

2017 Regular Session

HOUSE BILL NO. 483

BY REPRESENTATIVES JACKSON, JOHNSON, LEBAS, POPE, RICHARD, AND STAGNI

Prefiled pursuant to Article III, Section 2(A)(4)(b)(i) of the Constitution of Louisiana.

HEALTH/CANCER: Provides relative to disclosure of data maintained by the Louisiana Tumor Registry and for a cancer investigation initiative

1 AN ACT

2 To amend and reenact R.S. 40:1105.10(B) and to enact R.S. 40:5.12, 1105.8.1, and 1105.8.2,

3 relative to collection, maintenance, and reporting of data on cancer by the Louisiana

4 Tumor Registry of the Louisiana State University System; to provide authorizations

5 and restrictions concerning reporting of data by the registry; to provide relative to

6 requests for registry data by the office of public health of the Louisiana Department

7 of Health; to provide for cooperation between the registry and the office of public

8 health in certain functions; to provide for state cancer investigation and prevention

9 functions; to establish procedures for processing of data requests submitted to the

10 registry; to provide for duties of the research committee of the registry; to provide

11 standards for the data collection process of the registry and for maintenance of data

12 collected; to provide for annual reports of certain registry activities and data on

13 cancer to designated parties; to provide for electronic notifications and reports

14 concerning cancer data; and to provide for related matters.

15 Be it enacted by the Legislature of Louisiana:

16 Section 1. R.S. 40:1105.10(B) is hereby amended and reenacted and R.S. 40:5.12,

17 1105.8.1, and 1105.8.2 are hereby enacted to read as follows:

1 case-specific, data. The tumor registry shall not disclose any information that would
2 potentially identify a patient or a healthcare provider or facility.

3 B. The tumor registry shall provide diagnostic, treatment, and follow-up
4 information concerning a patient, if requested, to a physician or medical facility
5 diagnosing or treating the case as authorized pursuant to 45 CFR 164.506.

6 C.(1) The tumor registry is hereby authorized to collaborate with the
7 National Cancer Institute, the Centers for Disease Control and Prevention, and other
8 national and international cancer surveillance programs designated by the tumor
9 registry, including but not limited to the North American Association of Central
10 Cancer Registries and the International Agency for Research on Cancer, in providing
11 cancer data and participating in cancer studies.

12 (2)(a) The tumor registry shall cooperate with the office of public health of
13 the Louisiana Department of Health, referred to hereafter in this Section as the
14 "office of public health", in investigating cancer concerns and other cancer-related
15 issues and in evaluating programs. Because the tumor registry data are an integral
16 part of national and state cancer prevention and control programs, the use of registry
17 data by office of public health officials and registry-designated national cancer
18 surveillance programs shall be considered an in-house activity and shall be processed
19 expeditiously.

20 (b) The tumor registry shall cooperate with the office of public health in
21 implementing the program of cancer investigation and prevention provided for in
22 R.S. 40:5.12.

23 (3) Requests by the office of public health for case-specific data shall require
24 annual approval by the office of public health institutional review board and by the
25 institutional review board of the Louisiana State University Health Sciences
26 Center-New Orleans, referred to hereafter in this Section as the "LSUHSC-New
27 Orleans". Additionally, the office of public health shall comply with all applicable
28 confidentiality standards of the tumor registry, and the tumor registry shall review

1 reports written for public release using tumor registry data in advance of their public
2 release.

3 D.(1) The tumor registry may release case-specific data to qualified persons
4 or organizations for the purposes of cancer prevention, control, and research.
5 However, no such data shall include information collected for special studies or other
6 research projects. The tumor registry shall have and shall reserve the right to
7 prioritize its responses to data requests.

8 (2) Requests from researchers for case-specific tumor registry incidence
9 data, including data linkages, shall be submitted in writing and shall be reviewed and
10 approved by the tumor registry research committee following the established policies
11 of the registry. These policies shall require, without limitation, all of the following:

12 (a) Approval from the LSUHSC-New Orleans institutional review board and
13 compliance with the LSUHSC-New Orleans HIPAA research policy.

14 (b) Approval from the researcher's institutional review board and compliance
15 with that institution's HIPAA research policy.

16 (c) Signature of the tumor registry's form entitled "Agreement to Maintain
17 Confidentiality of Data", or any successor form, by each investigator who will have
18 access to the data indicating agreement by the investigator to adhere to the tumor
19 registry confidentiality provisions and prohibiting the disclosure of tumor registry
20 data in any civil, criminal, administrative, or other proceeding.

21 (d) Provision of a copy of the complete protocol for the project.

22 (e) Completion of all requirements provided in the document entitled
23 "Louisiana Tumor Registry: Researchers' Requests for Data", or any successor
24 document.

25 (f) Prior to contacting a patient or his next of kin, notification to the patient's
26 physician, if required.

27 (g) Destruction or return of data once the research is completed.

1 E.(1) The director of the tumor registry or his designee shall coordinate the
2 research committee of the tumor registry. The research committee may include,
3 without limitation, the following members:

4 (a) The director of the tumor registry.

5 (b) A qualified representative selected from each of the following entities:

6 (i) The LSUHSC-New Orleans.

7 (ii) The office of public health.

8 (iii) The Louisiana Cancer and Lung Trust Fund Board.

9 (2) The research committee shall verify that the researchers are able to
10 execute the proposal, in terms of both financial support and professional
11 qualifications; that the study has scientific and ethical merit; and that the researchers
12 will obtain appropriate consent.

13 F.(1) In determining the order of processing requests for data, the tumor
14 registry shall give priority to requests for data from the office of public health for use
15 in responding to concerns about threats to the public health.

16 (2) Subject to the provisions of the Public Records Law, R.S. 44:1.1 et seq.,
17 the tumor registry shall process requests for aggregate data other than those provided
18 for in Paragraph (1) of this Subsection in the order of receipt. The tumor registry
19 shall respond to any public request in a timely manner, as resources permit, if the
20 request meets the applicable requirements of R.S. 40:3.1 and 1105.8.

21 (3)(a) The tumor registry may seek reimbursement from a requestor of data
22 for actual costs of compiling and providing the data.

23 (b) The tumor registry shall make available to the public information
24 concerning its costs of compiling and providing data.

25 (4)(a) Except as provided in Subparagraph (b) of this Paragraph, the zip code
26 and census tract are the smallest geographic areas for which the tumor registry may
27 release aggregate data.

28 (b) The tumor registry may release aggregate data for geographic areas
29 smaller than those provided in Subparagraph (a) of this Paragraph if requested by an

1 elected member of the Legislature of Louisiana, an elected official serving in the
2 executive branch of state government, or the secretary of a department of the
3 executive branch of state government.

4 (5) The tumor registry shall not be required in any instance to perform
5 original work to create data not currently in existence; however, the tumor registry
6 may be obligated to extract existing data collected as independent variables.

7 G.(1) As a part of the data collection process, the tumor registry shall collect
8 demographic and geographic data as reportable, separated variables. When feasible,
9 the tumor registry shall collect census tract data as reportable, separated variables.
10 Dates of birth shall be reported separately as day, month, and year.

11 (2) The tumor registry shall maintain the data provided for in this Subsection
12 in such a manner that the data may be retrieved from tumor registry computer
13 systems without necessity of creating new tabulations, programs, records, or reports.

14 The tumor registry shall maintain such data in a manner which facilitates all of the
15 following:

16 (a) Provision of data in response to requests for aggregate data for any cancer
17 data or related data.

18 (b) Extraction by a simple query of the specific data fields.

19 H.(1) In considering for approval or denial a request for aggregate data, the
20 research committee of the tumor registry shall determine whether the request
21 complies with applicable state and federal privacy laws. If the research committee
22 finds that disclosure of data in response to the request would violate any such law,
23 then the committee shall collaborate with the requestor to revise the request in order
24 to preclude such violation.

25 (2) In collaborating with a requestor as provided in Paragraph (1) of this
26 Subsection, the research committee may employ methods for de-identifying
27 case-specific data as defined by the Centers for Disease Control and Prevention and
28 any other de-identification or statistical methods for disclosure protection including,
29 without limitation, the following:

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

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.