The original instrument and the following digest, which constitutes no part of the legislative instrument, were prepared by Christopher D. Adams.

DIGEST

Johns (SB 259)

Present law provides for the health care consumers' right to know.

Proposed law adds to the legislative findings to find that as a result of the rapidly expanding availability and access to patient sensitive health care data, the citizens of Louisiana deserve protection of their patient encounter data to the greatest extent possible relative to health care data reporting and dissemination of protected health information datasets for use in research projects intended to improve the population health of Louisiana's citizens.

Proposed law amends present law to include to that the Department of Health and Hospitals (the department), in consultation with the Health Data Panel, shall maintain the computerized database of consumer's personal health information in a secure environment in compliance with federal laws ensuring the security of the system containing such data. Further, in the event of a data breach or suspected data breach, the department shall within 30 days notify any resident of the state whose personal information was, or is reasonably believed to have been, acquired by an unauthorized person.

Present law provides the department shall create the Health Data Panel, and the purpose of the Health Data Panel shall be to make recommendations to the secretary of the department for the implementation of the requirements of present law. Present law provides the Health Data Panel shall consider the provisions set forth in present law.

Proposed law amends present law and removes the provision that provides the Health Data Panel shall consider the provisions set forth in present law.

Present law provides members of the Health Data Panel shall be appointed by the secretary and shall represent all interests involved in the collection and publication of provider and health plan specific cost, quality, and performance data elements. Further, members shall include but not be limited to health care purchasers, hospitals and other service providers, consumer and patient advocacy groups, quality improvement and health information technology groups, physicians, and any other individuals or groups as deemed necessary by the secretary.

Proposed law provides the Health Data Panel shall consider the provisions set forth in present law. Further provides that changes to the mandatory health care data elements or the methodology by which data shall be reported by health care providers and health plans to the department shall be approved by a majority vote of the members of the Health Data Panel and promulgated by a rule in accordance with the Administrative Procedure Act by the department.

Present law provides the secretary or his designee shall serve as the chairman of the meetings of

the Health Data Panel. Further, the secretary may use the recommendations of the Health Data Panel to fulfill the department's responsibilities as set forth in present law.

Proposed law provides the secretary or his designee shall serve as the chairman of the meetings of the Health Data Panel. The secretary shall convene meetings of the Health Data Panel on an annual basis and as needed to fulfill the provisions of present law. Further, the secretary shall use the recommendations of the Health Data Panel to fulfill the department's responsibilities as set forth in present law.

Proposed law provides data collected pursuant to present 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 healthcare outcomes through education and community engagement.

(2) The data sought to be used for research qualifies a de-identified personal health information as defined in 45 CFR 164.514.

Proposed law provides all requests for data shall be submitted to the department, then reviewed and approved by a majority vote of the Health Data Panel.

Proposed law provides the data request shall 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, including a project timeline, definition of project scope, and justification for the particular fields and records necessary for the project or study.

(4) Signed data use agreement pursuant to present law by the requesting entity and any subcontractors.

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

Proposed law provides the department shall enter into a data use agreement outlining the permitted uses and disclosures of the de-identified personal health information. The agreement shall include at a minimum 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) Identify all parties who may use or receive the information and prohibit any recipient from using or further disclosing the data, except as permitted by the agreement.

(5) Include an affirmation that data shall be used only for the stated purpose, and that no attempts shall be made to combine data provided for in the request with other data to identify confidential information.

(6) Require the recipient to use and demonstrate that appropriate safeguards are in place to prevent the use or disclosure of data that is not permitted by the agreement.

(7) Require the recipient to report to the department any unauthorized use or disclosure of data.

(8) Require the recipient to ensure that any agents, including subcontractors to whom it provides the information, agree to the data use restrictions.

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

(10) Signed by the requesting health care research entity and any subcontractors. Any future subcontractors shall be disclosed and approved by the department.

(11) Prohibit the recipient from identifying the information or contacting the individuals.

Effective August 1, 2014.

(Amends R.S. 40:1300.111-1300.114; adds R.S. 40:1300.115 and 1300.116)