## TENNESSEE

### 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>
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<tr>
<td>TN</td>
<td>Statute: T.C. Title 68, Chapter 5, Part 5</td>
<td>68-5-506. Creation of birth defects registry — Advisory committee — Confidentiality — Penalty for unauthorized disclosure of confidential information.</td>
<td>68-5-506. ... (e)(2) The department shall maintain an accurate record of all persons who are given access to the information in the registry. The record shall include: (A) The name of the persons authorizing access; (B) The name, title, and organizational affiliation of persons given access; (C) The dates of access; (D) The specific purpose for which the information is to be used; and (E) The results of the independent research.</td>
<td>68-5-506. (d) The staff of the registry shall use the information collected pursuant to this section and information available from other reporting systems and health providers to conduct studies to investigate the causes of birth defects, and to determine and evaluate measures designed to prevent their occurrence. The department's investigation shall not be limited to geographic, temporal, or occupational associations, but may include investigation of past exposures. (e)(1) All information collected and analyzed pursuant to this section shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes provided in this section; provided, that the commissioner may provide access to those scientists approved by the advisory committee who are engaged in demographic, epidemiological or other similar studies related to health, and who agree, in</td>
<td>NO</td>
<td>NO</td>
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The department shall maintain a system for the collection of information necessary to accomplish the outlined purposes of this section. For purposes related to the registry, the department shall have access to any medical record that pertains to a diagnosed or suspected birth defect, including the records of the mother. Providers acting pursuant to this section shall not be liable for the release of medical records as authorized by this section. The department shall develop and disseminate information about the birth defects registry to the participating perinatal centers that will be made available to the family that explains and describes the purpose and process of the registry and how confidentiality will be protected. The commissioner, with guidance from the advisory committee, shall promulgate by rule a mechanism for the active verification of reports through the use of multiple sources.

The registry shall collect information on birth defects, whether they occur as live births, stillbirths, or fetal deaths.

The registry shall collect information on birth defects diagnosed in children up to five (5) years of age.

The registry shall be implemented as a pilot project to include reporting by any of the five (5) designated perinatal centers choosing to be included in the pilot project. Perinatal centers participating in the pilot project shall report to the birth defects registry as required by the commissioner.

The department, with guidance from the advisory committee, shall establish a program in the registry for referring families of children born with birth defects or the mothers of children lost to birth defects to available appropriate state resources. In order for a family of a child with a birth defect to participate in the referral program established by this subsection (c), the child's parents or legal guardian must contact the department and request to be included in the program.

“The TBDR gathers data from hospital discharge reports and vital records (birth, fetal death, and infant death certificates) to ascertain birth defect information for infants born to Tennessee resident. Gathering data from archival data systems such as these is sometimes called a passive surveillance approach. The TBDR also employs an active surveillance approach reviewing and abstracting medical records of infants identified with specific birth defects… - "Tennessee Birth Defects 2002 – 2006," Tennessee Birth Defects Registry (2010). Tennessee Department of Health."
### Cancer Surveillance System

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<td>TN</td>
<td>STATUTE: T.C. Title 68, Chapter 1 RULE: TAR, Chapter 1200-7-2</td>
<td>68-1-1001. Short title. his part shall be known and may be cited as the “Tennessee Cancer Reporting System Act of 1983.”</td>
<td>68-1-1003 (b) In order to accomplish the purpose described in (a), all hospitals, laboratories, facilities, and health care practitioners shall report to the department, within six (6) months after the date of diagnosis of cancer in a patient, information contained in the medical records of patients who have cancer; provided, that health care practitioners are not required to report information on patients with cancer who are directly referred to or have been previously admitted to a hospital or a facility for cancer diagnosis or treatment…</td>
<td>68-1-1006. Confidentiality of data. (a) (1) All data obtained from the reports required by this part are for the confidential use of the department and persons that the commissioner determines are necessary to carry out the intent of this part. (2) Information that could possibly identify individuals whose medical records have been used for collecting data may not be included in materials available to the public.</td>
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68-1-1003. Purpose of chapter — Reports to department — Format and contents of reports — Persons authorized to have access to patients medical records — Reimbursement — Failure to report or give access to records.

68-1-1006. Confidentiality of data.

(a) (1) All data obtained from the reports required by this part are for the confidential use of the department and persons that the commissioner determines are necessary to carry out the intent of this part.

(b) Information that could possibly identify individuals whose medical records have been used for collecting data may not be included in materials available to the public.

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(a) The purpose of this part is to ensure an accurate and continuing source of data concerning cancer and to provide appropriate data to members of the medical, scientific, and academic research communities for purposes of authorized institutional research, approved by the appropriate research committee of the applying institution, into the causes, types and demography of cancer, including, but not limited to, the occupation, family history, and personal habits of persons diagnosed with cancer.

68-1-1007. Liability for release of information — Compliance not violative of confidentiality.
A hospital, laboratory, facility, or health care practitioner that reports information to the department or allows the commissioner or the commissioner's authorized representative access to the medical records of cancer patients, as required by this part, shall not be held liable to any person for the release of the information to the department, nor shall the release of the information to the department be construed as a violation of any requirement of law or professional obligation to maintain the confidentiality of patient information.

68-1-1010. Interstate sharing of information — Confidentiality.
(a) In order to obtain complete information on Tennessee cancer patients who have been diagnosed or treated in other states, and in order to provide information to other states regarding their residents who have been diagnosed or treated for cancer in Tennessee, the commissioner or the commissioner's authorized representative is authorized to enter into appropriate written agreements with other states that maintain statewide cancer registries, allowing the exchange of information on cancer patients.
(b) Each state with which the commissioner agrees to exchange information must agree in writing to keep all patient-specific information confidential and to require any research personnel to whom the information is made available to keep it confidential.

c) Guidelines for such research applications shall be set out by departmental regulations. For the purposes of this part, those approved to obtain data for research shall not be considered agents of the commissioner.

1200-7-.07 RELEASE OF DATA (1)…(d) To Others: 1. The TCR is authorized to collaborate with the North American Association of Central Cancer Registries (NAACCR) to provide cancer incidence statistics and participate in cancer studies.
(2) Release of identifying information (a) Identifying information collected form any hospital, laboratory, facility, or health care practitioner may be released to qualified persons for the purposes of cancer prevention, control, and research, provided that each request for identifying information follows the established procedure outlined in the TCR Policies and Procedures Manual and receives prior approval by the department. Identifying information that is collected solely by the Tennessee Cancer Registry for its own special studies shall not be released. [Emphasis added]
## Newborn Genetic Testing & Surveillance System

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<tr>
<td>TN</td>
<td>STATUTE: T.C., Title 68, Chapter 5 Part 4 and Part 5 (genetic testing) Sections 68-1-801 – 68-5-404 RULE: TAR, Chapter 1200-15-1.01 - .07</td>
<td>68-5-401. Testing required — Public policy. (a) (1) The general assembly declares that, as a matter of public policy of this state and in the interest of public health, every newborn infant shall be tested for phenylketonuria, hypothyroidism, galactosemia and other metabolic/genetic defects that would result in intellectual disability or physical dysfunction as determined by the department, through rules and regulations duly promulgated in accordance with the provisions of the Uniform Administrative Procedures Act, compiled in title 4, chapter 5, and that the people of this state shall be extensively informed as to the nature and effects of such defects. 68-5-403. Exemptions for religious beliefs. Nothing in this part shall be construed to require the testing of or medical treatment for the minor child of any person who files with the department a signed, written statement that such tests or medical treatment conflict with the person's religious tenets and practices, affirmed under penalties of perjury. 68-5-404. Failure to have child tested — Misdemeanor. Any person violating the provisions of this part or parts of this chapter or the rules promulgated pursuant thereto, relative to testing of newborn infants, commits a Class C misdemeanor. 68-5-502. Establishment of genetics program. (a) The department shall establish a statewide genetics program to ensure the availability of genetic services to citizens of the state who need them for the prevention and treatment of mental retardation or other physical dysfunction. (b) The program shall include comprehensive genetic services programs, including genetic and metabolic screening programs, genetic counseling services, and other related services that will aid in the prevention and treatment of particular genetic disorders and birth defects or related conditions as determined by the department...</td>
<td>68-5-403. Exemptions for religious beliefs. Nothing in this part shall be construed to require the testing of or medical treatment for the minor child of any person who files with the department a signed, written statement that such tests or medical treatment conflict with the person's religious tenets and practices, affirmed under penalties of perjury. 1200-15-1-.01. Tests. (1) Exemptions for religious beliefs. Nothing in this part shall be construed to require the testing of or medical treatment for the minor child of any person who shall file with the Department of Health a signed, written statement that such tests or medical treatment conflict with such person's religious tenets and practices, affirmed under penalties of perjury pursuant to T.C.A. 68-5-403. The newborn screening refusal form provided by the State should be completed and retained in the medical record for the period of time defined by the hospital or provider policy. (2) Failure to have a child tested for the genetic/metabolic disorders is a Class C misdemeanor. Reporting of hearing screening is not to be construed as mandatory testing. Therefore, failure to have a child tested for hearing loss will not be considered a misdemeanor...</td>
<td>NO</td>
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### Vaccination Surveillance System

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<td>TN</td>
<td>T.C., Title 37, Chapter 10, Part 4</td>
<td>37-10-401. Responsibility of parents to have children immunized — Specific vaccines — Immunization registry. ...(c) The department shall establish and maintain an immunization registry for children. …</td>
<td>37-10-401. (c) …By January 1, 1996, the department shall incrementally require all local public health departments to report, in a designated format, the record of each immunization given. Other health care providers or any third party payer or health insurance entity regulated by the department of commerce and insurance doing business in Tennessee, or any entity that has elected, organized and qualified as a self-insured entity may likewise report such records. Information from the registry shall be available to parents and legal guardians; health care providers; any third party payer or health insurance entity regulated by the department of commerce and insurance doing business in Tennessee; any entity that has elected, organized and qualified as a self-insured entity; and schools, child care facilities, and other institutions having care or custody of children.</td>
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