## Texas

### Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX</td>
<td>STATUTE: Texas Statutes (T.S.) Chapter 87, Subchapters A and B</td>
<td>Sec. 87.021. SURVEILLANCE PROGRAM; REGISTRY ESTABLISHED. (a) The board shall establish in the department a program to: (1) identify and investigate certain birth defects in children; and (2) maintain a central registry of cases of birth defects. (b) The board may authorize the department to implement a statewide program or to limit the program to a part or all of one or more public health regions, depending on the funding available to the department. In establishing the program, the board shall consider: (1) the number and geographic distribution of births in the state; (2) the trained personnel and other departmental resources that may be assigned to the program activities; and (3) the occurrence or probable occurrence of an urgent situation that requires or will require</td>
<td>Sec. 87.002. CONFIDENTIALITY. (a) Except as specifically authorized by this chapter, reports, records, and information furnished to a department employee or to an authorized agent of the department that relate to cases or suspected cases of a health condition are confidential and may be used only for the purposes of this chapter. (b) Reports, records, and information relating to cases or suspected cases of a health condition are not public information under Chapter 552, Government Code, and may not be released or made public on subpoena or otherwise</td>
<td>Sec. 87.002. …(c) The department may release medical, epidemiological, or toxicological information: (1) for statistical purposes, if released in a manner that prevents the identification of any person; (2) with the consent of each person identified in the information or, if the person is a minor, the minor's parents, managing conservator,</td>
<td>NO</td>
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an unusual commitment of the department's personnel and other resources.

(c) The board and the department shall design the program so that the program will:

1. provide information to identify risk factors and causes of birth defects;
2. provide information on other possible causes of birth defects;
3. provide for the development of strategies to prevent birth defects;
4. provide for interview studies about the causes of birth defects;
5. together with other departmental programs, contribute birth defects data to a central registry;
6. provide for the appointment of authorized agents to collect birth defects information; and
7. provide for the active collection of birth defects information.

(d) The board shall adopt rules to govern the operation of the program and carry out the intent of this chapter. At a minimum, the rules shall:

1. use a medically recognized system to specify the birth defects to be identified and investigated;
2. select a system for classifying the

except as provided by this chapter.

Sec. 87.004. LIMITATION OF LIABILITY. A health professional, a health facility, or an administrator, officer, or employee of a health facility subject to this chapter is not civilly or criminally liable for divulging information required to be released under this chapter, except in a case of gross negligence or willful misconduct.

Sec. 87.022. DATA COLLECTION. (a) To ensure an accurate source of data necessary to investigate the incidence, prevalence, and trends of birth defects, the board may require a health facility, health professional, or midwife to make available for review guardian, or other person who is legally authorized to consent;

(3) to medical personnel, appropriate state agencies, health authorities, regional directors, and public officers of counties and municipalities as necessary to comply with this chapter and board rules relating to the identification, monitoring, and referral of children with birth defects;

(4) to appropriate federal agencies, such as the Centers for Disease Control of the United States Public Health Service…
birth defects according to the public health significance of each defect to prioritize the use of resources; (3) develop a system to select and specify the cases to be investigated; (4) specify a system for selecting the demographic areas in which the department may undertake investigations; and (5) prescribe the training and experience a person must have for appointment as an authorized agent of the department.

(e) In adopting the rules required by Subsection (d), the board shall consider at least: (1) the known incidence and prevalence rates of a birth defect in the state or portions of the state; (2) the known incidence and prevalence rates of a particular birth defect in specific population groups who live in the state or portions of the state; (3) the morbidity and mortality resulting from the birth defect; and (4) the existence, cost, and availability of a strategy to prevent and treat the birth defect.

(f) In addition to providing for the active collection of birth defects by the department or by an authorized agent medical records or other information that is in the facility's, professional's, or midwife's custody or control and that relates to the occurrence of a birth defect specified by the board. (b) The board by rule shall prescribe the manner in which records and other information are made available to the department.

(c) The board shall adopt procedural rules to facilitate cooperation between the health care facility, health professional, or midwife and a department employee or authorized agent, including rules for notice, requests for medical records, times for record reviews, and record management during review.

Sec. 87.063. Research; Review and Approval.
(a) The commissioner and the department’s committee for the protection of human subjects shall review each research proposal that requests the use of information in the central registry. …

Sec.87.065. Coordination with Mexico.
In developing the central registry and conducting research in areas of this state that border Mexico, the department shall make every effort to coordinate its
RULE §37.305  Surveillance of Birth Defects: Central Registry  
(a) The central registry shall use a birth defects coding scheme used by the Centers for Disease Control and Prevention (CDC) of the United States Public Health Service in their birth defects monitoring programs.  
(b) In order for information related to a child to be included in the central registry, the following conditions must be met.  
(1) The county of occurrence of birth or the mother’s residence at the time of birth must have been in Texas.  
(2) The child must have a structural or genetic birth defect or other specified outcome that can adversely affect his or her health and development as

| Rule § 37.304, Confidentiality of Information Provided to the Department. (a) Reports, records, and other information collected by, or provided to the department relating to persons known to have, or suspected of having a birth defect are confidential records and not public information and may not be released except as described in subsection (b) of this section. The confidential records include medical and other information obtained as part of epidemiologic or other investigations and the records and information gathered as part of the operation of the central registry.  
(b) The department may release demographic, medical, epidemiological, or toxicological information:  
   (6) to medical researchers conducting bona fide medical research under the conditions described in §37.306 of this title (relating to Access to Information in the Central Registry), and Health and Safety Code, §87.063.  

|   | defined in subsection (a) of this section. (3) The defect must be diagnosed prenatally or within one year after delivery. In certain circumstances (e.g., the diagnosis of fetal alcohol syndrome, special studies and childhood genetic disorders diagnosed after infancy), the upper age limit will be extended to age six. (4) In addition, reports of Fetal Alcohol Spectrum Disorders (FASD), regardless of the affected person's age, will be collected under Health and Safety Code, §87.021(f), of the statute providing for passive data collection. (c) A reportable defect as defined in subsection (a) of this section occurring in a fetal death or pregnancy termination shall be included in the central registry. (d) Interaction between department staff and health facility staff is detailed below: (1) The chief operating officer, administrator, manager, director, and/or person in charge of each facility or office or center shall appoint one staff member as the contact person for the central | information: (1) for statistical purposes, if released in a manner that prevents the identification of any person; (2) with the consent of each person identified in the information or, if the person is unable to consent or is a minor, the minor's parents, managing conservator, guardian, or other person who is legally authorized to consent; (3) to medical personnel, appropriate state agencies, health authorities, regional directors, and public officers of counties and municipalities relating to the identification, monitoring, and referral of children with birth defects; (4) to appropriate federal agencies such as the |   |   |   |
A staff member will coordinate scheduled visits and/or remote electronic access by central registry staff to review logs, discharge indices and other case-finding sources, and will be responsible for arranging visits and/or remote electronic access for medical records review and providing the needed records at the time scheduled. Potential cases are obtained by department staff through review of medical and health records, logs, indices, appointment rosters, and other records. Cases may also be obtained through passive reporting from health facilities and health professionals.

Central registry staff and the contact individual shall establish a general schedule of visits and/or remote electronic access for case-finding and record review. This schedule shall take into account the capabilities of the health care facility in responding to requests, as well as the expected

| Centers for Disease Control and Prevention of the United States Public Health Service; |
| (5) to medical personnel to the extent necessary to protect the health or life of the child identified in the information; or |
| (6) to medical researchers conducting bona fide medical research under the conditions described in §37.306 of this title (relating to Access to Information in the Central Registry), and Health and Safety Code, §87.063. |
needs of the central registry workload. [emphasis added]

(e) The medical records and other materials provided by the health care facility shall not be removed from that facility. If copies are made, registry staff must abide by procedures regarding copier use agreed upon with each health care facility. All information, either on paper or in electronic form, which is removed from the health care facility shall be transported by secure means at all times. Forms, notes, and other information will be carried in locked brief cases and will be stored in locked offices or locked file cabinets.