

SUBJECT: Sharing health data within Department of State Health Services programs

COMMITTEE: Public Health — committee substitute recommended

VOTE: 11 ayes — Kolkhorst, Naishtat, Alvarado, Coleman, S. Davis, V. Gonzales, S. King, Laubenberg, Schwertner, Truitt, Zerwas

0 nays

SENATE VOTE: On final passage, March 17 — 31-0, on Local and Uncontested Calendar

WITNESSES: *(On House companion bill, HB 396:)*

For — Nancy Weiss, American Cancer Society; *(Registered, but did not testify: Troy Alexander, Texas Medical Association; Lauren Hutton Bibighaus, Lance Armstrong Foundation; Lauren Dimitry, Texans Care for Children; Carrie Kroll, Texas Pediatric Society; Marcus Mitias, Texas Health Resources; Denise Rose, Texas Hospital Association; Morgan Sanders, March of Dimes)*

Against — Deborah Peel, Patient Privacy Rights

On — Melanie Williams, Department of State Health Services; *(Registered, but did not testify: Ramdas Menon and John Villanacci, Department of State Health Services)*

BACKGROUND: Under HB 2292, enacted by the 78th Legislature during the 2003 regular session, the Department of State Health Services (DSHS) assumed the responsibility for the collection, dissemination, and analysis of health data from the Texas Health Care Information Council.

“Public use data” means patient level data relating to individual hospitalizations that has not been summarized or analyzed, that has had patient identifying information removed, that identifies physicians only by use of uniform physician identifiers, and that is severity and risk adjusted, edited, and verified for accuracy and consistency.

Current law does not permit programs within DSHS to access or combine datasets for the confidential health information collected by another

program in DSHS. Other health and human services agencies also are restricted from access to this data.

DIGEST:

SB 156 would amend Health and Safety Code, sec. 108.013 to authorize the Department of State Health Services (DSHS) to share data collected under ch. 108 that was not included in the public use data with any program within DSHS if the disclosure were reviewed and approved by the department's institutional review board. Confidential data disclosed to a program within DSHS would remain subject to the confidentiality provisions of ch. 108 and other applicable law. DSHS would have to identify the confidential data that was disclosed to a program, and the program would have to maintain the confidentiality of the disclosed confidential data. Disclosure of physician-identifying data would not be authorized by the bill.

The bill would authorize DSHS to share certain confidential data with HHSC or other health and human services agencies, provided the receiving agency had appropriate controls in place to ensure that confidentiality of personal information contained in the shared information was subject to certain limits on disclosure and penalties under current law.

The bill would change the name of the body that reviews the use of personal health information from the scientific review panel to the institutional review board (IRB). Any approval to release personal health information made by the IRB would require that all related confidentiality provisions be followed for current and future use of the data. To assist the IRB in determining whether to approve requests for information, the executive commissioner of the Health and Human Services Commission would be directed to adopt rules in line with the guidelines established by the federal Centers for Medicare and Medicaid Services' (CMS). The department would accept data in the format developed by the American National Standards Institute or its successor or other nationally accepted standardized forms that hospitals and providers used for handling personal health information.

SB 156 would repeal or strike all statutory references to the Texas Health Care Information Council throughout the chapter.

The bill would take immediate effect if finally passed by a two-thirds record vote of the membership of each house. Otherwise, it would take effect September 1, 2011.

**SUPPORTERS
SAY:**

SB 156 would improve public health research by permitting DSHS to combine health datasets within the department and share this de-identified dataset with other health and human service agencies. Current law prohibits certain data collected by DSHS from being shared. This makes this data somewhat incomplete and less effective in combating chronic diseases.

The bill would allow the six data registries within DSHS – Cancer Registry, Birth Defect Registry, Trauma Registry, Vital Statistics Unit, Center for Health Statistics and Immunization Registry — to link up and improve the quality and comprehensiveness of the data. This would enhance the data’s value to the state by allowing researchers to identify correlations between specific illnesses, such as the relationship between certain birth defects and increased odds of developing cancer, and prove invaluable in assisting DSHS in accomplishing its public health goals. By streamlining this information among the registries, the data could be better used to advance public health research, improve patient treatments, and increase efficiency in public health care programs.

**OPPONENTS
SAY:**

SB 156 could jeopardize the trust that is built between a patient and a provider because a patient’s private health information could be shared without adequate confidentiality protections between agencies. This could discourage individuals from sharing important aspects of their medical history and negatively impact health outcomes. Patients have expressed concerns about DSHS’s sale of patient data in the past and worry that permitting other agencies to handle this sensitive information could result in additional unethical purchasing of personal health information. Further, this data could be used by other state agencies, and if leaked and re-identified, could prevent an individual from being able to purchase health insurance.

NOTES:

The House companion bill, HB 396 by V. Gonzales, was considered in a public hearing by the House Public Health Committee on March 9 and left pending.

SB 156 differs from HB 396 as filed by including a provision that would permit the sharing of confidential health information among health and human services agencies provided confidentiality was protected at the receiving agency.