
DIGEST

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HB 968 Engrossed

2022 Regular Session

Phelps

Abstract: Requires the La. Dept. of Health to establish and maintain a sickle cell disease registry to be known as the "Skylar-Cooper Database" which shall function as a repository of accurate, complete records to aid in the cure and treatment of sickle cell disease.

Proposed law requires the La. Dept. of Health (LDH) to establish and maintain a registry of individuals diagnosed with sickle cell disease which shall be known as the "Skylar-Cooper Database". Provides that the purpose of the registry shall be to function as a single repository of accurate, complete records to aid in the cure and treatment of sickle cell disease in this state.

Proposed law requires that the sickle cell disease registry (registry) encompass, without limitation, all of the following:

- (1) A record of individuals in this state who have been diagnosed with sickle cell disease.
- (2) All data and other information associated with individuals who have been diagnosed with sickle cell disease that the secretary of LDH deems necessary and appropriate for inclusion in the registry.

Proposed law requires that upon making a diagnosis of sickle cell disease, a healthcare provider shall provide to LDH data regarding the individual who has been diagnosed with the disease.

Proposed law requires LDH to facilitate access to data in the registry through administrative rules. Stipulates that registry data as well as medical and vital records obtained by LDH or its agent in accordance with proposed law, as well as the results of any sickle cell disease study, shall be confidential and shall not be available for subpoena, nor shall such information be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

Proposed law requires the secretary of LDH to take such actions as are necessary to support the facilitation of care coordination for sickle cell patients, assist in reducing wait times to access healthcare services, and assist in promoting continuity of care for young people who age out of La. Children's Health Insurance Program coverage.

Proposed law requires the secretary of LDH to promulgate all such rules as are necessary to implement the provisions of proposed law. Provides that these rules shall include but not be limited

to the following:

- (1) Data elements to be included in the registry.
- (2) Guidelines and procedures for obtaining from healthcare facilities information regarding individuals diagnosed with sickle cell disease.
- (3) Standards for ensuring that the registry is developed and operated in a manner that comports with all applicable requirements of the Health Insurance Portability and Accountability Act (HIPAA), the HIPAA Privacy Rule, and other applicable laws and regulations governing disclosure of health information.

Proposed law establishes an exception to present law relative to public records, R.S. 44:1 et seq., exempting data in the registry from disclosure pursuant to present law.

Proposed law consolidates certain sections of present law relative to sickle cell disease (R.S. 40:1081.5 through 1081.8 and 2018.3) within the new part of law established by proposed law which pertains exclusively to sickle cell disease.

Proposed law provides that proposed law shall be known as the "Remington Skylar Watts and Betty Cooper Phelps Act".

(Amends R.S. 36:259(B)(13) and R.S. 44:4.1(B)(26); Adds R.S. 40:1125.1-1125.33)

Summary of Amendments Adopted by House

The Committee Amendments Proposed by House Committee on Health and Welfare to the original bill:

1. Delete proposed law requiring healthcare facilities to provide to LDH data regarding individuals who have been diagnosed with sickle cell disease; add in lieu thereof a requirement that upon making a diagnosis of sickle cell disease, a healthcare provider shall provide to LDH data regarding the individual who has been diagnosed with the disease.
2. Delete proposed law authorizing access to data in the sickle cell disease registry by certain specifically identified entities; add in lieu thereof a requirement that LDH facilitate access to data in the registry through administrative rules.
3. Authorize LDH or its agent to access medical and vital records in the custody of physicians, hospitals, clinics, other healthcare providers, and the office of public health in order that it may conduct sickle cell disease studies.
4. Stipulate that the data contained in the sickle cell disease registry as well as medical and vital records obtained by LDH or its agent in accordance with proposed law, as well as

the results of any sickle cell disease study, shall be confidential and shall not be available for subpoena, nor shall such information be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

5. Establish an exception to present law relative to public records, R.S. 44:1 et seq., exempting data in the sickle cell disease registry from disclosure pursuant to that law.
6. Make technical changes.