SUBJECT: Consent for information maintained in the state's immunization registry

COMMITTEE: Public Health — committee substitute recommended

VOTE: 10 ayes — Crownover, Naishkat, Blanco, Coleman, S. Davis, Guerra, R. Miller, Sheffield, Zedler, Zerwas

0 nays

1 absent — Collier

WITNESSES: For — Patrick Hodges, March of Dimes; Sobha Fuller and Courtney Sherman, Texas DNP Society; Ryan Van Ramshorst, Texas Pediatric Society, Texas Medical Association, Texas Public Health Coalition; Anna Dragsbaek, The Immunization Partnership; Roberta Mercer; Maria Perez; (Registered, but did not testify: Teresa Devine, Blue Cross and Blue Shield of Texas; Kathy Eckstein, Children's Hospital Association of Texas; Hayley Harris and Katherine Truettner, Dell Children's Hospital; Mary Staples, National Association of Chain Drug Stores; Georgia Armstrong, People's Community Clinic; Amber Pearce, Pfizer; Eileen Garcia, Texans Care for Children; Tom Banning, Texas Academy of Family Physicians; Jaime Capelo, Texas Academy of Physician Assistants; Rebekah Schroeder, Texas Children Hospital; Carrie Kroll, Texas Hospital Association; Thomas Ratliff, Texas Nurse Practitioners Association; Andrew Cates, Texas Nurses Association, Texas School Nurse Organization; David Reynolds, Texas Osteopathic Medical Association; Christine Cortelyou, Sarah Gammons, Rachael Johnston, Atoosa Kourosh, Julie Len, Miranda Loh, Jackson Londeree, Gaile Vitug, Julie Vo, and Krystyna Wesp, Texas Pediatric Society; Ellen Arnold, Texas PTA; James Swan, Texas Public Health Association; Will Decker and Gwen Emmett, The Immunization Partnership; Jason Terk, Texas Pediatric Society, Texas Medical Association, Texas Public Health Coalition; Casey Smith, United Ways of Texas; and 31 individuals)

Against — Dawn Richardson, National Vaccine Information Center and Parents Requesting Open Vaccine Education; Judy Powell, Parent
Guidance Center; Michelle Schneider, Texans for Vaccine Choice; Chelsea Barlow; Dianne Doggett; Read King; Lindsey Scheibe; (Registered, but did not testify: Betty Anderson, Montgomery County Eagle Forum; Cathie Adams, Texas Eagle Forum; MerryLynn Gerstenschlager, Texas Eagle Forum; Nancy Mccarthy, Texas Health Freedom Coalition; and 18 individuals)

On — Kelly Patson, Department of State Health Services

BACKGROUND: Health and Safety Code, sec. 161.007 requires the Department of State Health Services to establish and maintain an immunization registry. Under this section of code, the commissioner of the Health and Human Services Commission must develop guidelines to require written or electronic consent from an individual or their legally authorized representative before the individual's information can be included in the immunization registry.

Written or electronic consent for an individual younger than 18 years old is required to be obtained only one time. Giving consent would allow an individual's immunization information to be included in the registry until the individual turns 18 years old, unless consent is withdrawn in writing or electronically.

After the individual turns 18 years old, the individual or the individual’s legally authorized representative must consent in writing or electronically for the individual's information to remain in the registry after the individual’s 19th birthday. DSHS may not include in the registry the immunization information of an individual who is 18 years old or older until written or electronic consent has been obtained as provided by sec. 161.007(a-2) of Health and Safety Code.

DIGEST: CSHB 2171 would require an individual's parent, managing conservator, or guardian to submit written or electronic consent to the Department of State Health Services before the individual's 18th birthday for immunization information to be included in the state's immunization registry for an individual under 18 years old. Giving consent would allow
an individual's immunization information to be included in the registry until the individual turned 26 years old, unless the consent was withdrawn. For information to be retained in the immunization registry after an individual turned 26 years old, the individual would have to give written or electronic consent only once after the individual’s 18th birthday.

The bill would require DSHS to make a reasonable effort to provide notice to individuals who had turned 18 years old to inform them that:

- their immunization records would be included in the registry until their 26th birthday unless the individual or a representative withdrew consent in writing or electronically before that date; and
- the individual or a representative would need to give consent before the individual’s 26th birthday for the immunization records to remain in the registry after the individual turned 26 years old.

DSHS also would have to make a reasonable effort to provide notice to an individual who had turned 25 years old and whose parents had consented for the individual's information to be included in the immunization registry to inform the individual that their immunization records would remain in the immunization registry only until their 26th birthday unless the individual or the individual's representative renewed consent before that date.

Under the bill, a reasonable effort to provide notice would include at least two attempts by DSHS to provide notice to an individual by telephone or email, by regular mail to the individual's last known address, or by general outreach efforts through the individual's health care provider, school district, or institution of higher education. The bill would require DSHS to make a reasonable effort to obtain current contact information for written or electronic notices sent after an individual’s 25th birthday that were returned due to incorrect address information.

The bill would repeal Health and Safety Code, sec. 161.007(a-3) that required the HHSC executive commissioner to develop by rule guidelines
and procedures for obtaining consent from an individual after the individual’s 18th birthday, including procedures for retaining immunization information in a separate database that would be inaccessible by anyone other than DSHS during the one-year period during which an 18 year old could consent to inclusion in the immunization registry.

The bill would take effect September 1, 2015, and would apply only to immunization information in the immunization registry for a person who turned 18 years old on or after that date.

**SUPPORTERS SAY:**

By extending the time an individual's immunization record was maintained in the state's immunization registry, ImmTrac, from age 18 to age 26, CSHB 2171 would ensure that these important immunization records could be accessed securely, upon request, when they were needed most.

Currently, when an individual turns 18, the individual’s immunization records are held separately from other ImmTrac data in “pending adult” status for a year and only added back to the regular ImmTrac system if the 18 year old provides consent before the individual’s 19th birthday. Otherwise, the records are permanently deleted from ImmTrac. The current practice of deleting records when an individual does not consent to retain their records in ImmTrac within a year of the individual’s 19th birthday causes increased health care costs when individuals have to be re-vaccinated to provide a health record for enrolling in school, entering the military, international travel, or changing health care providers. Under the current system, individuals often do not know that their records will expire and do not intend for their records to be deleted from ImmTrac.

CSHB 2171 would give individuals more time to re-authorize the inclusion of their immunization records in ImmTrac by requiring DSHS to notify individuals who turned 18 and whose parents had already consented for them to be included in ImmTrac that their records would expire when they turn 26 if they did not renew their consent. The required consent under the bill would also notify individuals that their parents had
consented for their immunization records to be included in ImmTrac and would give those individuals the notice they need to opt out of the system.

The bill would not change DSHS' practice of keeping the records of 18-year-olds separate from the rest of the ImmTrac system before they had given consent. Under the bill, those aged 18 to 25 who had not consented or withdrawn consent for their records to be included in ImmTrac would not have their records included in ImmTrac proper; those records would be kept separate from the main ImmTrac system until the young adult gave positive consent. If the person had still not given consent or withdrawn consent when the person turned 26, the data would be deleted permanently.

The bill would not affect an individual whose parents had never consented to include the individual's records in ImmTrac and would not require anyone to be vaccinated or included in the registry without consent. State law prohibits the government from including individuals' immunization records in ImmTrac without their consent. For this reason, an adult's records would be held separately from ImmTrac under the bill until DSHS received positive consent.

**OPPONENTS SAY:**

The bill would reduce an adult's control over their medical information. Even with the notice requirements in the bill, an adult may not receive notice that their parents had consented for their immunization records to be included in ImmTrac and would not know that their records would be kept in the system, even separately from the regular ImmTrac system, for the next eight years. The current system of deleting an individual's records when they turn 19 and have not provided consent should be kept in place.

The ImmTrac system can be accessed by the state government for public health purposes. For this reason, the bill would not adequately protect adults from having their immunization records included as part of this system and would not adequately prevent another entity from viewing immunization records.