

Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Genetic Clinics, Laboratories,

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1998

Organizational location: Department of Health (Maternal and Child Health)

Population covered annually: 56,000

Statewide: Yes

Current legislation or rule: Kentucky Revised Statute 211.660 Kentucky birth surveillance registry - Department's authority to promulgate administrative regulations. Effective: July 15, 2002

Legislation year enacted: 1992

Case Definition

Outcomes covered: KBSR collects information concerning birth defects, stillbirths, and high-risk conditions for Kentucky residents birth to age five. Diagnoses include the following ICD-10 codes: • All congenital anomalies codes - Q00-Q99 • Metabolic/storage disorders - D80-D82, E70-E72, E74-E83, E88, and all subcategories. • Teratogens (noxious influences) - P04.0-P04.9. • Zika Virus Disease - A92.5 And any additional condition deemed necessary for public health surveillance.

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (A fetal death of twenty (20) completed weeks' gestation or more, calculated from the date last normal menstrual period began to the date of delivery or in which the fetus weighs three hundred fifty (350) grams or more.)

Age: Up to 5 years of age

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

Other state based registries: Newborn CCHD Screening, NAS Public Health Reporting Registry

Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All prenatally diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Any infant with a codable defect

Coding: ICD-9-CM/ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Online database developed in-house

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file

System integration: Birth records from vitals statistics are linked with all cases in the KBSR database. Data from the state Newborn CCHD Screening database and the state Neonatal Abstinence Syndrome Reporting Registry are incorporated into KBSR.

Funding

Funding source: 100% CDC grant

Other

Web site: <https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/kbsr.aspx>

Surveillance reports on file: Birth Defect Specific Fact Sheets (English and Spanish) and Data Briefs; Contact of Partners; 10-Year Report

Contacts

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