Kentucky Birth Surveillance Registry (KBSR)

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State Website: https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/kbsr.aspx

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Why is it used?

- Provides data for use in various projects by non-profit organizations to educate the public on birth defects and to facilitate birth defect prevention activities.
- For participation in multi-state studies with the CDC and National Birth Defects Prevention Network.
- Data are used annually to monitor trends of birth defects among specific populations, geographical areas and the state, to monitor any cluster outbreaks and to evaluate health disparities as part of a nationwide publication on birth defects surveillance.
- Data is used to generate fact sheets, data briefs and presentations.
- Promotes academic research on birth defects by facilitating access to a statewide dataset.
- To refer children with automatically qualifying conditions to Kentucky's Early Intervention System (KEIS).
- Formed the basis of the media campaign, Start a Healthy Today, for preconception and pregnancy wellness.
- Data is shared annually with the EPHT network for inclusion in their portal.

What data is collected?

- Data, including personal identifiable information (PII), is collected on all children from birth to 5 years of age who are diagnosed with any structural, functional or biochemical abnormality determined to be genetic or induced during gestation.
- Hospital discharge data and lab reporting.
- Vital records including live births, stillbirths and deaths.
- Linked to other MCH data systems including congenital critical heart defects screening and the neonatal abstinence syndrome (NAS) registry.

How is data collected?

- From vital records.
- Acute care and birthing hospitals.
- Laboratory reporting.
- Mandatory reporting to KDPH by inpatient facilities. Voluntary reporting to KDPH by outpatient facilities.
- Congenital critical heart defects screening and the NAS registry.

Data Strengths:

- Provides data on certain birth defects, genetic and disabling conditions, pregnancy outcomes and maternal risk factors that are not collected by other surveillance systems.
- Data is submitted by all birthing hospitals through a vendor on a quarterly basis.
- Medical records abstraction is conducted on a continuous schedule, with the target of completing abstractions by the child's second birthday.
- All data sources are linked to a single case, with ongoing quality checks.
- Nurses review medical records of children with selected conditions on an ongoing basis to confirm reported information.

Data Limitations:

- Small numbers regarding individual defects.
    - Data must be presented in an aggregate fashion and often needs to be suppressed.
- Sensitive nature of data means that some data cannot be released to requestors.
- There is currently no interstate data sharing, so Kentucky resident children who seek medical care out-of-state may not be in the registry.
- KBSR does not collect prenatally diagnosed cases of birth defects that are lost prior to 20 weeks gestation.
- Due to the nature of birth defects data, as well as reporting processes, cases are considered fully complete when the child exits the registry at age five. However, most of the case information and abstractions are completed by age two.

How is the system evaluated?

- Data collection is monitored closely with monthly analysis of timeliness, specifically, the number of days from birth to when the data is imported into the system.
- Quarterly data submissions from medical facilities are checked for omissions, errors and incomplete records.
- Medical records abstraction is subject to quality control audits.
- Annual review of the number of birth defects and rates by the CDC.
- System generated reports that detect invalid cases for manual review and voiding.

Data Set Availability:

- Available only in aggregate form.
- Available from 2005 onward, with the limitation that birth cohorts take 2-5 years to have complete reporting.
- Data will be completely de-identified.

Data Release Policy:

- IRB review and approval, in addition to a memorandum of understanding (MOU), are often required for these requests.
- KBSR staff reserves the right to deny any data request they deem would violate state and/or federal laws governing the data set, as well as data requests that do not have a sound scientific backing supported by a literature review.
- The sensitive nature of the data determines what can and cannot be released to requestors.

Data Publications:

- Selected data is publicly available through the EPHT portal on the CDC’s website.
- KBSR participates in the annual report on birth defect surveillance systems published in a special issue of Birth Defects Research.
- KBSR published a 10-year report in 2016 using 2005-2014 data and related data briefs.

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