

2017 Regular Session

HOUSE BILL NO. 483

BY REPRESENTATIVES JACKSON, BAGNERIS, BILLIOT, BOUIE, TERRY BROWN, COX, GISCLAIR, JIMMY HARRIS, HUNTER, JEFFERSON, JENKINS, JOHNSON, JORDAN, LEBAS, LYONS, MARCELLE, NORTON, PIERRE, POPE, RICHARD, SMITH, AND STAGNI AND SENATORS PEACOCK AND THOMPSON

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 maintenance and reporting of data on cancer by the Louisiana Tumor
4 Registry of the Louisiana State University System; to provide authorizations and
5 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 intervention
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 for annual reports of cancer data to designated parties; to provide for electronic
12 notifications and reports concerning cancer data; and to provide for related matters.

13 Be it enacted by the Legislature of Louisiana:

14 Section 1. R.S. 40:1105.10(B) is hereby amended and reenacted and R.S. 40:5.12,
15 1105.8.1, and 1105.8.2 are hereby enacted to read as follows:

16 §5.12. Cancer investigation and intervention

17 A. Cancer control is hereby declared to be an urgent public health priority
18 of this state.

19 B. The state health officer and the office of public health of the Louisiana
20 Department of Health are hereby authorized to operate a program of cancer
21 investigation and subsequent intervention if sufficient funding is available for this
22 purpose.

1 C. The source of monies for the cancer investigation and intervention
2 program provided for in this Section may be any appropriation by the legislature,
3 including appropriations of federal funds; appropriations from the Health Excellence
4 Fund created by Article VII, Section 10.8(A)(2) of the Constitution of Louisiana, and
5 appropriations from the Louisiana Fund created by Article VII, Section 10.9(A) of
6 the Constitution of Louisiana; any public or private donations, gifts, or grants from
7 individuals, corporations, nonprofit organizations, or other business entities; and any
8 other monies which may be provided by law.

9 D. The state health officer and the office of public health of the Louisiana
10 Department of Health shall engage and collaborate with the Louisiana Tumor
11 Registry, the Louisiana Cancer Research Center, and the Louisiana Advisory
12 Committee on Populations and Geographic Regions With Excessive Cancer Rates
13 in administering the cancer investigation and intervention program provided for in
14 this Section.

15 E. The program provided for in this Section shall be conducted in addition
16 to the activities of, and shall not replace or supplant, the Louisiana Cancer
17 Prevention and Control Programs of the School of Public Health of the Louisiana
18 State University Health Sciences Center-New Orleans.

19 * * *

20 §1105.8.1. Louisiana Tumor Registry; research committee; disclosure of registry
21 data

22 A. The Louisiana Tumor Registry, referred to hereafter in this Section as the
23 "tumor registry", shall provide diagnostic, treatment, and follow-up information
24 concerning a patient, if requested, to a physician or medical facility diagnosing or
25 treating the case as authorized pursuant to 45 CFR 164.506.

26 B.(1) The tumor registry shall collaborate with the National Cancer Institute,
27 the Centers for Disease Control and Prevention, the North American Association of
28 Central Cancer Registries, the International Agency for Research on Cancer, and any
29 other national or international cancer surveillance program it may designate in
30 providing cancer data and participating in cancer studies.

1 (2) The tumor registry shall cooperate with the office of public health of the
2 Louisiana Department of Health, referred to hereafter in this Section as the "office
3 of public health", in evaluating programs and investigating cancer concerns and other
4 cancer-related issues through activities including, without limitation, cooperating
5 with the office of public health in implementing the program of cancer investigation
6 and intervention provided for in R.S. 40:5.12. Because the tumor registry data are
7 an integral part of national and state cancer prevention and control programs, the use
8 of registry data by office of public health officials and registry-designated national
9 cancer surveillance programs shall be considered an in-house activity and shall be
10 processed expeditiously.

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

16 C.(1) Subject to the limitations of Subsection F of this Section, the tumor
17 registry shall release case-specific data to persons or organizations for the purposes
18 of cancer prevention, control, and research in accordance with Paragraph (2) of this
19 Subsection. However, no such data shall include information collected for special
20 studies or other research projects. The tumor registry shall have and shall reserve the
21 right to prioritize its responses to data requests.

22 (2) Requests from persons or organizations for case-specific tumor registry
23 incidence data, including data linkages, shall be submitted in writing and shall be
24 reviewed and approved by the tumor registry research committee following the
25 established policies of the registry. These policies shall require, without limitation,
26 all of the following:

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

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

1 (c) Execution of the tumor registry's form entitled "Agreement to Maintain
2 Confidentiality of Data", or any successor form, by each investigator who will have
3 access to the data indicating agreement by the investigator to adhere to the tumor
4 registry confidentiality provisions and prohibiting the disclosure of tumor registry
5 data in any civil, criminal, administrative, or other proceeding.

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

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

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

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

13 (3) If a request for data submitted in accordance with the provisions of this
14 Subsection is denied by the LSUHSC-New Orleans institutional review board, the
15 institutional review board shall provide to the requestor notice in writing of the
16 reason for the denial electronically or by postal mail.

17 D.(1) The director of the tumor registry or his designee shall coordinate the
18 research committee of the tumor registry. The research committee shall include,
19 without limitation, the following members:

20 (a) The director of the tumor registry.

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

22 (i) The LSUHSC-New Orleans.

23 (ii) The office of public health.

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

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

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

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

9 (3) The tumor registry may assess a charge to a requestor of data for actual
10 costs of compiling and providing the data, and may require payment before
11 proceeding to fulfill the data request.

12 (4) The tumor registry shall not be required in any instance to perform
13 original work to create data not currently in existence.

14 F.(1) The tumor registry shall not release data in cases in which such data
15 would disclose the identity of any person to whom the data relate and thus violate the
16 requirements of the Health Insurance Portability and Accountability Act relating to
17 uses and disclosure of protected health information (45 CFR 164.514). In such
18 situations, the tumor registry may combine more years of cancer data together at the
19 census tract level or suppress the data according to the suppression rule of the United
20 States Cancer Statistics program.

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

27 (3) In collaborating with a requestor as provided in Paragraph (2) of this
28 Subsection, the research committee shall employ methods for de-identifying
29 case-specific data as defined by the Centers for Disease Control and Prevention and
30 any other de-identification or statistical methods for disclosure protection.

1 (4) The research committee of the tumor registry shall not deny any request
 2 for aggregate data for any reason that is unrelated to compliance with state or federal
 3 privacy laws.

4 G. The tumor registry shall annually prepare a statistical report concerning
 5 cancer rates and counts which includes data at the census tract level, and shall submit
 6 the report to the office of the president for inclusion with the annual cancer report
 7 required by R.S. 40:1105.10. The tumor registry shall also provide the statistical
 8 report required by this Subsection to the Louisiana State University Health Sciences
 9 Center at New Orleans, the Louisiana State University Health Sciences Center at
 10 Shreveport, the Louisiana Cancer and Lung Trust Fund Board, and each participating
 11 hospital.

12 §1105.8.2. Cancer data; electronic notifications and reports

13 The Louisiana Tumor Registry shall develop and publish on its website a
 14 mechanism by which individuals may elect to receive in electronic format
 15 notifications and reports issued by the tumor registry.

16 * * *

17 §1105.10. Annual cancer report

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19 B. The ~~report~~ office of the president shall cause the report to be submitted
 20 by March 31 ~~thirty-first~~ of each year to the governor, the speaker of the House of
 21 Representatives, the president of the Senate, and the House and Senate ~~Committees~~
 22 committees on ~~Health and Welfare~~ health and welfare, and the governing body of
 23 each parish in the state of Louisiana.

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 SPEAKER OF THE HOUSE OF REPRESENTATIVES

 PRESIDENT OF THE SENATE

 GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____

CODING: Words in ~~struck through~~ type are deletions from existing law; words underscored are additions.