

REFERENCE TITLE: genetic testing information; confidentiality; exceptions

State of Arizona
Senate
Fifty-fourth Legislature
First Regular Session
2019

SB 1297

Introduced by
Senator Brophy McGee

AN ACT

AMENDING SECTIONS 12-2801, 12-2802 AND 20-448.02, ARIZONA REVISED
STATUTES; RELATING TO GENETIC TESTING.

(TEXT OF BILL BEGINS ON NEXT PAGE)

1 Be it enacted by the Legislature of the State of Arizona:

2 Section 1. Section 12-2801, Arizona Revised Statutes, is amended to
3 read:

4 12-2801. Definitions

5 In this chapter, unless the context otherwise requires:

6 1. "Genetic test" or "genetic testing":

7 (a) Means a test of a person's genes, genetic sequence, gene
8 products or chromosomes for abnormalities or deficiencies, including
9 carrier status, that:

10 (i) Are linked to physical or mental disorders or impairments.

11 (ii) Indicate a susceptibility to any illness, disease, impairment
12 or other disorder, whether physical or mental.

13 (iii) Demonstrate genetic or chromosomal damage due to any
14 environmental factor.

15 (b) Does not include:

16 (i) Chemical, blood and urine analyses that are widely accepted and
17 used in clinical practice and that are not used to determine genetic
18 traits.

19 (ii) Tests **THAT ARE** used in a criminal investigation or prosecution
20 or as a result of a criminal conviction.

21 (iii) Tests for the presence of the human immunodeficiency virus.

22 (iv) Tests to determine paternity **THAT ARE** conducted pursuant to
23 title 25, chapter 6, article 1.

24 (v) Tests **THAT ARE** given for use in biomedical research that is
25 conducted to generate scientific knowledge about genes or to learn about
26 the genetic basis of disease or for developing pharmaceutical and other
27 treatment of disease.

28 (vi) **DIRECT TO CONSUMER TESTS THAT ARE PERFORMED IN A PERSON'S**
29 **HOME, THAT ARE NOT ORDERED BY A LICENSED HEALTH CARE PROVIDER AND THAT ARE**
30 **NOT USED FOR DIAGNOSTIC PURPOSES.**

31 2. "Health care decision maker" means a person who is authorized to
32 make health care treatment decisions for the patient, including a parent
33 of a minor and a person who is authorized to make these decisions pursuant
34 to title 14, chapter 5, article 2 or 3 or section 8-514.05, 36-3221,
35 36-3231 or 36-3281.

36 3. "Health care provider" means physicians licensed pursuant to
37 title 32, chapter 13 or 17, physician assistants licensed pursuant to
38 title 32, chapter 25, registered nurse practitioners licensed pursuant to
39 title 32, chapter 15, health care institutions as defined in section
40 36-401 and clinical laboratories licensed pursuant to title 36,
41 chapter 4.1.

1 Sec. 2. Section 12-2802, Arizona Revised Statutes, is amended to
2 read:

3 12-2802. Confidentiality of genetic testing results;
4 disclosure

5 A. Except as otherwise provided in this article, genetic testing
6 and information derived from genetic testing are confidential and
7 considered privileged to the person tested and shall be released only to:

8 1. The person tested.

9 2. Any person who is specifically authorized in writing by the
10 person tested or by that person's health care decision maker to receive
11 this information.

12 3. The health care decision maker of the person tested.

13 4. A researcher for medical research or public health purposes only
14 if the research is conducted pursuant to applicable federal or state laws
15 and regulations governing clinical and biological research or if the
16 identity of the individual providing the sample is not disclosed to the
17 person collecting and conducting the research.

18 5. A third person if approved by a human subjects review committee
19 or a human ethics committee, with respect to persons who are subject to an
20 Arizona cancer registry.

21 ~~6. An authorized agent or employee of a health care provider if all~~
22 ~~of the following are true:~~

23 ~~(a) The health care provider performs the test or is authorized to~~
24 ~~obtain the test results by the person tested for the purposes of genetic~~
25 ~~counseling or treatment.~~

26 ~~(b) The agent or employee provides patient care, treatment or~~
27 ~~counseling.~~

28 ~~(c) The agent or employee needs to know the information in order to~~
29 ~~conduct the test or provide patient care, treatment or counseling.~~

30 6. A HEALTH CARE PROVIDER WHO IS PROVIDING CARE TO THE PERSON
31 TESTED AND AN AGENT OR EMPLOYEE OF THE HEALTH CAR PROVIDER.

32 7. A health care provider that procures, processes, distributes or
33 uses:

34 (a) A human body part from a deceased person with respect to
35 medical information regarding that person.

36 (b) Semen or ova for the purpose of artificial insemination.

37 8. A health care provider to conduct utilization review, peer
38 review and quality assurance pursuant to section 36-441, 36-445, 36-2402
39 or 36-2917.

40 9. The authorized agent of a federal, state or county health
41 department to conduct activities specifically authorized pursuant to the
42 laws of this state for the birth defects registry, children's
43 rehabilitative services, newborn screening and sickle cell diagnosis and
44 treatment programs and chronic, environmentally provoked and infectious
45 disease programs.

10. To obtain legal advice, the legal representative of a health care provider OR CLINICAL LABORATORY that is in possession of the medical record.

~~11. A health care provider that assumes the responsibility to provide care for, or consultation to, the patient from another health care provider that had access to the patient's genetic records.~~

11. A PERSON OR ENTITY THAT PROVIDES SERVICES TO A HEALTH CARE PROVIDER OR CLINICAL LABORATORY IF THE HEALTH CARE PROVIDER OR CLINICAL LABORATORY HAS AN AGREEMENT REQUIRING THE PERSON OR ENTITY TO PROTECT THE CONFIDENTIALITY OF THE GENETIC TESTING AND INFORMATION AND AS REQUIRED BY THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996 PRIVACY STANDARDS (45 CODE OF FEDERAL REGULATIONS PART 160 AND PART 164, SUBPART E).

12. A STATEWIDE HEALTH INFORMATION EXCHANGE.

13. A NATIONALLY RECOGNIZED ACCREDITATION ORGANIZATION.

14. A HEALTH PROFESSIONAL LICENSING BOARD IN THIS STATE.

15. AN ENTITY, OTHER THAN A DISABILITY INSURER, THAT IS RESPONSIBLE FOR THE PAYMENT OF A HEALTH CARE PROVIDER'S CHARGES AND THAT USES THE INFORMATION ONLY FOR THE PURPOSE OF THE PAYMENT OF THOSE CHARGES.

B. A PATHOLOGIST WHO IS LICENSED PURSUANT TO TITLE 32, CHAPTER 13 OR 17 MAY ORDER AND PERFORM GENETIC TESTING FOR A PATIENT AND RECEIVE THE RESULTS OF THAT TESTING.

~~B.~~ C. A person shall not disclose or be compelled to disclose the identity of any person on whom a genetic test is performed or the results of a genetic test in a manner that allows identification of the person tested except to the persons specified in the circumstances set forth in subsection A of this section.

~~C.~~ D. If genetic testing information is subpoenaed, a health care provider shall respond pursuant to section 12-2294.01, subsection E. In determining whether to order production of the genetic testing information, the court shall take all steps necessary to prevent the disclosure or dissemination of that information.

~~D.~~ E. Except as provided in this section, chapter 13, article 7.1 of this title does not apply to genetic testing information that is contained within a patient's medical record.

~~E.~~ F. Following the death of a person who had genetic testing performed, the release of the testing information is governed by section 12-2294, subsection D, except that the person may deny, release or limit release of the genetic testing results by adopting a provision in a testamentary document.

~~F.~~ G. Except as specifically provided in this article, a person to whom test results have been disclosed pursuant to this article, other than the person tested, shall not disclose the test results to any other person.

1 ~~G.~~ H. A health care provider and the provider's agents and
2 employees that act in good faith and that comply with this article are not
3 subject to civil liability. The good faith of a health care provider that
4 complies with this article is presumed. The presumption may be rebutted
5 by a preponderance of the evidence.

6 ~~H.~~ I. This article does not limit the effect of title 20
7 provisions governing the confidentiality and use of genetic testing
8 information.

9 Sec. 3. Section 20-448.02, Arizona Revised Statutes, is amended to
10 read:

11 20-448.02. Genetic testing; informed consent; definitions

12 A. Except as otherwise specifically authorized or required by this
13 state or by federal law, a person shall not order or require the
14 performance of a genetic test without first receiving the specific written
15 informed consent of the subject of the test who has the capacity to
16 consent or, if the person subject to the test lacks the capacity to
17 consent, of a person authorized pursuant to law to consent for that
18 person. Written consent shall be in a form prescribed by the director.
19 EXCEPT AS AUTHORIZED IN SECTION 12-2802, the results of a genetic test
20 performed are privileged and confidential and may not be released to any
21 party without the express consent of the subject of the test or the person
22 authorized pursuant to law to consent for that person.

23 B. For the purposes of this section:

24 1. "Gene products" means gene fragments, nucleic acids or proteins
25 derived from deoxyribonucleic acids that would be a reflection of or
26 indicate DNA sequence information.

27 2. "Genetic test" means an analysis of an individual's DNA, gene
28 products or chromosomes that indicates a propensity for or susceptibility
29 to illness, disease, impairment or other disorders, whether physical or
30 mental, or that demonstrates genetic or chromosomal damage due to
31 environmental factors, or carrier status for a disease or disorder.