

Amend **HB 107** (senate committee report) as follows:

(1) In SECTION 1 of the bill, in added Section 52B.004(c), Health and Safety Code (page 1, line 61, through page 2, line 9), strike Subdivisions (2) and (3) and substitute the following:

(2) require consent of an individual or the individual's legally authorized representative before any information relating to the individual is included in the sickle cell disease registry;

(3) allow the individual or the individual's legally authorized representative to withdraw consent for inclusion of the individual's information in the registry;

(4) protect the confidentiality of individuals diagnosed with sickle cell disease in accordance with Section 159.002, Occupations Code; and

(5) ensure the registry is developed in a manner consistent with:

(A) the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) and regulations adopted under that Act; and

(B) other applicable laws and rules governing the disclosure of health information.

(d) The executive commissioner shall ensure the rules adopted under this section provide protections to restrict the use or disclosure of Medicaid information to purposes only directly connected with the administration of the Medicaid program.

Sec. 52B.005. CONFIDENTIALITY. (a) Reports, records, and information obtained under this chapter:

(1) are not public information;

(2) are not subject to the requirements of Chapter 552, Government Code;

(3) are not subject to subpoena; and

(4) may not otherwise be released or made public except as provided by this section or Section 52B.004.

(b) The reports, records, and information obtained under this chapter are for the confidential use of the department and the persons or public or private entities the department determines are necessary to carry out the purposes of this chapter.

(c) Medical or epidemiological information may be released:

(1) for statistical purposes in a manner that prevents identification of individuals, health care facilities, clinical laboratories, or health care practitioners; or

(2) with the consent of each person identified in the information.

(d) A state employee may not testify in a civil, criminal, special, or other proceeding as to the existence or contents of records, reports, or information concerning an individual's medical records used in submitting information required under this chapter unless the individual consents in advance.

(e) Information furnished to a sickle cell disease registry or a sickle cell researcher under Subsection (c) is for the confidential use of the sickle cell disease registry or the sickle cell researcher, as applicable, and is subject to Subsection (a).

(f) The department's institutional review board established under Chapter 108 shall review and approve requests for access to information that identifies individuals in the sickle cell disease registry.

(2) In SECTION 1 of the bill, in added Section 52B.005, Health and Safety Code (page 2, line 10), strike "52B.005" and substitute "52B.006".

(3) Immediately following SECTION 1 of the bill, adding Chapter 52B, Health and Safety Code (page 2, between lines 16 and 17), add the following appropriately numbered SECTION to the bill and renumber subsequent SECTIONS of the bill accordingly:

SECTION _____. The Department of State Health Services is required to implement a provision of this Act only if the legislature appropriates money specifically for that purpose. If the legislature does not appropriate money specifically for that purpose, the department may, but is not required to, implement a provision of this Act using other money available for that purpose.