
DIGEST

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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)