMER GENOMIC TESTING COMPANY.—

(A) IN GENERAL.—The term ''direct-to-consumer genomic testing company'' means a person that does any of the following:

(i) Sells, markets, interprets, analyzes, or otherwise offers genomic testing products or services directly to consumers.

(ii) Analyzes genomic data obtained from a consumer.

(iii) Collects, uses, maintains, or discloses genomic data collected or derived from a direct-to-consumer genomic testing product or service.

(iv) Purchases or acquires genomic data from a direct-to-consumer genomic testing company.

(B) EXCLUSION FOR HEALTH CARE PROFESSIONALS.—The term ''direct-to-consumer genomic testing company'' shall not include a health care professional (as defined in section 225 of the Public Health Service Act (42 U.S.C. 234)) that performs an action described in subparagraph (A) for purposes of diagnosis or treatment of a medical condition.

(5) GENOMIC DATA.—

(A) IN GENERAL.—The term ''genomic data''—

(i) means any data, regardless of its format or whether the data has been deidentified, that results from the analysis of a biological sample from a consumer and concerns genomic material; and

(ii) includes—

(I) deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations or modifications to DNA or RNA, and

single nucleotide polymorphisms (SNPs);

(II) uninterpreted data that results from the analysis of the biological sample; or

(III) any information extrapolated, derived, or inferred therefrom.

(B) EXCLUSION OF DEIDENTIFIED GENOMIC DATA.—The term ''genomic data'' shall not include the deidentified genomic data of a consumer to the extent that such data is used to conduct medical or scientific research, consistent with the privacy regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d–2 note).

(6) GENOMIC TESTING PRODUCT OR SERVICE.—The term ''genomic testing product or service'' means any testing product or service that analyzes or otherwise uses the genomic data or biological sample of a consumer.

(d) RELATIONSHIP TO FEDERAL AND STATE LAWS.—

(1) FEDERAL LAW PRESERVATION.—Nothing in this Act, or a regulation promulgated under this Act,

shall be construed to limit any other provision of Federal law, except as specifically provided in this Act.

(2) STATE LAW PRESERVATION.—Nothing in this Act, or a regulation promulgated under this Act, shall be construed to preempt, displace, or supplant any State law, except to the extent that a provision of State law conflicts with a provision of this Act, or a regulation promulgated under this Act, and then only to the extent of the conflict.

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