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HOUSE BILL 2485

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State of Washington

66th Legislature

2020 Regular Session

By Representatives Kloba, Slatter, Senn, Lekanoff, and Thai

1 AN ACT Relating to collection, use, and disclosure of genetic  
2 data by direct-to-consumer genetic testing companies; adding a new  
3 chapter to Title 19 RCW; and prescribing penalties.

4 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

5 NEW SECTION. **Sec. 1.** The definitions in this section apply  
6 throughout this chapter unless the context clearly requires  
7 otherwise.

8 (1) "Biological sample" means any material part of the human  
9 body, discharge therefrom, or derivative thereof, such as tissue,  
10 blood, urine, or saliva, known to contain deoxyribonucleic acid  
11 (DNA).

12 (2) "Consumer" means a natural person who is a Washington  
13 resident.

14 (3) "Direct-to-consumer genetic testing company" or "company"  
15 means an entity that offers consumer genetic testing products or  
16 services directly to consumers without requiring the involvement of a  
17 health care provider.

18 (4) "Employer" has the same meaning as defined in RCW 50.04.080.

19 (5) "Express consent" means a consumer's affirmative written  
20 response to a clear, meaningful, and prominent notice regarding the

1 collection, use, or disclosure of genetic data for a specific  
2 purpose.

3 (6) (a) "Genetic data" means any data, regardless of its format,  
4 that concerns a consumer's genetic characteristics.

5 (b) "Genetic data" includes, but is not limited to:

6 (i) Raw sequence data that result from sequencing of a consumer's  
7 complete extracted or a portion of the extracted DNA;

8 (ii) Genotypic and phenotypic information that results from  
9 analyzing the raw sequence data; and

10 (iii) Self-reported health data that a consumer submits to a  
11 company regarding the consumer's health conditions and that is used  
12 for scientific research or product development and analyzed in  
13 connection with the consumer's raw sequence data.

14 (c) "Genetic data" does not include deidentified data. For  
15 purposes of this subsection, "deidentified data" means data that  
16 cannot reasonably be used to infer information about, or otherwise be  
17 linked to, an identifiable consumer, and that is subject to:

18 (i) Administrative and technical measures to ensure that the data  
19 cannot be associated with a particular consumer;

20 (ii) Public commitment by the company to maintain and use data in  
21 deidentified form and not to attempt to reidentify data; and

22 (iii) Legally enforceable contractual obligations that prohibit  
23 any recipients of the data from attempting to reidentify the data.

24 (7) "Genetic testing" means any laboratory test of a consumer's  
25 complete DNA, regions of DNA, chromosomes, genes, or gene products to  
26 determine the presence of the genetic characteristics in a consumer  
27 or a consumer's offspring.

28 NEW SECTION. **Sec. 2.** (1) To safeguard the privacy,  
29 confidentiality, security, and integrity of a consumer's genetic  
30 data, a direct-to-consumer genetic testing company shall:

31 (a) Provide clear and complete information regarding the  
32 company's policies and procedures for collection, use, or disclosure  
33 of genetic data by making available to a consumer:

34 (i) A high-level privacy policy overview that includes basic,  
35 essential information about the company's collection, use, or  
36 disclosure of genetic data; and

37 (ii) A prominent, publicly available, and easy to read privacy  
38 notice that includes, at a minimum, information about the company's

1 data collection, consent, use, access, disclosure, transfer,  
2 security, and retention and deletion practices;

3 (b) Obtain a consumer's consent for collection, use, or  
4 disclosure of the consumer's genetic data including, at a minimum:

5 (i) Initial express consent that clearly describes the uses of  
6 the genetic data collected through the genetic testing product or  
7 services purchased by the consumer, and specifies who has access to  
8 test results and how the genetic data may be shared;

9 (ii) Separate express consent for transferring or disclosing the  
10 consumer's genetic data to third parties other than vendors and  
11 services providers, or for using genetic data beyond the primary  
12 purpose of the purchased genetic testing product or service and  
13 inherent contextual uses;

14 (iii) Informed consent in compliance with the federal policy for  
15 the protection of human research subjects, 45 C.F.R. Sec. 46 (2019),  
16 when the consumer's genetic data is transferred or disclosed to third  
17 parties for research purposes or when research is done under the  
18 control of the company for the purpose of publication or  
19 generalizable knowledge; and

20 (iv) Express consent for marketing to a consumer based on the  
21 consumer's genetic data or the consumer having ordered or purchased a  
22 genetic testing product or service;

23 (c) Require valid legal process for disclosing genetic data to  
24 law enforcement without a consumer's express consent;

25 (d) Develop, implement, and maintain a comprehensive security  
26 program to protect a consumer's genetic data against unauthorized or  
27 inappropriate access, disclosure, or use; and

28 (e) Provide a process for a consumer to:

29 (i) Access the consumer's genetic data;

30 (ii) Correct or amend inaccurate genetic data or other personal  
31 information in the consumer's account;

32 (iii) Specify how long the consumer's genetic data and biological  
33 sample may be retained by the company;

34 (iv) Delete the consumer's account and genetic data; and

35 (v) Request and obtain the destruction of the consumer's  
36 biological sample.

37 (2) Notwithstanding any other provisions in this section, a  
38 direct-to-consumer genetic testing company may not disclose a  
39 consumer's genetic data to any entity offering health insurance or  
40 life insurance, or to any employer of the consumer.

1        NEW SECTION.        **Sec. 3.**        (1) The legislature finds that the  
2 practices covered by this chapter are matters vitally affecting the  
3 public interest for the purpose of applying the consumer protection  
4 act, chapter 19.86 RCW. A violation of this chapter is not reasonable  
5 in relation to the development and preservation of business and is an  
6 unfair or deceptive act in trade or commerce and an unfair method of  
7 competition for the purpose of applying the consumer protection act,  
8 chapter 19.86 RCW.

9        (2) The attorney general may bring an action in the name of the  
10 state, or as parens patriae on behalf of persons residing in the  
11 state, to enforce this chapter. In any action brought by the attorney  
12 general to enforce this chapter, a violation of this chapter is  
13 subject to a civil penalty of two thousand five hundred dollars for  
14 each violation of this chapter.

15        (3) A consumer prevailing in an action under this chapter may  
16 recover actual damages, but not less than statutory damages of two  
17 thousand five hundred dollars per violation.

18        (4) A court must award costs and reasonable attorneys' fees to a  
19 plaintiff who prevails in an action under this chapter.

20        NEW SECTION.        **Sec. 4.**        Sections 1 through 3 of this act  
21 constitute a new chapter in Title 19 RCW.

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