

2017 Regular Session

HOUSE BILL NO. 483

BY REPRESENTATIVE JACKSON

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

1 AN ACT

2 To enact R.S. 40:1105.8.1, relative to collection, maintenance, and reporting of data by the

3 Louisiana Tumor Registry of the Louisiana State University System; to provide

4 authorizations and restrictions concerning reporting of data by the registry; to

5 provide relative to requests for registry data by the office of public health of the

6 Louisiana Department of Health; to provide for cooperation between the registry and

7 the office of public health in certain functions; to establish procedures for processing

8 of data requests submitted to the registry; to provide for duties of the research

9 committee of the registry; to provide standards for the data collection process of the

10 registry and for maintenance of data collected; to provide for annual reports of

11 certain registry activities to the legislature, the governor, and other designated

12 parties; and to provide for related matters.

13 Be it enacted by the Legislature of Louisiana:

14 Section 1. R.S. 40:1105.8.1 is hereby enacted to read as follows:

15 §1105.8.1. Louisiana Tumor Registry; research committee; disclosure of registry

16 data to qualified persons and organizations

17 A. Reports published or presented by the Louisiana Tumor Registry, referred

18 to hereafter in this Section as the "tumor registry", shall include aggregate, not

19 case-specific, data. The tumor registry shall not disclose any information that would

20 potentially identify a patient or a healthcare provider or facility.

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

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

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

18 (3) Requests by the office of public health for case-specific data shall require
19 annual approval by the office of public health institutional review board and by the
20 institutional review board of the Louisiana State University Health Sciences
21 Center-New Orleans, referred to hereafter in this Section as the "LSUHSC-New
22 Orleans". Additionally, the office of public health shall comply with all applicable
23 confidentiality standards of the tumor registry, and the tumor registry shall review
24 reports written for public release using tumor registry data in advance of their public
25 release.

26 D.(1) The tumor registry may release case-specific data to qualified persons
27 or organizations for the purposes of cancer prevention, control, and research.
28 However, no such data shall include information collected for special studies or other

1 research projects. The tumor registry shall have and shall reserve the right to
2 prioritize its responses to data requests.

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

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

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

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

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

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

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

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

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

26 (a) The director of the tumor registry.

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

28 (i) The LSUHSC-New Orleans.

29 (ii) The office of public health.

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

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

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

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

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

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

18 (4) The zip code and census tract are the smallest geographic areas for which
19 the tumor registry may release aggregate data.

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

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

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

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

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

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

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

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

17 (a) Suppression.

18 (b) Random perturbations.

19 (c) Recoding.

20 (d) Top- or bottom-coding.

21 (e) Numerator and denominator cell aggregation.

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

25 I. The tumor registry shall annually prepare a statistical report concerning
26 disclosure of data to qualified persons and organizations, and shall submit the report
27 to the office of the president for inclusion with the annual cancer report required by
28 R.S. 40:1105.10. The tumor registry shall also provide the statistical report required
29 by this Subsection to the Louisiana State University Health Sciences Center at New

1 Orleans, the Louisiana State University Health Sciences Center at Shreveport, the
2 Louisiana Cancer and Lung Trust Fund Board, and each participating hospital.

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 Original

2017 Regular Session

Jackson

Abstract: Provides relative to disclosure of data maintained by the Louisiana Tumor Registry and for duties of the registry's research committee with respect to requests for data.

Proposed law requires that reports published or presented by the Louisiana 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 Louisiana Department of Health ("OPH"), in investigating cancer concerns and other cancer-related issues and in evaluating programs. 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 Louisiana State University Health Sciences Center-New Orleans ("LSUHSC-New Orleans"). Provides further for compliance 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 such requests 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 Louisiana 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 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 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 to the legislature and the governor required by present law (R.S. 40:1105.10). Provides that the tumor registry shall also submit the statistical report to the following entities:

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

(Adds R.S. 40:1105.8.1)