

RÉSUMÉ DIGEST

ACT 647 (HB 968)

2022 Regular Session

Phelps

New 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.

New law requires that the sickle cell disease 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.

New 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.

New 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 new 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.

New 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.

New law requires the secretary of LDH to promulgate all such rules as are necessary to implement the provisions of new 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 providers 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.

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

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

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

Effective August 1, 2022.

(Amends R.S. 36:259(B)(13) and R.S. 44:4.1(B)(26); Adds R.S. 40:1125.1, 1125.11-1125.16, 1125.21, and 1125.31-1125.33)