Louisiana Tumor Registry Law, 2017 Revision

PART III. CANCER AND CARDIO-PULMONARY DISEASES PROGRAMS

§1105.1. Definitions

As used in this Part:

(1) "President" shall mean the president of the Louisiana State University System or his designee.

(2) "Participating hospital" shall mean every hospital operating as such in the state of Louisiana.

(3) "Pathology laboratory" shall mean every pathology laboratory located or doing business in the state of Louisiana.

(4) "Office" shall mean the office of the president.

(5) "Board" shall mean the Louisiana Cancer and Lung Trust Fund Board.

(6) "Health care provider" shall mean every licensed health care facility and licensed health care provider, as defined in R.S. 40:1231.1(A), in the state of Louisiana.

(7) "Radiation center" shall mean every freestanding radiation diagnostic and treatment facility in the state of Louisiana.

Added by Acts 1978, No. 653, §1. Amended by Acts 1982, No. 812, §1; Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.80 by HCR 84 of 2015 R.S.

§1105.2. Cancer registry program; data; statewide

The president of the Louisiana State University System shall establish in the office of the president a statewide registry program for reporting cancer cases for the purpose of gathering statistical data to aid in the assessment of cancer incidence, survival rates, possible causes of specific cancers, and other related aspects of cancer in Louisiana. The program shall collect and disseminate cancer incidence data on a statewide level in accordance with the provisions of this Part.

Added by Acts 1978, No. 653, §1. Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.81 by HCR 84 of 2015 R.S.

§1105.3. Powers; duties

The president shall:

(1) Collaborate with each participating health care provider and radiation center in the state of Louisiana to establish a uniform statewide registry system for collecting cancer incidence data and shall promulgate rules and regulations therefor in accordance with policies established by the board.

(2) Establish quality control programs and a training program for health care providers and the personnel of the participating radiation centers.

(3) Cooperate with the National Cancer Institute, the Centers for Disease Control, and other national and international cancer surveillance programs designated by the Louisiana Tumor Registry in providing cancer data.

(4) Comply with reporting procedures and requirements established by the board for tumor registry.

(5) Collaborate in studies with clinicians and epidemiologists and publish reports on the results of such studies, and

(6) Establish, in accordance with policies of the board, rules and regulations to provide for the confidentiality of a patient's records.

(7) Establish and promulgate, in accordance with policies established by the board, the rules and regulations necessary to effectuate the purposes of this Part.

(8) Contract with private tumor registries for the collection and furnishing of data to the statewide registry and for the necessary planning and coordination incident thereto.

Added by Acts 1978, No. 653, §1. Amended by Acts 1982, No. 812, §1; Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Acts 2003, No. 225, §1; Redesignated from R.S. 40:1299.82 by HCR 84 of 2015 R.S.

§1105.4. Authority

In addition to other authority, the president may:

(1) Accept on behalf of the state any federal funds to assist in meeting the cost of carrying out purposes of this Part.

(2) Accept on behalf of the state funds from any private agency, such as the American Cancer Society, to assist in the cost of carrying out the purposes of this Part.

(3) Repealed by Acts 1985, No. 345, §1, eff. July 9, 1985.

Added by Acts 1978, No. 653, §1. Amended by Acts 1982, No. 812, §1; Acts 1985, No. 345, §1, eff. July 9, 1985; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.83 by HCR 84 of 2015 R.S.

§1105.5. Participation in program

A. Any health care provider or radiation center diagnosing or providing treatment to cancer patients shall report each case of cancer to the president in a format prescribed by the president within six months of admission or diagnosis. If the facility fails to report in a format prescribed by the president, the president may enter the facility, obtain the information, and report it in the appropriate format. In these cases, the facility shall reimburse the president for the cost of obtaining and reporting the information.

B. Any health care provider or radiation center diagnosing or providing treatment to cancer patients shall report each cancer case. In addition, health care providers shall furnish follow-up data on each cancer patient when requested.

C. Any health care provider or radiation center which provides diagnostic or treatment services to patients with cancer shall report any additional demographic, diagnostic, or treatment information requested by the president concerning any person presently or previously receiving services who has or had a malignant tumor. Additionally, the president shall have physical access to all records which would identify cases of

cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient.

Added by Acts 1978, No. 653, §1; Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.84 by HCR 84 of 2015 R.S.

§1105.6. Reports; liability for

A. No action for damages arising from the disclosure of confidential or privileged information may be maintained against any person, or the employer or employee of any person, who participates in good faith in the reporting of cancer registry data or data for cancer morbidity or mortality studies in accordance with this Part.

B. No license of a health care provider may be denied, suspended, or revoked for good faith disclosure of confidential or privileged information or the reporting of cancer registry data or data for cancer morbidity studies in accordance with this Part.

C. Nothing in this Part shall be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct.

D. All information reported pursuant to this Part shall be confidential and privileged. The president shall take strict measures to ensure that all identifying information is kept confidential.

E. All information regarding case specific data, as distinguished from group, tabular, or aggregate data concerning patients or health care providers contained in records of interviews, written reports, and statements procured by the president or by any other person, agency, or organization acting in connection with cancer morbidity and mortality studies shall be confidential and privileged and shall be used solely for the purposes of the study. Nothing in this Section shall prevent the president from publishing compilations relating to morbidity and mortality studies which do not identify case specific data or sources of information.

Added by Acts 1978, No. 653, §1; Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.85 by HCR 84 of 2015 R.S.

§1105.7. Advisory functions

A. The tumor registry shall be operated under policies developed by the board and administered by the president.

B. The board shall establish policies for the development, accumulation, and distribution of data obtained under this Part.

C. The board shall exercise its powers, duties, functions, and responsibilities in the manner provided for agencies transferred in accordance with R.S. 36:802. The terms "secretary" and "undersecretary" as used in such Section and as applicable to the board shall mean the president or the president's designee.

Added by Acts 1978, No. 653, §1. Amended by Acts 1982, No. 812, §1; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.86 by HCR 84 of 2015 R.S.

§1105.8. Disclosure of medical records to cancer registries

A. Notwithstanding any other provision of law to the contrary, all health care providers and radiation centers shall release an abstract of the patient's record reflecting the past or present physical condition of a patient upon request of the Louisiana cancer registry program established pursuant to the provisions of this Part. The cancer registry shall take strict measures to assure that all identifying information contained in patient record abstracts will be kept confidential.

B. The president may enter into agreements to exchange confidential information with other cancer registries in order to obtain complete reports of Louisiana residents diagnosed or treated in other states and to provide information to other states regarding their residents diagnosed or treated in Louisiana. However, before releasing confidential information the president shall obtain from such state registries, agencies, or researchers an agreement in writing to keep nonaggregate, case-specific information confidential and privileged. In no event shall either cancer registry bear liability for loss, expense, attorney fees, or claims for injury or damages arising out of acts or omissions in the performance of this agreement on the part of the other registry.

C. The office of the president shall promulgate rules and regulations in accordance with the Administrative Procedure Act to specify the extent to which confidential data may be disclosed to other local, state, or federal public health or environmental agencies, or to corroborating medical researchers, when the confidential information is necessary to carry out the duties of the agency or researchers in the investigation, control, or surveillance of disease, as determined by the office of the president. Before releasing confidential information to the researchers, the president shall obtain an agreement in writing from the researchers that they will keep nonaggregate, case-specific information confidential and privileged and that neither the office of the president nor the other entity shall bear liability for loss, expense, attorney fees, or claims for injury or damages arising out of acts or omissions in the performance of this agreement on the part of the other.

D. Any disclosure authorized by this Part shall include only the information necessary for the stated purpose of the requested disclosure, and shall be made only upon written agreement that the information will be kept confidential and will not be further disclosed without written authorization of the office of the president.

E. The furnishing of confidential data in accordance with this Part shall not expose any person, agency, or entity furnishing data to liability and shall not be considered to be in violation of any privileged or confidential relationship, provided the participant has acted in good faith in the reporting as required in this Part.

F. No case specific data shall be available for subpoena nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason. Nothing in this Section shall supersede the provisions of R.S. 40:3.1(A) through (H).

G. Nothing in this Part shall be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct.

Added by Acts 1978, No. 660, §2. Amended by Acts 1982, No. 812, §1; Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.87 by HCR 84 of 2015 R.S.

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

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

B.

(1) The tumor registry shall 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.

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

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

C.

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

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

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

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

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

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

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

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

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

(3) If a request for data submitted in accordance with the provisions of this Subsection 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.

D.

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

(a) The director of the tumor registry.

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

(i) The LSUHSC-New Orleans.

(ii) The office of public health.

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

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

E.

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

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

(3) 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.

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

F.

(1) 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 violate the requirements of the Health Insurance Portability and Accountability Act relating to uses and disclosure of protected health information (45 CFR 164.514). 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.

(2) In considering for approval or denial 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. 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.

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

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

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

Acts 2017, No. 373, §1.

§1105.8.2. Cancer data; electronic notifications and reports

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

Acts 2017, No. 373, §1.

§1105.9. Louisiana Cancer and Lung Trust Fund Board

A.

(1) There is hereby created the Louisiana Cancer and Lung Trust Fund Board, which shall consist of the following members appointed and reappointed by the

governor, to serve at his pleasure, upon recommendation of each institution and organization represented:

(a) A representative from Tulane University School of Medicine.

(b) A representative from the Louisiana State University School of Medicine, New Orleans.

(c) A representative from the Louisiana State University School of Medicine, Shreveport.

(d) A representative from the Alton Ochsner Medical Foundation.

(e) A representative of the American Cancer Society, Louisiana Division, Inc.

(f) A representative of the American Lung Association of Louisiana, Inc.

(g) A representative of the Leukemia Society of America, Inc., Louisiana Chapter.

(h) A representative of the Mary Bird Perkins Cancer Radiation and Research Foundation, Inc.

(i) A representative of the Xavier University School of Pharmacy.

(j) A representative of the Louisiana State Medical Society.

(k) A representative of the Acadiana Medical Research Foundation.

(l) A representative of the American Heart Association, Louisiana Affiliation.

(2) Each appointment by the governor shall be subject to Senate confirmation.

B. The board shall determine the eligibility of medical research programs and clinical investigation and training projects to receive funds; however, sufficient funds shall be allocated annually to the statewide registry program for reporting cancer cases under the provisions of R.S. 40:1105.1 et seq. Administration of funds shall be exercised by the office of the president.

C.

(1) The board shall establish rules and regulations for its own procedures, establish policies for the operation of the statewide registry program for reporting cancer cases established under the provisions of R.S. 40:1105.1 et seq., establish criteria for review panels, and establish guidelines and deadlines for grant applications to be submitted. The appointment of review panels for the purpose of evaluating grant applications and making recommendations to the board on a priority basis shall be made before monies are allocated. Any member of the board or review panels with a direct conflict of interest shall excuse himself or herself from voting on any grant proposal.

(2) The board shall elect from among its members a chairman, a vice chairman, a secretary, and a treasurer. Any member may hold two of these positions. In the absence of the chairman, the vice chairman shall preside and in the absence of the chairman and vice chairman, the secretary shall preside.

(3) The members shall not receive compensation for their services but shall be entitled to reimbursement for expenses, including travel expenses, incurred in the discharge of their duties.

(4) Six members shall constitute a quorum for the transaction of business; however, no board action shall be taken by a vote of less than a majority of the full board.

(5) The secretary shall keep complete and accurate records of all meetings and actions taken by the board.

(6) The treasurer shall keep full and accurate financial records, make periodic reports to the board, and submit a complete annual report, in written form, to the secretary.

(7) Meetings of the board shall be held at regular intervals as provided in the bylaws. Emergency meetings may be held upon twenty-four hours actual notice and business transacted, provided that not less than a majority of the full board concurs in the proposed action.

D. For purposes of this Section, the following definitions shall apply:

(1) "Medical research" shall mean a program to determine the cause and prevention of disease.

(2) "Clinical investigation" shall mean the application of the results of medical research to treat patients.

(3) "Training" shall mean the educational preparation for a subspecialist career in cancer or lung disease.

E. A current report on the programs funded shall be made to the House Committee on Ways and Means and to the Senate Committee on Revenue and Fiscal Affairs, meeting jointly, prior to each regular session of the legislature.

F. Any member of the board or of a review panel, whether or not such member is compensated by the institution or organization he represents, shall recuse himself from participating in any discussion or voting regarding any matter relating to awarding a grant or contracting with the institution or organization he is appointed to represent. No member of the board or of a review panel who complies with the recusal provisions contained in this Subsection shall be deemed to have violated the Code of Governmental Ethics. The appointment of a compensated employee as a representative of a designated institution or organization shall not constitute a prohibited relationship under the provisions of the Code of Governmental Ethics.

Added by Acts 1980, No. 825, §1, eff. Aug. 1, 1980. Amended by Acts 1982, No. 812, §1; Acts 1984, 1st Ex. Sess., No. 14, §1, eff. July 1, 1984; Acts 1985, No. 929, §1; Acts 1989, No. 355, §1; Acts 1992, No. 227, §1; Acts 1992, No. 984, §12; Acts 1993, No. 1004, §1; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.88 by HCR 84 of 2015 R.S.

§1105.10. Annual cancer report

A. The office of the president shall annually publish a comprehensive report based on available information on the incidence of cancer in Louisiana and the progress made in reducing or eliminating the high cancer rates in Louisiana.

B. The office of the president shall cause the report to be submitted by March thirty-first of each year to the governor, the speaker of the House of Representatives, the president of the Senate, the House and Senate committees on health and welfare, and the governing body of each parish in the state of Louisiana.

C. The Joint Subcommittee on Health of the Joint Committee on Health and Welfare shall oversee the compilation of the report during the year.

Added by Acts 1983, No. 711, §1. Amended by Acts 1995, No. 1197, §1, eff. June 29, 1995; Acts 2001, No. 197, §1; Redesignated from R.S. 40:1299.89 by HCR 84 of 2015 R.S.; Acts 2017, No. 373, §1.

§1105.11. Annual lung cancer report

A. The Louisiana Cancer and Lung Trust Fund Board shall annually publish a comprehensive report on the incidence of lung cancer in Louisiana and the progress made in reducing or eliminating the high lung cancer rates in Louisiana. The report shall place special emphasis on the lung cancer rate in the southern portion of the state.

B. The report shall be submitted to the governor, the speaker of the House of Representatives, the president of the Senate, and the House and Senate Committees on Health and Welfare.

C. The Joint Subcommittee on Health of the Joint Committee on Health and Welfare shall oversee the compilation of the report.

Acts 1984, No. 468, §1; Redesignated from R.S. 40:1299.90 by HCR 84 of 2015 R.S.