Stuart Bishop   HB No. 350

Abstract: Adds conditions and protections relative to use of patient health care data to the La. Health Care Consumers' Right to Know law.

Present law, the La. Health Care Consumers' Right to Know (R.S. 40:1300.111 et seq.), provides relative to access to provider specific health care cost, quality, and outcome data on health care facilities, providers, and insurance plans. Proposed law generally retains present law and adds thereto certain conditions and restrictions for use of health care information.

Proposed law requires the Dept. of Health and Hospitals (DHH), in consultation with the Health Data Panel created as an advisory council within the department by present law, to maintain a computerized data base of personal health information of consumers in a secure environment in compliance with federal laws providing for the security of the system containing such data. Requires that in the event of a known or suspected data breach, DHH shall, within 30 days of the breach, notify each La. resident whose personal information was, or is reasonably believed to have been, acquired by an unauthorized person.

Proposed law requires that changes to the mandatory health care data elements or the methodology by which data is to be reported by health care providers and health plans to DHH be approved by a majority vote of the members of the Health Data Panel and promulgated by DHH in rule.

Proposed law requires DHH to ensure confidentiality of patient data collected from hospitals and other health care providers by adhering to and complying fully with appropriate privacy protection protocols that are at least as stringent as the HIPAA Privacy Rule. Provides that DHH shall not release to an outside party or subcontractor any of the following:

(1)   Patient level data.

(2)   Information collected from a health care provider that identifies a patient or person under whom the patient is insured.

(3)   Any physician, facility, payer, or employer identifiers.

Proposed law provides that data collected pursuant to present law and proposed law may be disclosed for research purposes, but only under the following circumstances:

(1)   The requesting entity is recognized as a health care research organization, focused on the improvement of health care outcomes through education and community engagement.

(2)   The data sought for use in research qualifies as a de-identified personal health information as defined in the HIPAA Privacy Rule.

Proposed law provides that all requests for data shall be submitted to DHH and reviewed and approved by a majority vote of the Health Data Panel. Requires that each data request include:

(1)   A description of the requesting entity including its ownership structure.

(2)   Rationale for the study or data use.

(3)   A summary of the project or study plan that includes a project timeline, definition of project scope, and justification for the particular fields and records necessary for the project or study.

(4)   A data use agreement that conforms with all of the requirements of proposed law and is signed by a representative of the requesting entity and by representatives of any contractors of the entity.

(5)   Affirmation that the entity requesting data will destroy the data in its entirety upon completion of the research project.

Proposed law requires DHH to enter into a data use agreement outlining the permitted uses and disclosures of de-identified personal health information. The agreement shall, at a minimum, include all of the following:

(1)   A description of the requesting entity including its ownership structure.

(2)   Rationale for the study or data use.

(3)   A summary of the project or study plan, including a project timeline, definition of project scope, and justification for the particular fields and records necessary for the project or study.

(4)   Identification of all parties who may use or receive the information and affirmative acknowledgment of understanding that any recipient is prohibited from using or further disclosing the data, except as permitted by the agreement.

(5)   An affirmation by the recipient of all of the following:

(a)   That data will be used only for the purpose or purposes stated.

(b)   That no attempts will be made to combine data provided for in the request with

other data to identify confidential information.

    (c)   That the recipient will not derive the identity of any person whose information is contained in the data for the purpose of contacting any individual, or for any other purpose.

(6)   Provisions explicitly requiring all of the following:

    (a)   That the recipient will use appropriate safeguards to prevent the use or disclosure of data that is not permitted by the agreement, and be able to demonstrate that such safeguards are in place.

    (b)   That the recipient report to DHH any unauthorized use or disclosure of data.

    (c)   That the recipient ensure that any agents, including contractors and subcontractors to whom it provides the information, agree to the data use restrictions.

(7)   Detail of the method by which the data will be destroyed after the qualifying research project is completed.

(8)   The signature of an authorized representative of the requesting health care research entity and the signatures of authorized representatives of any subcontractors.

Proposed law provides that after the execution of a data use agreement, if the recipient seeks to contract with any entity not identified in the agreement, then the recipient shall disclose to DHH the prospective subcontractor and the contractual arrangement shall be subject to approval by DHH.

(Amends R.S. 40:1300.111-114; Adds R.S. 40:1300.115-117)