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## DIGEST

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HB 483 Engrossed

2017 Regular Session

Jackson

**Abstract:** Provides relative to disclosure of data maintained by the La. Tumor Registry, for duties of the registry's research committee, and for a cancer investigation and prevention program.

Proposed law requires that reports published or presented by the La. Tumor Registry (tumor registry), include aggregate-level data and not case-specific data. Provides that the tumor registry shall not disclose any information that would potentially identify a patient or a healthcare provider or facility.

Proposed law requires that the tumor registry provide diagnostic, treatment, and follow-up information concerning a patient at the request of a physician or medical facility diagnosing or treating the case as authorized by federal regulations relative to privacy of health information (45 CFR 164.506).

Proposed law authorizes the tumor registry to collaborate with the National Cancer Institute, the Centers for Disease Control and Prevention, and other national and international cancer surveillance programs designated by the tumor registry, including but not limited to the North American Association of Central Cancer Registries and the International Agency for Research on Cancer, in providing cancer data and participating in cancer studies.

Proposed law requires the tumor registry to cooperate with the office of public health of the La. Department of Health (OPH) in all of the following:

- (1) Investigating cancer concerns and other cancer-related issues and in evaluating programs.
- (2) Implementing the program of cancer investigation and prevention provided for in proposed law.

Proposed law provides that the use of registry data by OPH officials and registry-designated national cancer surveillance programs shall be considered an in-house activity and be processed expeditiously.

Proposed law provides that requests by OPH for case-specific data shall require annual approval by the institutional review boards of OPH and the La. State University Health Sciences Center-New Orleans (LSUHSC-New Orleans). Requires compliance by OPH with confidentiality standards of the tumor registry.

Proposed law authorizes the tumor registry to release case-specific data to qualified persons or organizations for the purposes of cancer prevention, control, and research; but prohibits inclusion in such data of information collected for special studies or other research projects. Requires requests for such data to be submitted in writing and reviewed and approved by the tumor registry research committee.

Proposed law requires the director of the tumor registry or his designee to coordinate the registry's research committee. Provides that the research committee may include, without limitation, the following members:

- (1) The director of the tumor registry.
- (2) A qualified representative selected from each of the following entities:
  - (a) The LSUHSC-New Orleans.
  - (b) OPH.
  - (c) The La. Cancer and Lung Trust Fund Board.

Proposed law provides for duties of the research committee with respect to requests for tumor registry data.

Proposed law requires that in determining the order of processing requests for data, the tumor registry shall give priority to requests for data from OPH for use in responding to concerns about threats to the public health. Provides that the registry shall process other requests for data in order of receipt, and that the registry may seek reimbursement from a requestor for actual costs of compiling and providing the data.

Proposed law provides standards for the tumor registry's data collection process and for maintenance by the registry of data collected.

Proposed law stipulates that the zip code and census tract are the smallest geographic areas for which the tumor registry may release aggregate data. However, provides an exception which authorizes the registry to release aggregate data for smaller geographic areas if requested by any of the following parties:

- (1) An elected member of the Legislature of La.
- (2) An elected official serving in the executive branch of state government.
- (3) The secretary of a department of the executive branch of state government.

Proposed law provides that in considering for approval a request for aggregate data, the research committee of the tumor registry shall determine whether the request complies with applicable state

and federal privacy laws. Provides that if the research committee finds that disclosure of data in response to the request would violate any such law, then the committee shall collaborate with the requestor to revise the request in order to preclude such violation.

Proposed law prohibits the research committee of the tumor registry from denying any request for aggregate data for any reason that is unrelated to compliance with state or federal privacy laws.

Proposed law requires the tumor registry to prepare an annual statistical report concerning disclosure of data to qualified persons and organizations pursuant to proposed law, and to submit the report to the office of the president of the LSU System for inclusion with the annual cancer report provided for in present law (R.S. 40:1105.10). Provides that the tumor registry shall also submit the statistical report to the following entities:

- (1) The La. State University Health Sciences Center at New Orleans.
- (2) The La. State University Health Sciences Center at Shreveport.
- (3) The La. Cancer and Lung Trust Fund Board.
- (4) Each participating hospital.

Present law (R.S. 40:1105.10) requires that an annual cancer report be developed by the LSU System and issued to the governor, the speaker of the House of Representatives, the president of the Senate, and the legislative committees on health and welfare. Proposed law requires that this report also be transmitted to the governing body of each parish in the state.

Proposed law requires the tumor registry to develop and publish on its website a mechanism by which individuals may elect to receive in electronic format notifications and reports.

Proposed law grants OPH legislative authority to operate a program of cancer investigation and prevention if sufficient funding is available for this purpose. Provides that the source of monies for the program may be any appropriation by the legislature, including appropriations of federal funds; appropriations from the Health Excellence Fund and the La. Fund created by present constitution; any public or private donations, gifts, or grants from individuals, corporations, nonprofit organizations, or other business entities; and any other monies which may be provided by law.

Proposed law requires OPH to engage and collaborate with the tumor registry and the La. Advisory Committee on Populations and Geographic Regions With Excessive Cancer Rates in administering the cancer investigation and prevention program provided for in proposed law. Stipulates that the program shall be conducted in addition to the activities of, and shall not replace or supplant, the Breast Cancer Control Program provided for in present law (R.S. 40:1105.13).

(Amends R.S. 40:1105.10(B); Adds R.S. 40:5.12, 1105.8.1, and 1105.8.2)

Summary of Amendments Adopted by House

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

1. Grant the office of public health (OPH) legislative authority to operate a cancer investigation and prevention program, subject to availability of funds for this purpose.
2. Provide that the source of monies for the cancer investigation and prevention program may be from any lawful source.
3. Stipulate that OPH shall engage and collaborate with the La. Tumor Registry (tumor registry) and the La. Advisory Committee on Populations and Geographic Regions With Excessive Cancer Rates in administering the cancer investigation and prevention program.
4. Provide that the cancer investigation and prevention program shall be conducted in addition to the activities of, and shall not replace or supplant, the Breast Cancer Control Program provided for in present law.
5. Authorize the tumor registry to release aggregate data for geographic areas smaller than the zip code and census tract level if requested by any of the following parties:
  - (a) An elected member of the Legislature of La.
  - (b) An elected official serving in the executive branch of state government.
  - (c) The secretary of a department of the executive branch of state government.
6. Require the tumor registry to develop and publish on its website a mechanism by which individuals may elect to receive in electronic format notifications and reports.
7. Require that the annual cancer report issued pursuant to present law by the president of the LSU System to the governor, the speaker of the House of Representatives, the president of the Senate, and the legislative committees on health and welfare also be transmitted to the governing body of each parish in the state.
8. Make technical changes.