
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 1291 Session of
2022

INTRODUCED BY GORDNER, PHILLIPS-HILL, BARTOLOTTA, LAUGHLIN,
DUSH, STEFANO AND MENSCH, JUNE 16, 2022

REFERRED TO CONSUMER PROTECTION AND PROFESSIONAL LICENSURE,
JUNE 16, 2022

AN ACT

1 Providing for genetic information privacy and setting penalties
2 for violations.

3 The General Assembly of the Commonwealth of Pennsylvania
4 hereby enacts as follows:

5 Section 1. Short title.

6 This act shall be known and may be cited as the Genetic
7 Information Privacy Act.

8 Section 2. Definitions.

9 The following words and phrases when used in this act shall
10 have the meanings given to them in this section unless the
11 context clearly indicates otherwise:

12 "Biological sample." Human material known to contain DNA.

13 The term includes tissue, blood, urine or saliva.

14 "Company." A direct-to-consumer entity that:

15 (1) offers consumer genetic testing products or services
16 directly to consumers; or

17 (2) collects, uses or analyzes genetic data that a

1 consumer provides to the entity.

2 "Consumer." A resident of this Commonwealth.

3 "Deidentified data." Data that:

4 (1) cannot be reasonably linked to an identifiable
5 individual; and

6 (2) is possessed by a company that:

7 (i) takes administrative or technical measures to
8 ensure that the data cannot be associated with a
9 particular consumer;

10 (ii) makes a public commitment to maintain and use
11 data in deidentified form and not attempt to re-identify
12 data; and

13 (iii) enters into a legally enforceable contractual
14 obligation that prohibits a recipient of the data from
15 attempting to re-identify the data.

16 "DNA." Deoxyribonucleic acid.

17 "Express consent." A consumer's affirmative response to a
18 clear, meaningful and prominent notice regarding the collection,
19 use or disclosure of genetic data for a specific purpose.

20 "Genetic data." Data, regardless of format, containing
21 information of a consumer's genetic characteristics. The term
22 includes any of the following:

23 (1) Raw sequence data that results from sequencing all
24 or a portion of a consumer's extracted DNA.

25 (2) Genotypic and phenotypic information obtained from
26 analyzing a consumer's raw sequence data.

27 (3) Self-reported health information regarding a
28 consumer's health conditions that the consumer provides to a
29 company for:

30 (i) Scientific research or product development.

1 (ii) Analysis in connection with the consumer's raw
2 sequence data.

3 (4) The term does not include deidentified data.

4 "Genetic testing." A laboratory test of a consumer's
5 complete DNA, regions of DNA, chromosomes, genes or gene
6 products to determine the presence of genetic characteristics of
7 the consumer or an interpretation of the consumer's data.

8 Section 3. Consumer genetic information.

9 (a) Disclosure to consumer.--A company shall provide the
10 following information to consumers:

11 (1) Essential information about the company's data
12 collection, use and disclosure of genetic data.

13 (2) A privacy notice that is prominently and publicly
14 available and includes information about the company's data
15 collection, consent, use, access, disclosure, transfer,
16 security, retention and deletion practices.

17 (b) Express consent.--A company shall obtain each consumer's
18 express consent for collecting, use or disclosure of the
19 consumer's genetic data. Prior to giving express consent, the
20 company shall provide information to the consumer that:

21 (1) Clearly describes the company's use of the genetic
22 data that the company collects through the company's genetic
23 testing product or service.

24 (2) Specifies who has access to test results.

25 (3) Specifies how the company may share the genetic
26 data.

27 (c) Specific consent.--A company shall obtain:

28 (1) Separate express consent for the following services:

29 (i) The transfer or disclosure of the consumer's
30 genetic data to other than the company's vendors and

1 service providers.

2 (ii) The use of genetic data beyond the primary
3 purpose of the company's genetic testing product or
4 service.

5 (iii) The retention of biological samples provided
6 by the consumer following the company's completion of the
7 initial testing service requested by the consumer.

8 (2) Informed consent in accordance with the Federal
9 Policy for Protection of Human Subjects under 45 CFR Pt. 46
10 (relating to protection of human subjects), for transfer or
11 disclosure of the consumer's genetic data to a third party
12 for:

13 (i) Research purposes.

14 (ii) Research conducted under the control of the
15 company for the purposes of publication or generalized
16 knowledge.

17 (3) Express consent for:

18 (i) Marketing to a consumer based on the consumer's
19 genetic data.

20 (ii) Marketing by a third party person to a consumer
21 based on the consumer having ordered or purchased a
22 genetic testing product or service.

23 (d) Legal process.--A company must have a valid legal
24 process to disclose a consumer's genetic data to law enforcement
25 or a governmental entity without the consumer's express written
26 consent.

27 (e) Security of data.--A company shall develop, implement
28 and maintain a comprehensive security program to protect a
29 consumer's genetic data against unauthorized access, use or
30 disclosure.

1 (f) Consumer access to data.--A company shall provide a
2 process for a consumer to:

3 (1) Access the consumer's genetic data.

4 (2) Delete the consumer's genetic data.

5 (3) Destroy the consumer's biological sample.

6 (g) First-party data.--A company with a first-party
7 relationship to a consumer may, without obtaining the consumer's
8 express consent, provide customized content or offers on the
9 company's publicly accessible Internet website or through the
10 company's application or service.

11 Section 4. Prohibited disclosures.

12 A company may not disclose a consumer's genetic data without
13 written consent to:

14 (1) An entity that offers health insurance, life
15 insurance or long-term-care insurance.

16 (2) An employer of the consumer.

17 Section 5. Penalty.

18 The Office of Attorney General shall enforce this act by
19 filing civil actions against individuals or entities which are
20 in violation of this act. To enforce this act, the Office of
21 Attorney General may seek one or more of the following:

22 (1) Actual damages to the consumer.

23 (2) Costs.

24 (3) Attorney fees.

25 (4) A \$2,500 penalty for each violation of this act.

26 Section 6. Applicability.

27 This act does not apply to:

28 (1) Protected health information that is collected by a
29 covered entity or business associate as defined in 45 CFR
30 Pts. 160 (relating to general administrative requirements)

1 and 164 (relating to security and privacy).

2 (2) A public or private institution of higher education.

3 (3) An entity owned or operated by a public or private
4 institution of higher education.

5 Section 7. Effective date.

6 This act shall take effect in 60 days.