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 (<=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

Contacts
Alyson Dalrymple, MPH
Kansas Department of Health and Environment
1000 SW Jackson, Suite 220
Topeka, Kansas 66612-1274
Phone: 785-296-6134 Fax: 785-559-4280
Email: Alyson.Dalrymple@ks.gov

Jamie Kim, MPH
Kansas Department of Health and Environment
1000 SW Jackson, Suite 220
Topeka, Kansas 66612-1274
Phone: 785-296-6467 Fax: 785-559-4280
Email: Jamie.Kim@ks.gov