### KENTUCKY

**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>KY</td>
<td>STATUTE:</td>
<td>211.660 Kentucky birth surveillance registry – Department's authority to promulgate administrative regulations. (1) The Department for Public Health shall establish and maintain a Kentucky birth surveillance registry that will provide a system for the collection of information concerning birth defects, stillbirths, and high-risk conditions…(3) (a) The department may require general acute-care hospitals licensed under KRS Chapter 216B to maintain a list of all inpatients and voluntarily to maintain a list of all outpatients up to the age of five (5) years with a primary diagnosis of a congenital anomaly or high-risk condition as defined by the department…Hospital participation regarding its outpatients shall be voluntary and subject to the discretion of each hospital. (b) The department may require medical laboratories…to maintain medical records for all persons up to the age of five (5) years with a primary diagnosis of or a laboratory test result indicating congenital anomaly or high-risk condition as defined by the department…</td>
<td>211.660. …(4) Each licensed free-standing birthing center, general acute-care hospital licensed under KRS Chapter 216B, and medical laboratory…shall grant…to any Kentucky Birth Surveillance Registry personnel or his or her designee, upon presentation of proper identification, access to the medical records of any patient meeting the criteria in subsection (3) of this section …(5) No liability of any kind, character, damages, or other relief shall arise or be enforced against any licensed free-standing birthing center, general acute-care hospital, or medical laboratory by reason of having provided the information or material to the Kentucky Birth Surveillance Registry.</td>
<td>NO</td>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>
## Cancer Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Registry</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
</tr>
</thead>
<tbody>
<tr>
<td>KY</td>
<td>STATUTE: K.R.S. Chapter 214 NO RULE FOUND</td>
<td>214.556 Kentucky Cancer Registry – Cancer patient data management system. (1) There is hereby established within the Kentucky cancer program, the Kentucky Cancer Registry and the cancer patient data management system…The cancer patient data management system shall be administered by the Lucille Parker Markey Cancer Center. (2) Each licensed health facility which provides diagnostic services, or diagnostic services and treatment, or treatment to cancer patients shall report to the Kentucky Cancer Registry, through the cancer patient data management system and in a format prescribed by the Kentucky Cancer Registry, each case of cancer seen at that health facility. Failure to comply may be cause for assessment of an administrative fine for the health facility, the same as for violation of KRS 216B.250.</td>
<td>214.556 …(3) Each health facility shall grant to the cancer registry access to all records which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or status of any identified cancer patient. Hospitals actively participating and enrolled in the cancer patient data management system of the Kentucky Cancer Program as of July 13, 1990, shall be considered to be in compliance with this section. The Lucille Parker Markey Cancer Center shall provide staff assistance in compiling and reporting required information to hospitals which treat a low volume of patients. (4) No liability of any kind or character for damages or other relief shall arise or be enforced against any licensed health facility by reason of having provided the information or material to the Kentucky Cancer Registry pursuant to the requirements of this section. (5) …(a) The Kentucky Cancer Registry may exchange patient-specific data with any other cancer control agency or clinical facility for the purpose of obtaining information necessary to complete a case record…</td>
<td>214.556 … (5) … (b) The Kentucky Cancer Registry may contact individual patients if necessary to obtain follow-up information which is not available from the health facility. … (7) …The Kentucky Cancer Registry may conduct analyses and studies as are indicated to advance cancer control in the Commonwealth.</td>
<td>NO</td>
</tr>
</tbody>
</table>
### Newborn Genetic Testing & Surveillance System

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>KY</td>
<td>STATUTE: KRS 214.155 RULE: KAR 902</td>
<td>214.155 Screening and tests for heritable disorders for newborns and infants -- Information provided to parent or guardian -- Application for federal grants -- Section cited as James William Lazzaro and Madison Leigh Heflin Newborn Screening Act. (1) The Cabinet for Health and Family Services shall operate a newborn screening program for heritable disorders that includes but is not limited to procedures for conducting initial newborn screening tests on infants twenty-eight (28) days or less of age and definitive diagnostic evaluations provided by a state university-based specialty clinic for infants whose initial screening tests resulted in a positive test…(2)…The listing of tests for heritable disorders to be performed shall include all conditions consistent with the recommendations of the American College of Medical Genetics (3) Each health care provider of newborn care shall provide an infant’s parent or guardian with information about the newborn screening tests required under subsection (2) of this section. The institution or health care provider shall arrange for appropriate and timely follow-ups to the newborn screening tests, including but not limited to additional diagnoses, evaluation, and treatment when indicated…(6) A parent or guardian shall be provided information by the institution or health care provider of newborn care about the availability and costs of screening tests not specified in subsection (2) of this section. The parent or guardian shall be responsible for costs relating to additional screening tests performed under this subsection…</td>
<td>214.155 (4) Nothing in this section shall be construed to require the testing of any child whose parents are members of a nationally recognized and established church or religious denomination, the teachings of which are opposed to medical tests, and who object in writing to the testing of his or her child on that ground.</td>
<td>Title XVII, Chapter 194A Cabinet for Health and Family Services: 194A.060 Confidentiality of records and reports. (1) The secretary shall develop and promulgate administrative regulations that protect the confidential nature of all records and reports of the cabinet that directly or indirectly identify a client or patient or former client or patient of the cabinet and that insure that these records are not disclosed to or by any person except as, and insofar as: (a) The person identified or the guardian, if any, shall give consent; or (b) Disclosure may be permitted under state or federal law. (2) The cabinet shall share pertinent information from within the agency’s records on clients, current and former clients, recipients, and patients as may be permitted by federal and state confidentiality statutes and regulations governing release of data with other public, quasi-public, and private agencies involved in providing services to current or former clients or patients subject to confidentiality agreements as permitted by federal and state law if those agencies demonstrate a direct, tangible, an legitimate interest in the records. In all instance, the individual’s right to privacy is to be respected.</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>
### Vaccination Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Exemption</th>
<th>Data Sharing</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
</table>
| KY    | NO STATUTE FOUND | **902 KAR 2:055. Immunization data reporting and exchange.**  
**Section 2.** Immunization Reporting.  
(1) Day care centers, head start programs, kindergartens and public and private elementary and secondary schools shall submit to the local health department in their area vaccination results on the Commonwealth of Kentucky School/Facility Annual Immunization Survey.  
(2) The annual survey shall include the number of:  
   (a) Students in the grade surveyed;  
   (b) Missing vaccination records;  
   (c) Religious exemptions;  
   (d) Medical exemptions; and  
   (e) Children who have received age-appropriate vaccinations.  
**902 KAR 2:055. NECESSITY, FUNCTION, AND CONFORMITY:** EO 2003-64, effective December 16, 2003, reorganized the Cabinet for Health Services and placed the Department for Public Health and the Division of Epidemiology and Health Planning under the Health and Family Services Cabinet. KRS 211.180 requires the Cabinet for Health and Family Services to implement a statewide program for the detection, prevention and control of communicable diseases. KRS 214.034 requires public or private primary or secondary schools, day-care centers, certified family child-care homes, or any other licensed facility which cares for children to maintain a current immunization certificate on file for each child in attendance. KRS 158.035 prohibits a child from enrolling as a student in a public or private elementary or secondary school unless the child presents a current immunization certificate issued by a licensed medical or osteopathic physician.  
| NONE FOUND | **902 KAR 2:055. ...**Section 3. Immunization Data Exchange.  
(1) A public health entity may record and exchange immunization data, without authorization from the patient or the patient’s parent or guardian, if the patient is a minor, if the person requesting the data provides health related or educational services on behalf of the patient or has a public health interest.  
(2) Immunization data may be recorded and exchanged electronically via an immunization registry.  
(3) Immunization data that may be exchanged shall include:  
   (a) Patient’s name;  
   (b) Patient’s address;  
   (c) Date of birth;  
   (d) Gender;  
   (e) Social Security number;  
   (f) Medicaid number;  
   (g) Birth state;  
   (h) Birth County;  
   (i) Mother’s name;  
   (j) Mother’s maiden name;  
   (k) Mother’s date of birth;  
   (l) Mother’s Social Security number;  
   (m) Father’s name;  
   (n) Father’s date of birth;  
   (o) Father’s Social Security number;  
   (p) Guardian’s name;  
   (q) Date vaccines were administered;  
   (r) Vaccine type;  
   (s) Vaccine lot number;  
   (t) Vaccine manufacturer; and  
   (u) Vaccine contraindications or adverse reaction indications.  
(4) This section shall apply to immunization data regardless of when the immunizations occurred or the medium used to collect and exchange the data.  
------- | NO | NO |
<table>
<thead>
<tr>
<th>KRS 158.037 requires the Cabinet for Health and Family Services to promulgate administrative regulations for public or private schools to report immunization results to local health departments. 45 C.F.R. 164.512(b), Federal Health Insurance Portability and Accountability Act (HIPAA), permits disclosure of protected health information (PHI) to local and state public agencies for public health activities and purposes without written authorization of the individual. Vaccinations to prevent disease are a core public health function. Reporting vaccination status constitutes infectious disease control and surveillance. This administrative regulation establishes requirements for reporting immunization results in schools, preschools, and day care facilities and permits recording and exchange of immunization data.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>214.015 Reporting of authorized or required immunization.</strong> Any health care provider that administers or supervises an immunization authorized under this chapter or otherwise required by the Department for Public Health shall report information about the immunization upon request by, or as required by, the department. The department shall direct the method of reporting and the entity that will receive the report in an administrative regulation promulgated by the department in accordance with KRS Chapter 13A. The department shall not require any reporting of information contrary to the requirements of the federal Health Insurance Portability and Accountability Act of 1996.</td>
</tr>
</tbody>
</table>
| **The Electronic Public Health Record – Vision and Progress in Kentucky**

**Learning Objectives for this Presentation:** By the end of the presentation, all participants will be able to distinguish between an immunization registry and an Electronic Public Health Record System (EPHRS). The audience will understand the vision that the Kentucky Department for Public Health has established for the KY-EPHRS as well as the challenges and the benefits of an information system that treats the immunization registry as one part of a solution for a consolidated public health record. The audience will also gain an understanding of Kentucky's investment in resources to implement the EPHRS vision as well as an accounting of the progress to date.

As a module of the EPHRS, the Kentucky Immunization Registry Module (KY-IRM) shares the patient demographics tables and address tables with the Kentucky Disease Surveillance Module (KY-DSM). This single database strategy provides a Common Person Index (CPI) for all citizens of Kentucky who receive vaccinations by participating providers or for whom reportable diseases have been tracked through the KY-DSM. Other data sources include vital records, the state public health integrated public health system in use by all public health clinics, first responder tracking, hearing screening results, lead level test results and application training status of system users. Other public health related data sets are to be added as time goes on. Providers will benefit from a single, web-based, secure system giving access to the entire domain of public health related data for their patients. The ultimate goal of this system is the improved health of all Kentuckians of all age groups.

*(Taken from 2006 National Immunization Conference, http://cdc.confex.com/cdc/nic2006/techprogram/P10323.HTM)*