## KANSAS

### 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>
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<tr>
<td>KS</td>
<td>STATUTE: K.S. Chapter 65, Article 1, (1,241 to 1,245)</td>
<td>65-1,241. Definitions; establishment of birth defects information system; aspects of implementation of system... (b) The secretary of health and environment shall establish and, if funds for this purpose are available, implement a statewide or pilot birth defects information system for the collection of information concerning congenital anomalies, stillbirths and abnormal conditions of newborns. 65-1,244. Removal of information from system; form. A child's parent or legal guardian who wants information concerning the child removed from the birth defects information system shall request from the local health department or the child's physician a form prepared by the secretary. On request, a local health department or physician shall provide the form to the child's parent or legal guardian. The individual providing the form shall discuss with the child's parent or legal guardian the information contained in the system. If the child's parent or legal guardian signs the form, the local health department or physician shall forward it to the secretary. On receipt of the signed form, the secretary shall remove from the system any information that identifies the child. 65-1,245. Rules and regulations. ...the secretary of health and environment shall adopt rules and regulations [to]... (d) establish a form for use by parents or legal guardians who seek to have information regarding their children removed from the system and a method of distributing the form to local health departments and to physicians. The method of distribution must include making the form available on the internet.</td>
<td>65-1,241. ...(c) If the system is implemented under subsection (b) of this section, all of the following apply: (1) The secretary may require each physician, hospital and freestanding birthing center to report to the system information concerning all patients under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition... (2) On request, each physician, hospital and freestanding birthing center shall give the secretary or authorized employees of the department of health and environment access to the medical records of any patient described in subsection (c)(1) of this section... (d) A physician, hospital or freestanding birthing center that provides information to the system under subsection (c) shall not be subject to criminal or civil liability for providing the information.</td>
<td>65-1,242. Use of birth defects information system. The birth defects information system may be used for all of the following purposes: ... (2) to detect trends and epidemics in congenital anomalies, stillbirths and abnormal conditions of newborns; (3) to quantify morbidity and mortality of congenital anomalies and abnormal conditions of newborns; (4) to stimulate epidemiological research regarding congenital anomalies, stillbirths and abnormal conditions of newborns; (5) to identify risk factors for congenital anomalies, stillbirths and abnormal conditions of newborns...</td>
<td>NO</td>
<td>YES – limited</td>
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“The SSDI project has accomplished four significant priority tasks. First, the project staff involved in Kansas "Dream Team." The purpose of this team is to get all people in the Division of Health, Kansas Department of Health and Environment on-board with an integrated Division of Health Information System. The MCH, CSHCN and Newborn Screening programs are part of this integrated system, plus BDSS integration has been initiated, and WIC has built the bridge for connection. Second, the SSDI project assisted in obtaining the birth defects export file from the Vital Statistics Integrated Information System. The export file will be one of the two data sources of the BDSS and will be used to send letters to new parents with high risk infants informing them of the availability of state programs and resources and other useful information. Third, a Kansas State University PhD Student completed a project related to breastfeeding using WIC data. Fourth, Kansas MCH/CSHCN participates in the Heartland Genetics Consortium. As part of this collaboration, Kansas and the two Dakotas obtained technical assistance in October of 2005 on development of a state genetics plan. Kansas took a couple of steps in moving towards a State Genetics Plan: 1) state survey of providers as part of a needs assessment; 2) scholarship for a staff person to attend the Sarah Lawrence Genetics/Genomics Public Health Certificate Program.” –HRSA, MCHB, “Kansas State Systems Development Initiative – Fiscal Year 2008,” [emphasis added]
## Cancer Surveillance System

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<td>KS</td>
<td>STATUTE: K.S. Chapter 65, Article 1, 168 – 174</td>
<td>65-1,168. Cancer registry</td>
<td>65-1,172. Same; uses of confidential data. (a) Confidential data collected pursuant to this act shall be securely locked and used only for the following purposes…(5) As part of an exchange agreement with another state, confidential data collected on a resident of another state may be released to the cancer registry of that person’s state of residence if that state has confidentiality requirements that provide assurance of protection of confidentiality equivalent to that provided by Kansas under this act.</td>
<td>65-1,172. Same; uses of confidential data. (a) Confidential data collected pursuant to this act shall be securely locked and used only for the following purposes: (1) Ensuring the quality and completeness of the registry data. (2) Investigating the nature and cause of abnormal clusterings of cancer and the possible cancer risk related to having an abortion. (3) Offering…diagnostics and treatments not available except through clinical trials…7) Follow up for public health purposes. With the approval of the health and environmental institutional review board as provided for in title 45, part 46 of the code of federal regulations, the secretary of health and environment…may contact individuals who are the subjects of the reports…The secretary shall inform such individuals that the participation in such projects is voluntary and may only be conducted with the written consent of the person who is the subject of the information…Informed consent is not required if the person who is the subject of the information is deceased…</td>
<td>NO</td>
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<tr>
<td>RULES: K.A.R. 28-70-1 to 28-70-3</td>
<td>65-1,169 Same, collection of data; rules and regulations; reporting of cases. (a) The secretary is hereby authorized to collect data pertaining to all cancers occurring in Kansas into a registry which shall be the cancer registry for the state of Kansas. The secretary shall adopt rules and regulations…(b) Health care providers, as defined in K.S.A. 65-1,168 and amendments thereto, and other individuals and entities specified in rules and regulations shall report to the registry each case diagnosed or treated unless exempted by statute or regulation within six months of the date of diagnosis.</td>
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### Article 70. Cancer Registry.

**28-70-1 Definitions.** … (b) “Cancer registry director” means the person at the university of Kansas medical center, department of preventive medicine and public health, who is authorized by the secretary to administer the operations of the cancer registry of the state of Kansas…. (f) “Registry” means the cancer registry of the state of Kansas, as established by K.S.A. 65-1, 169, and amendments thereto. (Authorized by and implementing K.S.A. 2004 Supp 65-1, 169; effective Feb. 27, 1998; amended Aug. 5, 2005)

(b) Upon receipt of a request for information from the registry regarding a patient, each individual provider shall provide the requested information that is contained in medical records under the direct control of the provider. (1) An individual provider shall not be required to report cancer cases, unless it receives a request from the registry regarding a specific patient. (2) An individual provider shall not be required to contact the patient, the patient’s family, a health care institution, or another individual provider to obtain additional information not contained in the medical record that is in the direct control of the provider. (3) Each individual provider shall fulfill reporting requirements by completing any one of the following actions:

- Reporting to the registry the name of the hospital, outpatient surgery center, or radiation oncology center where the patient received cancer-related care;
- Submitting, to the registry, copies of outpatient records, including surgical reports, cancer diagnostic reports, tumor histologic reports, and patient identification form; or
- Submitting a short form, supplied by the registry, that request demographic, tumor histology and staging, patient identifiers, and names of treating institutions.

### 28-70-3. Use and access.

(a) For purposes of ascertaining the accuracy and completeness of cancer data, the medical diagnosis of each person cared for by any health care provider or licensee specified in K.A.R. 28-70-2 (a) or (b) or by any hospice or adult care home and the medical or administrative records of any person with cancer may be reviewed by the cancer registry director. Each review shall be made by prearrangement with the appropriate administrator or licensee. Pursuant to K.S.A. 65-1, 169 and amendments thereto, a copy of any death certificate may be requested by the cancer registry director from the secretary to ensure the completeness of cancer data and to achieve record closure. (b) Each person who requests access to confidential registry data shall submit a written request to a review panel, as specified in K.S.A. 65-1, 173, and amendments thereto. If the person meets the requirements specified in K.S.A. 65-1, 172 and amendments thereto, the confidential data may be released by the review panel.
## Newborn Genetic Testing & Surveillance System

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<td>KS</td>
<td><strong>Statute 65-180.</strong> <img src="statute" alt="Registry of cases: newborn screening programs. The secretary of health and environment shall:" /> (b) Provide recognized screening tests…(d) Maintain a registry of cases…<strong>&lt;br&gt;<strong>65-181. <strong>Same; tests in accordance with rules and regulations of secretary.</strong> The administrative officer or other person in charge of each institution or the attending physician, caring for infants 28 days of age or younger shall have administered to every such infant or child in its or such physician's care, tests for congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases which may be detected with the same specimen…</strong>&lt;br&gt;<strong>65-183. <strong>Same; report by physicians to secretary.</strong> Every physician having knowledge of a case of congenital hypothyroidism, galactosemia or phenylketonuria and other genetic diseases as may be detected with tests given pursuant to this act in one of such physician's own patients shall report the case …</strong>&lt;br&gt;<strong>KAR 28-4-509 Registry.</strong> (a) The registry shall be a computerized data system that includes the diagnosed individuals' name, birth-date, unique identification number, diagnosis, address including telephone number, parental names and addresses, guardian, nuclear family size and health status. □ (b) Persons or guardians of minor children with a confirmed diagnosis of phenylketonuria, hypothyroidism or galactosemia shall forward to the newborn screening coordinator any address □ and health status changes within three months of the change. (Authorized by K.S.A. 65-101; implementing K.S.A. 65-180 …)</strong></td>
<td>65-182. Same; provisions inapplicable where parents object on religious grounds. The provisions of this section shall not apply to any infant whose parents object thereto on the grounds that such tests and treatment conflict with their religious tenets and practices.</td>
<td>NO</td>
<td>YES</td>
<td></td>
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## Vaccination Surveillance System

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<tr>
<td>KS</td>
<td>NONE FOUND</td>
<td>From <a href="http://www.kdheks.gov/immunize/webiz.html">http://www.kdheks.gov/immunize/webiz.html</a></td>
<td>Consent forms combines consent for vaccination and registry making it difficult for parents to say no to the registry: <strong>VACCINE DOCUMENTATION/CONSENT FORM</strong> I have been offered a copy of the Vaccine Information Statement(s) (VIS) checked below. I have read, had explained to me, and understand the information in the VIS(s). I ask that the vaccinat(s) checked below be given to me or to the person named below for whom I am authorized to make this request. I consent to inclusion of this immunization data in the Kansas Immunization Registry for myself or on behalf of the person named below. Signature_______ Date_______</td>
<td>From <a href="http://www.kdheks.gov/immunize/webiz.html">http://www.kdheks.gov/immunize/webiz.html</a></td>
<td>YES, but NO (consent for vaccination and registry combined)</td>
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What is the Kansas Immunization Registry? The Kansas Immunization Registry, also referred to as KSWEBIZ, is the statewide immunization registry. It is a web-based centralized birth to death database that maintains complete, accurate, and secure immunization records for all Kansas residents.

The purpose of KSWEBIZ is to consolidate immunization information among health care professionals, assure adequate immunization levels, and avoid unnecessary immunizations. Registry data is used by healthcare professionals to: monitor the immunization status of children and adults; assure compliance with state statutes on immunization requirements for individuals; identify geographic areas at high risk due to low immunization rates; and document/assess vaccination coverage during disease outbreaks.

Where does the data come from?

- The registry is collecting this data from both public and private providers of immunizations without increasing work burden. As a centralized source of the most current and accurate information, the registry also serves as the resource for individuals in need of consolidated historical immunization information, including other state agencies and programs (SRS Medicaid, KDHE Bureau of Epidemiology and Disease Prevention, KDHE Bureau Family Health, and KDHE Bureau of Child Care Licensure), school nurses, local health departments, physicians, and health insurers.

In addition:

**Vital Statistics.** Legacy birth data (1994 – present) is extracted nightly from Vital Statistics*. This data includes birth certificate demographics and the birth dose of Hepatitis B. *Note: On average 95-98% of all parents consent to include their child’s record in KSWEBIZ through the birth certificate registration process.

**Medicaid Billing System.** Vaccinations billed to Medicaid are imported into KSWEBIZ nightly. Note: Vaccinations billed since 1990 have been imported.
### What is the Primary Goal of KSWebIZ?

The goal of KSWebIZ is to serve as a repository for immunization records that are accurate, up-to-date, and complete. This web-based system enables end users to accurately assess a patient's immunization status. Continuous enrollment of providers who actively use the registry on an ongoing basis, will ultimately result in readily accessible and complete immunization health records.

### Vital Statistics

Legacy birth data (1994 – present) is extracted nightly from Vital Statistics*. This data includes birth certificate demographics and the birth dose of Hepatitis B. *Note: On average 95-98% of all parents consent to include their child’s record in KSWebIZ through the birth certificate registration process. [emphasis added]

### What About HIPAA Compliance, Patient Privacy and Confidentiality, and Data Security?

Security measures are in compliance with HIPAA and Kansas statutes. Access is limited to individuals and entities that either provide immunization services or are required to ensure that persons are immunized. "Authorized users" are any one of the following: 1) an employee of a public agency or department, 2) health records staff of child care facilities and family day care homes, 3) a person other than a public employee who is entrusted with the regular care of those under the care and custody of a state agency including, but not limited to, operators of day care facilities, group homes, residential care facilities, and adoptive or foster homes, and/or 4) a health care professional (KSA 65-531).

### Legacy Data Imports

When an immunization provider decides to use the system, legacy electronic data is imported into KSWebIZ when possible so that manual data entry can be avoided.

### Direct Entry Providers

Patient demographic data, historical vaccinations, and administered doses are updated real-time at the time of service.

### Schools

School personnel access the system to update demographics, historical vaccinations, and track school immunization rates pending parental consent.

### Interface Providers

Providers with an electronic medical record (EMR) system, that has the capability, can search and update the registry electronically.

### And Other Sources
**General Enrollment Process:** KDHE is contacted by an interested provider. Information is collected on each applicant to substantiate eligibility and appropriate access. Upon approval, a provider is contacted by registry staff to begin the process of enrollment. The next step is for legacy data to be extracted from the provider system, if possible, and after having been “cleansed,” the data is imported into the registry. Once the data is ready to be loaded, training is scheduled. Secure tokens [devices that ensure extremely secure sign on to the system] are distributed. Confidentiality agreements are signed and the final data is imported into production.