

The Florida Senate
BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Rules

BILL: CS/SB 1140

INTRODUCER: Rules Committee and Senators Rodrigues and Garcia

SUBJECT: Unlawful Use of DNA

DATE: April 7, 2021

REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Looke</u>	<u>Brown</u>	<u>HP</u>	Favorable
2.	<u>McMillan</u>	<u>McKay</u>	<u>CM</u>	Favorable
3.	<u>Looke</u>	<u>Phelps</u>	<u>RC</u>	Fav/CS

Please see Section IX. for Additional Information:

COMMITTEE SUBSTITUTE - Substantial Changes

I. Summary:

CS/SB 1140 establishes the “Protecting DNA Privacy Act.” The bill establishes four new crimes related to the unlawful use of deoxyribose nucleic acid (DNA). The bill provides that:

- It is a first degree misdemeanor for a person to willfully, and without express consent, collect or retain another person’s DNA sample with the intent to perform DNA analysis.
- It is a third degree felony for a person to willfully, and without express consent, submit another person’s DNA sample for DNA analysis or to conduct or procure the conducting of another person’s DNA analysis.
- It is a third degree felony for a person to willfully, and without express consent, disclose another person’s DNA analysis results to a third party except that a person who discloses another person’s DNA analysis that were previously voluntarily disclosed by the person whose DNA was analyzed, or such person’s legal guardian or authorized representative, does not commit the crime.
- It is a second degree felony for a person to willfully, and without express consent, sell or otherwise transfer another person’s DNA sample or the results of another person’s DNA analysis to a third party, regardless of whether the DNA sample was originally collected, retained, or analyzed with express consent.

The bill specifies that each instance of the above crimes constitutes a separate violation which entails a separate penalty. The bill amends s. 760.40, F.S., which is the current law governing DNA privacy, to define the terms “express consent,” “exclusive property,” and “DNA sample”

and to conform to the changes made by the bill. The definitions established in s. 760.40, F.S., also apply to the newly created s. 817.5655, F.S.

The bill provides exceptions to the crimes established in the bill for:

- Criminal investigations and prosecutions;
- Complying with a subpoena, summons, or other lawful court order;
- Complying with federal law;
- The medical diagnosis and treatment of a patient under certain circumstances;
- The newborn screening program established in s. 383.14, F.S.;
- Determining paternity under ss. 409.256 or 742.12(1), F.S.; and
- Performing any activity authorized in s. 943.325, F.S., pertaining to the criminal DNA database.

The Legislature's Office of Economic and Demographic Research (EDR) estimates that the bill will have a "positive insignificant" prison bed impact (an increase in 10 or fewer prison beds). *See* Section V. Fiscal Impact Statement.

The bill provides an effective date of October 1, 2021.

II. Present Situation:

DNA

DNA, or deoxyribose nucleic acid, is the hereditary material in humans and almost all other organisms. Nearly every cell in a person's body has the same DNA, unique to that person. Most DNA is located in the cell nucleus (where it is called nuclear DNA), but a small amount of DNA can also be found in the mitochondria (where it is called mitochondrial DNA or mtDNA). Mitochondria are structures within cells that convert the energy from food into a form that cells can use.

The information in DNA is stored as a code made up of four chemical bases: adenine (A), guanine (G), cytosine (C), and thymine (T). Human DNA consists of about three billion bases, and more than 99 percent of those bases are the same in all people. The order, or sequence, of these bases determines the information available for building and maintaining an organism, similar to the way in which letters of the alphabet appear in a certain order to form words and sentences.

DNA bases pair-up with each other, A with T and C with G, to form units called base pairs. Each base is also attached to a sugar molecule and a phosphate molecule. Together, a base, sugar, and phosphate are called a nucleotide. Nucleotides are arranged in two long strands that form a spiral called a double helix. The structure of the double helix is somewhat like a ladder, with the base pairs forming the ladder's rungs and the sugar and phosphate molecules forming the vertical sidepieces of the ladder.

An important property of DNA is that it can replicate, or make copies of itself. Each strand of DNA in the double helix can serve as a pattern for duplicating the sequence of bases. This is

critical when cells divide because each new cell needs to have an exact copy of the DNA present in the old cell.¹

Genetics and Genomics

Genetics is a term that refers to the study of genes and their roles in inheritance. In other words, it is the way that certain traits or conditions are passed down from one generation to another. Genetics involves the scientific study of genes and their effects. Genes (units of heredity) carry the instructions for making proteins, which direct the activities of cells and functions of the body. Examples of genetic or inherited disorders include cystic fibrosis, Huntington's disease, and phenylketonuria.

Genomics is a more recent term that describes the study of all of a person's genes (the genome), including interactions of those genes with each other and with the person's environment. Genomics includes the scientific study of complex diseases such as heart disease, asthma, diabetes, and cancer because these diseases are typically caused by a combination of genetic and environmental factors rather than by individual genes. Genomics is offering new possibilities for therapies and treatments for some complex diseases, as well as new diagnostic methods.²

Genetic Testing

Genetic testing is a type of medical test that identifies changes in chromosomes, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition, as well as help determine the chance of developing or passing on a genetic disorder. More than 1,000 genetic tests are currently in use, and more are being developed. The following methods can be used for genetic testing:

- Molecular genetic tests (or gene tests) study single genes or short lengths of DNA to identify variations or mutations that lead to a genetic disorder;
- Chromosomal genetic tests analyze whole chromosomes or long lengths of DNA to see if there are large genetic changes, such as an extra copy of a chromosome, that cause a genetic condition; and
- Biochemical genetic tests study the amount or activity level of proteins; abnormalities in either can indicate changes to the DNA that result in a genetic disorder.³

Direct-to-Consumer Genetic Testing

In recent years, direct-to-consumer (DTC) genetic testing options have become widely available online and in stores. A DTC genetic test kit allows a person to spit into a tube or swab the inside of his or her mouth to obtain DNA, mail the sample off, and receive an analysis. According to an October 2020 Consumer Reports survey, about one in five Americans has taken a DTC genetic

¹ MedlinePlus, *What is DNA?*, available at <https://medlineplus.gov/genetics/understanding/basics/dna/>, (last visited March 19, 2021).

² *Genetics vs. Genomics Fact Sheet*, National Human Genome Research Institute, available at <https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics>, (last visited March 19, 2021).

³ *What is Genetic Testing?*, MedlinePlus, available at <https://medlineplus.gov/genetics/understanding/testing/genetic-testing/>, (last visited Mar. 5, 2021).

test.⁴ Some of the most common brands, such as 23andMe and Ancestry, offer a variety of information, including matching a person with unknown relatives, determining what country a person's ancestors are from, revealing a person's risk of having certain illnesses, and even suggesting what diet is best.⁵ However, in addition to potentially useful insights, the tests can reveal information a person may prefer not to know, and once a person's genetic data is shared, it can potentially be sold or used to discriminate against him or her.⁶ The U.S. Food and Drug Administration (FDA) reviews some DTC genetic tests, but in general, the FDA does not review tests intended for non-medical, general wellness, or low risk medical purposes or to help a person explore his or her ancestry.⁷

Surreptitious Genetic Testing

Surreptitious genetic testing is testing without the knowledge of the person being tested, and creates a potential threat to the privacy of that person's genomic information.⁸ Some companies offering DNA testing allow consumers to obtain genetic analyses of various biological samples without requiring the consent of the individual or individuals being tested.⁹ A variety of tests can be done using these DNA samples, including health-related testing and parentage determination.¹⁰

There is no federal law prohibiting surreptitious testing. Currently about half of the states in the U.S. have laws or regulations governing genomic privacy and illegitimate uses of genomic data.¹¹ However, there is great variation in these laws. While some states prohibit the unauthorized acquisition or analysis of genetic information, others prohibit only unauthorized disclosure.¹² They also differ regarding the enforcement of these laws.¹³

Florida's DNA Privacy Law

Except for purposes of criminal prosecution, for purposes of determining paternity,¹⁴ and for purposes of acquiring specimens,¹⁵ s. 760.40, F.S., requires DNA analysis¹⁶ to be performed only

⁴ Catherine Roberts, *Read This Before You Buy a Genetic Testing Kit*, Consumer Reports, (Feb. 2, 2021) <https://www.consumerreports.org/genetic-testing/genetic-testing-kit-read-this-before-you-buy/> (last visited March 19, 2021).

⁵ *Id.*

⁶ *Id.*

⁷ FDA, *Direct-to-Consumer Test*, (Dec. 12, 2019) <https://www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests#list> (last visited March 19, 2021).

⁸ See American Medical Association Journal of Ethics, *Shedding Privacy Along with our Genetic Material: What Constitutes Adequate Legal Protection Against Surreptitious Genetic Testing?* (March of 2016), available at <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/pfor2-1603.pdf> (last visited March 19, 2021).

⁹ Privacy in Genomics, National Human Genome Research Institute, available at <https://www.genome.gov/about-genomics/policy-issues/Privacy>, (last visited March 19, 2021).

¹⁰ *Id.*

¹¹ For details on state laws regulating DNA usage available at <https://www.genome.gov/about-genomics/policy-issues/Genome-Statute-Legislation-Database>, (last visited March 19, 2021).

¹² Privacy in Genomics, National Human Genome Research Institute, available at <https://www.genome.gov/about-genomics/policy-issues/Privacy>, (last visited March 19, 2021).

¹³ *Id.*

¹⁴ See ss. 409.256, F.S., and 742.12(1), F.S.

¹⁵ See s. 943.325, F.S.

¹⁶ Defined as "the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person's body. The term includes DNA typing and genetic testing."

with informed consent. Results of a DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.¹⁷ The information is also exempt from public records laws if held by a public entity.¹⁸ A violation of the above requirements is a misdemeanor of the third degree.¹⁹ Section 760.40, F.S., also requires that a person who performs DNA analysis or receives records, results, or findings of a DNA analysis must provide the person tested with notice²⁰ that the analysis was performed or that the information was received.²¹

III. Effect of Proposed Changes:

CS/SB 1140 establishes the Protecting DNA Privacy Act. The bill creates s. 817.5655, F.S., to prohibit certain unlawful uses of DNA. The bill amends s. 760.40, F.S., to make conforming changes and define the following terms:

- “Exclusive property” to mean the right of the person whose DNA has been extracted or analyzed to exercise control over his or her DNA sample and any results of his or her DNA analysis with regard to the collection, use, retention, maintenance, disclosure, or destruction of such sample or analysis results.;
- “Express consent” to mean authorization by the person whose DNA is to be extracted or analyzed, or such person’s legal guardian or authorized representative, evidenced by an affirmative action demonstrating an intentional decision, after the person receives a clear and prominent disclosure regarding the manner of collection, use, retention, maintenance, or disclosure of a DNA sample or results of a DNA analysis for a specified purpose; and
- “DNA sample” to mean any human biological specimen from which DNA can be extracted, or the DNA extracted from such specimen.

The bill also applies these definitions to the newly created s. 817.5655, F.S.

The bill establishes four new crimes as follows:

- It is a first degree misdemeanor for a person to willfully, and without express consent, collect or retain another person’s DNA sample with the intent to perform DNA analysis.
- It is a third degree felony for a person to willfully, and without express consent, submit another person’s DNA sample for DNA analysis or to conduct or procure the conducting of another person’s DNA analysis.
- It is a third degree felony for a person to willfully, and without express consent, disclose another person’s DNA analysis results to a third party except that a person who discloses another person’s DNA analysis that were previously voluntarily disclosed by the person whose DNA was analyzed, or such person’s legal guardian or authorized representative, does not commit the crime.

¹⁷ See s. 760.40, F.S.

¹⁸ *Id.*

¹⁹ *Id.* Punishable as provided in ss. 775.082 or 775.083, F.S.

²⁰ The bill provides that the notice must state that upon the request of the person tested, the information will be made available to his or her physician, state whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. Also, if the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.

²¹ See s. 760.40, F.S.

- It is a second degree felony for a person to willfully, and without express consent, sell or otherwise transfer another person's DNA sample or the results of another person's DNA analysis to a third party, regardless of whether the DNA sample was originally collected, retained, or analyzed with express consent.

The bill specifies that each instance of collection, retention, submission, analysis, or disclosure constitutes a separate violation for which a separate penalty is authorized.

The bill provides exceptions to the crimes established in the bill for:

- Criminal investigations and prosecutions;
- Complying with a subpoena, summons, or other lawful court order;
- Complying with federal law;
- The medical diagnosis and treatment of a patient when:
 - Express consent for clinical laboratory analysis of the DNA sample was obtained by the health care practitioner who collected the DNA sample; or
 - Performed by a clinical laboratory certified by the Centers for Medicare and Medicaid Services.
- The newborn screening program established in s. 383.14, F.S.;
- Determining paternity under ss. 409.256 or 742.12(1), F.S.; and
- Performing any activity authorized in s. 943.325, F.S., pertaining to the criminal DNA database.

The bill provides an effective date of October 1, 2021.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

The bill creates new criminal offenses relating to the unlawful use of DNA. Criminal laws are exempt from the requirements of Art. VII, s. 18(d) of the Florida Constitution, relating to unfunded mandates.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. State Tax or Fee Increases:

None.

E. Other Constitutional Issues:

None Identified.

V. Fiscal Impact Statement:**A. Tax/Fee Issues:**

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

The Legislature's Office of Economic and Demographic Research (EDR) estimates that the bill will have a "positive insignificant" prison bed impact (an increase in 10 or fewer prison beds).²²

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Statutes Affected:

The bill substantially amends section 760.40 of the Florida Statutes.

The bill creates section 817.5655 of the Florida Statutes.

IX. Additional Information:**A. Committee Substitute – Statement of Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

CS by Rules on April 6, 2021:

The CS:

- Labels the act as the "Protecting DNA Privacy Act."
- Moves definitions into s. 760.40, F.S., applies those definitions to s. 817.5655, F.S., and modifies the definitions as follows:
 - Replaces the definition of "authorization" with a new definition for "express consent;"
 - Eliminates the definition for "DNA analysis;" and
 - Adds a definition for "exclusive property."

²² See Office of Economic & Demographic Research, *Complete 2021 Conference Results*, available at <http://edr.state.fl.us/content/conferences/criminaljusticeimpact/index.cfm> (last visited March 19, 2021).

- Provides an exception for the criminal prohibition against disclosing a person's DNA results to a third party for when the results were previously voluntarily disclosed by the person.
- Provides that it is a second degree felony to sell or otherwise transfer another person's DNA sample or analysis results to a third party without express consent.
- Provides additional exceptions to the criminal prohibitions for complying with court orders or federal law; the medical diagnosis and treatment of a patient under certain circumstances; and the newborn screening program.

B. Amendments:

None.