

Kansas
Kansas Birth Defects Program

Purpose: Surveillance

Partner: Hospitals, Environmental Agencies/Organizations, Universities

Program status: Interested in developing a surveillance program

Start year: 1985

Earliest year of available data: 1985

Organizational location: Department of Health
(Epidemiology/Environment, Maternal and Child Health, Vital Statistics)

Population covered annually: 36,395

Statewide: Yes

Current legislation or rule: K.S.A. 65-1,241 through 65-1,246

Legislation year enacted: 2004

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and stillbirths (fetal deaths) information are used as part of the Birth Defects Information System (BDIS). Thirteen anomalies (and 'other' congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight ($\leq 1,200$ grams), low Apgar scores (≤ 5 at five minutes), seizure or serious neurologic dysfunction, and significant birth injury [skeletal fracture(s), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention] are also reported to BDIS.

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition

Residence: In state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Birth certificates, Stillbirth (fetal death) certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Reports

Pediatric & tertiary care hospitals: Reports

Other sources: Physician reports, Kansas Health Information Network

Case Ascertainment

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.), 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, 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: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through four data sources: live birth certificates, stillbirth (fetal death) certificates, Kansas Health Information Network and the congenital malformations and fetal alcohol syndrome reporting form. The live birth and stillbirth (fetal death) certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to Auris (the Birth Defects Information System). Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into Auris.

Database collection and storage: SQL Server

Data Analysis

Data analysis software: SAS

Quality assurance: Office of Vital Statistics conducts verification on live birth and stillbirth (fetal death) certificate data.

Data use and analysis: Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals, Ad-hoc upon request (e.g. cluster investigations)

System Integration

System links: Link case finding data to final birth file

System integration: Our program has a link with vital statistics records. The Birth Defects program uses the same data system (Auris) and shares information with Newborn Hearing Screening and Newborn Metabolic Screening program.

Funding

Funding source: 50% General state funds, 50% MCH funds

Other

Web site: http://www.kdheks.gov/bfh/birth_defects.htm

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