
DIGEST

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HB 483 Reengrossed

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 intervention program.

Proposed law requires the La. Tumor Registry (tumor registry) to 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 requires the tumor registry to collaborate with the National Cancer Institute, the Centers for Disease Control and Prevention, the North American Association of Central Cancer Registries, the International Agency for Research on Cancer, and any other national or international cancer surveillance program it may designate 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) Evaluating programs.
- (2) Investigating cancer concerns and other cancer-related issues.
- (3) Implementing the program of cancer investigation and intervention 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 requires that, subject to the limitations of federal law and proposed law relative to privacy of health information, the tumor registry shall release case-specific data to 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 provides that if a request for data submitted in accordance with proposed law is denied by the LSUHSC-New Orleans institutional review board, the institutional review board shall provide to the requestor notice in writing of the reason for the denial electronically or by postal mail.

Proposed law requires the director of the tumor registry or his designee to coordinate the registry's research committee. Provides that the research committee shall 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. Authorizes the tumor registry to assess a charge to a requestor of data for actual costs of compiling and providing the data, and to require payment before proceeding to fulfill the data request.

Proposed law prohibits the tumor registry from releasing data in cases in which such data would disclose the identity of any person to whom the data relate and thus violate the requirements of the Health Insurance Portability and Accountability Act relating to uses and disclosure of protected health information (45 CFR 164.514). Provides that in such situations, the tumor registry may combine more years of cancer data together at the census tract level or suppress the data according to the suppression rule of the United States Cancer Statistics program.

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 laws relating to privacy of health information. 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 cancer rates and counts which includes data at the census tract level, 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 intervention 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, the La. Cancer Research Center, and the La. Advisory Committee on Populations and Geographic Regions With Excessive Cancer Rates in administering the cancer investigation and intervention 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.

The House Floor Amendments to the engrossed bill:

1. Change the description of a program provided for in proposed law from a cancer investigation and prevention program to a cancer investigation and intervention program.

2. Add the La. Cancer Research Center as an entity with which the office of public health shall collaborate in administering the cancer investigation and intervention program provided for in proposed law.
3. Delete proposed law requiring that reports published or presented by the La. Tumor Registry (tumor registry) shall include aggregate, not case-specific, data.
4. Revise proposed law prohibiting disclosure by the tumor registry of information that would potentially identify a patient to specify that the tumor registry shall not release data in cases in which such data would disclose the identity of any person to whom the data relate and thus and thus violate requirements of the Health Insurance Portability and Accountability Act.
5. Delete proposed law requiring that persons or organizations to whom the tumor registry may release case-specific data in certain circumstances must be qualified persons or organizations.
6. Require that if a request for data submitted in accordance with the provisions of proposed law is denied by the LSU Health Sciences Center-New Orleans institutional review board, the institutional review board shall provide to the requestor notice in writing of the reason for the denial.
7. Revise proposed law authorizing the tumor registry to seek reimbursement for costs of compiling and providing data to provide that the tumor registry may assess a charge to a requestor of data for actual costs of compiling and providing the data, and may require payment before proceeding to fulfill the data request.
8. Delete proposed law providing all of the following:
 - (a) That the tumor registry shall make available to the public information concerning its costs of compiling and providing data.
 - (b) That the zip code and census tract are the smallest geographic areas for which the tumor registry may release aggregate data.
 - (c) That the tumor registry may release aggregate data for geographic areas smaller than the zip code and census tract if requested by a state legislator, an elected executive branch official, or the secretary of a department of the executive branch.
 - (d) That as part of the data collection process, the tumor registry shall collect demographic and geographic data as reportable, separated variables.
 - (e) That the tumor registry shall maintain data in such a manner that the data may be retrieved from tumor registry computer systems without necessity of creating new

tabulations, programs, records, or reports.

- (f) That the tumor registry shall maintain data in a manner which facilitates provision of data in response to requests for aggregate data and extraction by a simple query of the specific data fields.
 - (g) A listing of specific statistical methods which the tumor registry may employ in de-identifying data for purposes of disclosure protection.
9. Delete proposed law providing that the tumor registry may be obligated to extract existing data collected as independent variables.
 10. Delete proposed law requiring the tumor registry to prepare an annual statistical report concerning disclosure of data to qualified persons and organizations.
 11. Add proposed law requiring the tumor registry to prepare an annual statistical report concerning cancer rates and counts which includes data at the census tract level.