



KENTUCKY BIRTH SURVEILLANCE REGISTRY (KBSR)

Coordinator and Data Contact:

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State Web Site:

<http://chfs.ky.gov/dph/mch/ecd/kbsr.htm>

National Web Site:

<http://www.nbdpn.org>

Sources of Information for the Database

The Kentucky Birth Surveillance Registry (KBSR) is a state mandated surveillance system that is co-sponsored by the Centers for Disease Control and Prevention (CDC) and the Kentucky Department for Public Health. The system is designed to provide information on incidence, prevalence, trends and possible causes of stillbirths, birth defects and disabling conditions. The KBSR operates under the authority of Kentucky Revised Statute (KRS) 211.651-670 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Maternal and Child Health. The surveillance system is funded with a mix of agency funds and a cooperative agreement from the CDC.

Description of the Data Collected

The KBSR collects information from vital records, acute care and birthing hospitals, laboratory reporting, and voluntary outpatient reporting on all children from birth to five years of age who are diagnosed with any structural, functional, or biochemical abnormality determined genetically or induced during gestation. Newborn nursery, neonatal intensive care unit (NICU), and labor/delivery logbooks are reviewed on a monthly basis in participating hospitals with the largest number of births. Medical records of the child are reviewed on a monthly basis to verify a physician diagnosis of major structural anomalies.

Hospital discharge data and laboratory reporting are received on a quarterly basis, and the information is prepared for medical record abstraction. Vital records including live births and deaths are reported to KBSR on a monthly basis with stillbirths being reviewed on a weekly basis. Personal identifying information as well as diagnostic codes are collected by KBSR, and as such, it is considered a highly confidential database. Due to the sensitive nature of the data and laws designed to protect the individual, no personal identifying information is released from KBSR and data are only presented or released in aggregate fashion. The lowest demographic level of information that can be provided by KBSR is the Area Development District (ADD) level; county level data are not available.

Strengths of the Data

The KBSR provides data on certain birth defects, genetic and disabling conditions, pregnancy outcomes, and maternal risk factors that are not collected by other surveillance systems. The KBSR is a statewide mandated system; therefore, reporting entities are required by law to provide the data as described under KRS 211.651-670. Data are updated on a monthly basis. Data provided to KBSR occurs in a timely fashion with all birthing hospitals in the state currently submitting data through a vendor on a quarterly basis. Medical records abstraction is consistently conducted on a monthly schedule and data from 1998-2010 have been verified.

Specific Uses of Information

- Monitor *Healthy Kentuckians 2020 Goals*
- Monitor KIDS NOW Initiatives on Early Childhood Development
- Provide data for use in various projects by the Folic Acid Partnership of Kentucky, the March of Dimes Kentucky chapter, the Spina Bifida Association of Kentucky, and the National Birth Defects Prevention Network
- Data on specific abnormalities are currently being used for a National Birth Defects study.
- Data provided for the World Health Organization Craniofacial Study
- Data provided on specific birth defects for the Environmental Quality Commission report, "Children's Health"
- Data are used annually for the preparation of the grant application "Cooperative Agreements for the Development and Improvement of Population-Based Birth Defects Surveillance Programs."
- Data are used annually to monitor trends of birth defects among specific populations, geographical areas, and the state as a whole and to monitor any cluster outbreaks and to evaluate health disparities.

Data Limitations

There is one main limitation to KBSR data, small numbers when dealing with individual defects. As a result, data must be presented in an aggregate fashion and cannot be provided by county level. Also, the sensitive nature of the data plays a role in what can and cannot be released to data requestors. This limitation should not hinder the use of KBSR data but should be considered.

Another limitation that KBSR is working to correct involves capturing out-of-state births to Kentucky resident mothers as not all cases are being captured in KBSR, and currently KBSR does not collect prenatally diagnosed cases of birth defects that are lost prior to 20 weeks gestation.

System Evaluation

Data collection for KBSR is monitored closely with a quarterly analysis of timeliness (number of days from birth to import into the system) and uniqueness of reporting sources. In addition, with each quarterly submission of hospital discharge data, 23 analyses are completed for omissions, errors, and completeness of records. Those records found to have omissions, errors or incomplete information are returned to the vendor for correction. KBSR also monitors the number of UB-92 records submitted by each hospital by quarter to identify any changes. A report is also generated quarterly in terms of the total number of records abstracted to date and the total number of records received each quarter into the database. A proportion of the cases within KBSR are being re-abstracted to establish an error rate from the medical records abstraction component, and an annual comparison of the percentage of Kentucky residents reported with birth defects to national numbers is made.

Data Set Availability

KBSR data from 1998 to 2010 are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. KBSR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances. National data are available on the National Birth Defects Prevention Network web site. Data requests should be submitted to the coordinator listed above once Cabinet IRB approval is completed.

Data Release Policy

Data must be presented in an aggregate fashion and cannot be provided by county level. Also, the sensitive nature of the data plays a role in what can and cannot be released to data requestors. This limitation should not hinder the use of KBSR data but should be considered.

Data Publications

The KBSR produces an annual report that contains trend data on certain conditions collected by the registry. The data are classified by sex, race, and maternal age and when applicable by ADD. A separate report on neural tube defects is produced annually and also contains trend data broken out by sex, race, and maternal age and ADD. KBSR also participates in the annual report on birth defect surveillance systems published in *Birth Defects Research*, which includes a basic description of the surveillance system and data for five years broken out by race, and for chromosome disorders by maternal age.

Suggested Data Citation

Kentucky Birth Surveillance Registry Data, (Year); Kentucky Department for Public Health, Division of Maternal and Child Health.

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