# SOUTH DAKOTA

## Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
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<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
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QUESTION: “Does your MCH program have the ability to obtain data for program planning or policy purposes in a timely manner?”  
ANSWER FOR “Annual birth defects surveillance system” category: “No, the MCH agency does not have this ability.”  
QUESTION: Does your MCH program have direct access to the electronic database for analysis?  
ANSWER FOR “Annual birth defects surveillance system” category: “No”  
FROM: “Yet Alabama, Pennsylvania, Montana, Wyoming, Idaho, Oregon and South Dakota and the District of Columbia do not have birth defect registries at all and one of the largest states, California, only monitors 70,000 out of 526,774 births each year.” – “The Leading Cause of Infant Deaths Exposed,” Rachel Thomas (Birth Defect Research for Children), Healthy Child Healthy World website, July 27, 2011 [as also noted in the annual report of Birth Defect Research for Children]  
**1-43-19. Comprehensive health data system established—Purpose. The Department of Health shall coordinate the establishment and maintain oversight of a comprehensive health data system for the purposes of:**  
(1) Health care planning, policy development, policy evaluation, and research by federal, state, and local governments;  
(2) Monitoring payments for health services by the federal and state governments;  
(3) Assessing and improving the quality of health care;  
(4) Measuring and optimizing access to health care;  
(5) Supporting public health functions and objectives;  
(6) Improving the ability of health plans, health care providers, and consumers to coordinate, improve, and make choices about health care; and  
(7) Monitoring costs at provider and plan levels.  
**1-43-33. Promulgation of rules for comprehensive health data system. The Department of Health shall promulgate rules, pursuant to chapter 1-26, to specify criteria, procedures, and forms for submitting health related data and to establish standards for information collection.** |
## Cancer Surveillance System

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<tr>
<td>SD</td>
<td>STATUTE: SDCL, Title 1 Chapter 43 Section 11 Medical /Genetic Research Law: SDCL Chapter 34-14</td>
<td>1-43-11. Cancer data collection system. The Department of Health shall establish and maintain a central cancer data collection system for cancer cases in South Dakota in accordance with the confidentiality provisions of § 34-14-1 and the terms of §§ 1-43-11 to 1-43-17, inclusive.</td>
<td>1-43-14. Cancer detection or treatment reporting requirements. Any hospital licensed pursuant to chapter 34-12, physician licensed pursuant to chapter 36-4, physician assistant licensed pursuant to chapter 36-4A, nurse practitioner or nurse midwife licensed pursuant to chapter 36-9A, pathology laboratory, or free-standing radiology center that detects, diagnoses, or treats a cancer case in South Dakota shall submit a report to the Department of Health as required by §§ 1-43-11 to 1-43-17, inclusive.</td>
<td>34-14-4. Immunity from liability for furnishing information to research agencies. The furnishing of information described in § 34-14-1 in the course of a research project to the Department of Health, South Dakota State Medical Association, or allied medical societies or their authorized representatives, shall not subject any person, hospital, sanitarium, nursing, or rest home or any such agency to any action for damages or other relief.</td>
<td>NO</td>
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<tr>
<td></td>
<td>RULE: Article 44-22, Chapter 44:22:01 -</td>
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### Definitions

(1) "Abstract," a summary from the medical record of pertinent cancer information about the patient, the disease, the cancer-directed treatment, and the disease process from the time of diagnosis until the patient's death;
Reportable conditions -- General criteria.
The following conditions are reportable:

(1) Any malignant and in situ neoplasm of any site, excluding any basal and squamous cell carcinoma of the skin;

(2) Any basal and squamous cell carcinoma of any mucopidermoid site; and

(3) Any brain and central nervous system neoplasm regardless of malignancy;

(4) "Cancer," includes:

(a) Any malignant and in situ neoplasm of any site, excluding any basal and squamous cell carcinoma of the skin;

(b) Any basal and squamous cell carcinoma of any mucopidermoid site; and

(c) Any brain and central nervous system neoplasm regardless of malignancy;

(5) "Central cancer registry," "SDCR," the South Dakota Cancer Registry, the central database of cancer cases in South Dakota maintained by the department; [

(18) "Researcher," the primary investigator or project director of a study; and

(19) "Tumor registry," a data collection management system with complete cancer abstracts in a NAACCR layout.

44:22:01:03. Functions of central cancer registry.
The central cancer registry is a surveillance system and shall be used to:

(1) Monitor the incidence and mortality of cancer in the state to detect potential public health problems;

(2) Inform and educate by providing descriptive data on cancer incidence and mortality to health professionals and the general public about risks, prevention, and early detection of cancers known to be elevated in their communities;

(3) Guide decisions about how to use public-funded cancer control resources by more accurately targeting intervention resources for communities and patients and their families; and

(4) Respond to public concerns.

The research project has been reviewed and approved by an institutional review board on the lists of registered Institutional Review Boards or Independent Ethics Committees and approved Assurances of the Office for Human Research Protections, U.S. Department of Health and Human Services;

No patient, or patient's relatives or friends, will be contacted without prior approval of the patient's physician in accordance with SDCL 34-14-5;

The applicant will maintain the confidentiality and security of the data obtained by establishing adequate safeguards;

The applicant will comply with all federal and state laws, and department guidelines regarding release of data with identifying information and with de-identified information;

The applicant agrees to pay the department reasonable costs of data retrieval and data processing as determined and billed by the department; and

The applicant will provide the results of the research to the department at no cost and not publish the results until two months after submission to the department and that any publication will acknowledge the department and its central cancer registry.
## Newborn Genetic Testing & Surveillance System

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<tr>
<td>SD</td>
<td>SD STATUTE- SDCL, Chapter 34-24, Sections 34-24-17 – 34-24-25 Medical /Genetic Research Law; SDCL Chapter 34-14 RULE: SDAR, Article 44-19</td>
<td><strong>34-24-17. Screening of newborn infants for metabolic disease.</strong> All infants born in the State of South Dakota shall be screened for metabolic disease. This screening shall be as prescribed by the State Department of Health. <strong>34-24-18. Phenylketonuria, hypothyroidism, and galactosemia testing in newborn.</strong> The tests for detecting metabolic disorders of the newborn infant, as prescribed by the Department of Health, shall include, but not be limited to, the testing for excessive phenylalanine in the serum of the newborn, for hypothyroidism and for elevated blood galactose in the newborn. <strong>34-24-22. Testing for other metabolic diseases.</strong> When tests for detecting a metabolic disease other than phenylketonuria, hypothyroidism, and galactosemia are perfected, the Department of Health may require that tests for the syndrome or syndromes be made and reported to the health department.</td>
<td>44:19:02-05. Responsibilities of parents. The parents, guardian, or custodian of each infant is responsible for having blood tests for metabolic disorders performed within the first 48 hours of an infant’s life. If a parent, guardian, or custodian refuses to have a newborn tested for metabolic disorders, despite having been notified of the need for testing, the parent, guardian, or custodian shall sign a written statement regarding the refusal.</td>
<td><strong>34-14-4. Immunity from liability for furnishing information to research agencies.</strong> The furnishing of information described in § 34-14-1 in the course of a research project to the Department of Health, South Dakota State Medical Association, or allied medical societies or their authorized representatives, shall not subject any person, hospital, sanitarium, nursing, or rest home or any such agency to any action for damages or other relief.</td>
<td>NO</td>
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34-24-23. Reports to department on metabolic disease tests—Forms. Results of such tests for metabolic disorders in infants, as prescribed by the Department of Health, shall be sent to the department on forms to be prescribed and furnished by the department to all physicians, public health nurses, and hospitals.

34-24-24. Follow-up on children with metabolic disease. It shall be the responsibility of the Department of Health to follow the development of all children carrying the syndrome of any metabolic disease to ensure that those persons responsible for the care of the child are fully informed of accepted medical procedures for the detection, prevention, and treatment of such condition. [emphasis added]

44:19:02:06. Responsibilities of hospitals, physicians, and other health professionals. The attending physician, other health professional, hospital, or public health facility shall notify the parents, guardian, or custodian of each infant of the responsibility and need to have the newborn screening tests performed. The attending physician or other health professional shall place all newborn screening test results in the newborn patient's record. If a parent, guardian, or custodian refuses to have the newborn tested, the attending physician, other health professional, hospital, or public health facility shall obtain a written signed statement from the parent, guardian, or custodian of the infant regarding the refusal and place it in the newborn patient's record, notify the department within 24 hours of the refusal at 1-800-738-2301, and send a copy of the signed refusal to the department. If a parent, guardian, or custodian refuses to sign the statement, the attending physician, other health professional, hospital, or public health facility shall document such refusal, place it in the newborn patient's record, and send a copy of such documentation to the department.

FROM SD Newborn Screening Brochure: (Revised 11-10)

“What happens to my baby’s blood sample after the lab tests it?

“The newborn screening laboratory will destroy your baby’s blood sample once it is no longer needed for testing. It will not be used for any purpose other than newborn screening. If you have questions about how your baby’s blood sample is handled, call the South Dakota Newborn Screening Program at (605) 773-3361.”

NOTE: The brochure says, “All newborns in South Dakota are required by law to have a blood test shortly after birth...” but does not tell parents that the law allows them to refuse.
### Vaccination Surveillance System

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<td>SD</td>
<td>NO SPECIFIC LAW OR RULE FOUND</td>
<td>SPECIFIC LAW OR RULE FOUND</td>
<td>34-22-12.5. Sharing of certain immunization records without consent permitted—Violation as a misdemeanor. A patient's immunization record, even if the immunization was received prior to July 1, 1996, may be shared among health care providers, health care facilities, federal or state health agencies, child welfare agencies, schools, or family day care facilities, without the consent of the patient or the person acting on the patient's behalf unless the patient's signed refusal to release immunization information is part of the patient's medical record. If the patient is a minor, the refusal to release immunization information may be signed by the patient's parent or guardian on behalf of the minor patient. Any person who receives immunization data pursuant to this section and knowingly or intentionally discloses or fails to protect the confidentiality of the data is guilty of a Class 1 misdemeanor.</td>
<td>34-22-12.5. Sharing of certain immunization records without consent permitted—Violation as a misdemeanor. A patient's immunization record, even if the immunization was received prior to July 1, 1996, may be shared among health care providers, health care facilities, federal or state health agencies, child welfare agencies, schools, or family day care facilities, without the consent of the patient or the person acting on the patient's behalf unless the patient's signed refusal to release immunization information is part of the patient's medical record. If the patient is a minor, the refusal to release immunization information may be signed by the patient's parent or guardian on behalf of the minor patient. Any person who receives immunization data pursuant to this section and knowingly or intentionally discloses or fails to protect the confidentiality of the data is guilty of a Class 1 misdemeanor.</td>
<td>NO</td>
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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008. Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature. www.cchfreedom.org