Kentucky Department for Public Health

# Data Resource Guide

Our mission is to improve the health and safety of people in Kentucky through prevention, promotion and protection.

Kentucky Public Health

Prevent. Promote. Protect.

BECKY

Building Epidemiologic Capacity in Kentucky

Revised: May 2025

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The Kentucky Department for Public Health (KDPH) Data Resource Guide is a department-wide initiative that represents all KDPH divisions. The Data Resource Guide was completed on behalf of the KDPH by a Bulding Epidemiologic Capacity in Kentucky (BECKY) workgroup.

# Introduction

Health care data is vital to research and policy for continued community health, making it is essential to provide a complete and easily accessible point of reference for the various databases from within the Kentucky Department for Public Health (KDPH) and from external sources. In this year's edition, KDPH has over 30 data resources, compared to 20 resources in the first edition in 2005. As part of the department-wide effort to keep Kentucky's public health data as current and efficient as possible, this guide has been updated with new information, more resource systems, and a more streamlined format to increase ease of use.

There are three new resources in the 2024 edition: the Kentucky Colon Cancer Screening Program, Kentucky Harm Reduction Services, (formally called the Syringe Exchange Program Surveillance Database), and Kentucky COVID-19 Data. Resources that were included in previous versions but are no longer being updated have been removed. These include the Crash Outcome Data Evaluation System, the Kentucky Health Issues Poll, and the United States Zika Pregnancy Registry.

The Kentucky Department for Public Health Data Users' Workgroup created this guide to promote access to public health data; however, some data sources are highly confidential and cannot be released to the public. Program coordinators and data analysts must follow HIPAA guidelines when disseminating data. As a result, full data sets may not be available for all data sources presented. this will be noted where applicable within a section. Data summaries and reports should be available for most data sources.

In the appendix we have included links to useful national data resources, and a list of acronyms used throughout the Data Resource Guide. We also included relevant information for two of the datasets. For the Kentucky Trauma Data Bank, we included a list of designated/verified trauma facilities in the state of Kentucky. For the Office of Vital Statistics, we included more specific details about the data they collect.

This guide is a valuable resource for conducting public health research, monitoring public health goals or objectives, evaluating initiatives or exploring Kentucky related data sources. To recommend other useful and essential data sources for inclusion in future editions, please send a response to Mandy Fannin, Division of Epidemiology and Health Planning, amanda.fannin@ky.gov. Additional suggestions to make this guide more useful are welcome.

# Usage Summary

## So, you want to do research. . .

Whether you are a student pursuing a thesis or dissertation project, a government employee doing programmatic research or an experienced researcher doing a nationwide study, we would like to help you find out if the Kentucky Department for Public Health (KDPH) has the data you need, if it is available for use and how to request it.

These important points will help streamline the process:

1) Are you an experienced researcher, and if not (e.g., a student), do you have an experienced advisor to guide you? We highly recommend consulting someone with research experience.
2) Have you fully articulated your specific research question(s)?
3) Do you know exactly what data (variables) you need to answer the research question and the time frame of the data you would like to request?
4) Once you have answered the questions above and think you know the data you will need, this is the point where the Data Resource Guide can be helpful.
    a. Contact information is included for each dataset listed so that you can ask questions about a given dataset to determine if the data you want exists and is available for use.
    b. We recommend that you contact the program by email or phone to discuss the data you need, any specifics of that data (like variable characteristics, format of the needed variables), the feasibility of providing that data, and the time frame that might be needed.
5) If you find that KDPH has the data you want and that data is available to request, the flow chart on the following page shows the steps needed to request that data.

**IRB**

For most data requests (any data on or about people – i.e., human subject data), you will need to have Institutional Review Board (IRB) review to ensure that the research project you are doing or the use of the data that we release will not put people at unacceptable risk.

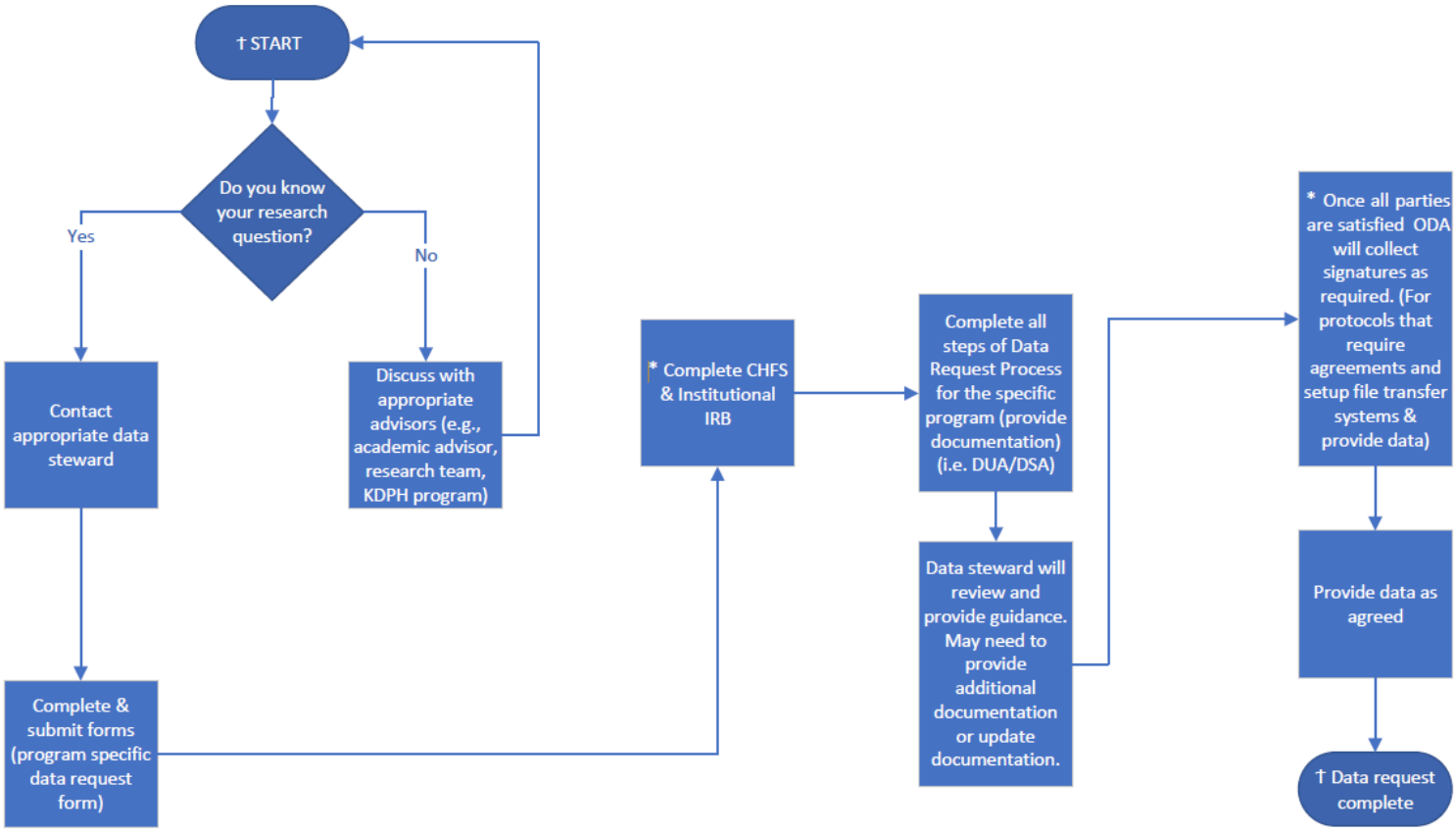
a. IRB approval for KDPH data requests are through the Cabinet for Health and Family Services (CHFS) IRB: https://www.chfs.ky.gov/agencies/ohda/Pages/Institutional%20Review%20Board.aspx
    1. The required forms for IRB submission can be found under “FORMS” on the CHFS IRB website.
    2. You will need both the “Research Request Form" and the “Research Proposal Outline”.
    3. If personally identifiable information is needed and patient consent is not possible, you must also submit a HIPAA Waiver Authorization Form.

Please Note**:** If a university or other IRB has approved (or exempted) your project, we ask that the project be submitted for CHFS IRB review if KDPH data is used.

**Data Use and Data Sharing Agreements**

The final step in obtaining data from KDPH is a “Data Use Agreement” (DUA) or Data Sharing Agreement (DSA) between the researcher and KDPH. A DUA/DSA specifies how the data can be used and how it will be protected. To put one of these in place, talk to the program supplying the data or contact the CHFS Office of Data and Analytics (ODA) by email at chfsdatagov@ky.gov or visiting the ODA website at: https://www.chfs.ky.gov/agencies/ohda/Pages/governance.aspx.

# Flow Chart




* Both CHFS IRB approval and establishing a data agreement with the KDPH program providing the requested data is required. These may be pursued simultaneously. IRB approval does not constitute an agreement to release data.
† The data acquisition process, including the IRB and data agreement processes, typically take 2 – 6 months, but could be more, depending on complexity, security concerns and amount of data needed.

# Behavioral Risk Factor Surveillance System (BRFSS)

**Coordinator:**
Sarojini Kanotra, PhD, MPH, CHES
Kentucky Department for Public Health
Division of Prevention and Quality Improvement
Chronic Disease Prevention and Control Branch
(502) 564-7996 ext. 4434
Sarojini.kanotra@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/brfss.aspx
**National Website:** http://www.cdc.gov/BRFSS

**Why is it used?**

- To reduce mortality due to lung cancer by collecting data on the prevalence of lung cancer screening rates.
- To determine the prevalence of self-monitored blood pressure in Kentucky's hypertensive population. This helps in preventing and managing cardiovascular disease in high-burden populations and communities.
- To support decision-making surrounding prevention, treatment and recovery activities for adult cannabis users.
- To collect data on adverse childhood experiences (ACE) and provide data to stakeholders as fact sheets.
- To identify the incidence and prevalence of eating disorders in the Commonwealth.
- To provide data to develop a baseline measure of the Healthy Kentuckians and Healthy People 2030 objectives.
- To collect data about health indicators of minority populations such as African Americans, Hispanics, and lesbian, gay, bisexual and transgender (LGBT) populations.
- To identify the prevalence of chronic conditions among adults with a diagnosed depressive disorder in each of the eight Medicaid managed care organization regions in Kentucky.
- To identify and address barriers to colorectal cancer screening to improve screening rates.
- To create a state plan for the coordinated Chronic Disease Prevention and Health Promotion program.
- To identify characteristics of women of reproductive age (18-50 years old) that may influence the type of contraceptives used.
- To determine the prevalence of Chronic Obstructive Pulmonary Disease (COPD) and its comorbidities and the differences in risk of COPD comorbidities across Area Development Districts (ADD).
- To provide data for reports such as:
    - Kentucky State Health Assessment, in preparation for the continued accreditation of the Kentucky Department for Public Health (KDPH).
    - Women's Health Profiles report for the Office of the Lieutenant Governor.
    - Health Equity Map Series, by the Northern Kentucky Health Department.

- Minority Health Status Report, a report on race, ethnicity and health in Kentucky, by the Office of Health Equity at KDPH.
- Kentucky Diabetes Report, 2021, a report to the Legislative Research Commission on collaborative diabetes-related efforts within the Department for Medicaid Services, KDPH, the Office of Health Data & Analytics and the Department for Employee Insurance within the personnel cabinet.
- Money Matters: Health Disparities in the Commonwealth, by The Foundation for a Healthy Kentucky.
- Kentucky Asthma Surveillance Report and asthma fact sheets by the Kentucky Asthma Program.

**What data is collected?**

Data related to preventive health practices and risk behaviors that are linked to chronic diseases, injuries and preventable infectious diseases that affect the adult population, including:

- Tobacco and alcohol use.
- Influenza.
- Immunization.
- Prevalence of diabetes and asthma.
- Hypertension awareness.
- HIV/AIDS.
- Colorectal cancer screening.
- Breast and cervical cancer screening.
- Weight control.

There is an optional module on social determinants of health that collects data on topics such as:

- Lack of employment.
- Limited transportation access.
- Social isolation.
- Effects of race on health and well-being.

Demographic data collected includes:

- Gender and age.
- Race and ethnicity.
- Income, education level and employment status.
- Rental status, zip code and county of residence.

**How is data collected?**

State-based system of telephone health surveys using Random Digit Dialing (RDD) techniques on both landlines and cell phones with three types of questions:

- Core questions asked by all states.
- Optional module questions developed by the CDC that may be selected to include in the questionnaire.
- State-added questions that states may develop or obtain related to the public health needs of their state.

**Data Strengths:**

- Provides data on elements that are not collected by other surveillance systems, such as risk behaviors, preventative health practices and chronic disease prevalence.
- For many states, the BRFSS is the only available source of timely and accurate data on health-related behaviors.
- Because landlines and cellphones are included in the survey, BRFSS can reach more people, producing a more representative sample and higher quality data.
- The KyBRFS sample size is large enough to provide yearly prevalence estimates by ADD.
- Data is usually available within six months of the collection year.
    - Data from survey year 2022 was available by August 2023.

**Data Limitations:**

- The BRFSS relies on information reported directly by the respondent, so it may be subject to measurement errors related to how the questions are worded.
- Response errors can occur because the ability to accurately recall details varies by person and how much time has passed since the event they are trying to recall.
- Selection biases may be reflected in the data.
    - Those who choose to participate are different than those who do not.
    - Interviews are only conducted in English, so adults who are not able to be interviewed in English are not included, and households without telephones are not contacted.
        - KyBRFS findings can only be generalized to English speaking adults living in households with telephones.

**How is the system evaluated?**

- Routinely monitored utilizing quality control standards developed by the CDC.
- Monitored remotely by a project coordinator.
- Evaluation of quality is determined through monthly and annual reports of performance standards.

**Data Set Availability:**

- Available to the public in yearly data sets.
- Available in both SAS and ascii.
- Includes a weighting variable so that prevalence estimates can be generalized to statewide populations.
- National data are available on the CDC BRFSS web site.
- Average yearly sample size - Landline: Cell Phone is 3,200: 800 (80:20).
- 2021 American Association for Public Opinion Research (AAPOR) response rate - Landline: Cell Phone: Combined is 51.8%: 49.8%: 46.8%.
- 2015 AAPOR cooperation rate - Landline: Cell Phone is 66.8%: 85.3%.
- Smallest geographic level released is the ADD.
- No charge for the data set.
- You can request data by completing the request form: https://KyBRFS Data Request Form.
    - Send the completed data request form to the KyBRFS epidemiologist/coordinator via e-mail or fax.

**Data Release Policy:**

- Data is not released for small sample sizes, e.g. county level.
    - Estimates produced from fewer than 50 unweighted records are not considered to meet standards of statistical reliability by the CDC.
    - There is also a possibility that individual respondents can be identified if the sample size is small.
- County identifiers are suppressed if data sets are released to requestors from out of state.
- It is highly recommended that 95% confidence intervals or standard errors be reported for all estimates produced using BRFSS data.
- If the data user is producing a report, the KyBRFS program must receive a copy of all printed and published materials using KyBRFS data. Please send copies to the address listed for the coordinator.

**Data Publications:**
The KyBRFS program produces statewide summary reports on several risk factors, health behaviors, chronic conditions and clinical preventive practices based on questions from the annual BRFSS survey. These reports include:

- ADD Profiles: a summary of selected prevalence estimates for each of the 14 Kentucky Area Development Districts with comparisons to statewide and national prevalence estimates.
- Regional Data Reports: in 2019 and 2020 the sample size for the state decreased making it difficult to collect data at ADD level. The ADDs had to be collapsed to six regions to provide sub-state level data. These two reports provide data tables by regions rather than by ADDs.
- KyBRFS Annual Report: a report featuring prevalence data stratified by gender, race, age, education, and household income.
    - Includes a section with ArcGIS maps showing prevalence estimates at the ADD level.
- The reports can be found on the KyBRFS website listed above.

**Suggested Citation:**
Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). Kentucky Behavioral Risk Factor Survey Data. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, **[appropriate data year or years].**

**Contributing Author:**
Sarojini Kanotra, PhD, MPH, CHES, Kentucky Department for Public Health

# Central Nervous System Injury Surveillance System (CNSI)

**Coordinator:**
Shannon Beaven
2365 Harrodsburg Road
Southcreek Building B, Suite B475
Lexington, KY 40504
(859) 257-4954
slbeav1@uky.edu

**State Website:** https://kiprc.uky.edu/programs/central-nervous-system-injury-surveillance
**National Website:** http://www.cdc.gov/ncipc/tbi/TBI.html

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**Why is it used?**

- To track cases of traumatic brain injury, spinal cord injury, non-traumatic brain injury and stroke as defined by the CDC and Kentucky Revised Statutes, KRS 211.470.
- To produce the annual CNSI surveillance report.
- For ad-hoc data requests and reporting.

**What data is collected?**

- Demographics such as age, gender and county of residence.
- Cause of injury including mechanism, manner and external cause of injury code.
- Information about injury severity including fatality indicator, injury severity score, length of stay in hospital and discharge diagnosis.
- Name of the hospital.
- Payers billed and total charges billed for those who were hospitalized.

**How is data collected?**

Data is taken from two sources:

- Kentucky Hospital Discharge Database (HDD) for inpatient hospital records and emergency department visits for CNSI.
- National Center for Health Statistics annual Multiple Cause of Death (MCOD) files for fatalities.

**Data Strengths:**

- Population-based rather than relying on a sampling strategy.
- Follows the 2002 CDC's Central Nervous System Injury data submission standards, meaning Kentucky's results are comparable to those of many other states who conduct CNSI surveillance.

**Data Limitations:**

- MCOD files are based on cases collected by Kentucky's Office of Vital Statistics (OVS) and can sometimes be incomplete.
- HDD records do not capture Kentucky residents treated out-of-state.
- HDD records are de-identified making it impossible to ascertain whether the visit is for a new first-time injury or a repeat visit.

**How is the system evaluated?**

- MCOD files are based on death certificate files provided to the National Center for Health Statistics (NCHS) by OVS.
    - OVS entry evaluation measures apply to CNSI as well.
- The system is also evaluated by computerized edit checks put in place by the collecting source for the HDD.

**Data Set Availability:**

- Case level data release from the CNSI database is not permitted.
- Aggregated data may be requested by contacting the coordinator listed above.

**Data Release Policy:**

- Data is not made generally available.
- Ad-hoc data requests are filled by way of summary data, with suppression of counts less than five in areas where confidentiality may be threatened.

**Data Publications:**

- Kentucky Injury Prevention and Research Center (KIPRC) publishes an annual report of the Traumatic Brain Injury and Spinal Cord Injury Project.
- Once finalized, the 2023 report will be available on the website: https://kiprc.uky.edu/programs/kentucky-brain-and-spinal-cord-injury-surveillance

**Suggested Citation:**

Kentucky Injury Prevention and Research Center (KIPRC). Central Nervous System Injury Surveillance Project. Lexington, Kentucky: University of Kentucky **[data year]**.

**Contributing Author:**

Shannon Beaven, Kentucky Injury Prevention and Research Center

# Child Fatality Review (CFR)

**Coordinator:**
Casey Reed, MPH
Epidemiologist II
Division of Maternal and Child Health
Kentucky Department for Public Health
(502) 564-2555
casey.reed@ky.gov

**State Website:** Child Fatality Review and Injury Prevention

**Why is it used?**

- KRS 211.680, established in 1996, was created to form priorities and develop programs to prevent child fatalities and requires collection and analysis of data to identify trends, patterns and risk factors, as well as evaluate the effectiveness of prevention and intervention strategies.
- A passive surveillance system that reviews all child deaths from birth to age 17.
- To monitor Healthy Kentuckians 2020 goals and KIDS NOW Initiatives on Early Childhood Development.
- Provides data for use in various projects.
- Provides data for the Annual CFR Report.
- To monitor select performance measures for the Title V Federal Maternal and Child Health (MCH) Block Grants.
- To evaluate health disparities.
- To monitor trends of child deaths among specific populations, geographical areas and across the state.
- To monitor any cluster of specific causes of death.

**What data is collected?**

The following information on all Kentucky resident children who die from any cause of death is collected:

- Personal identifying information.
- Cause of death codes.
- Circumstances surrounding the death.

**How is data collected?**

- Vital records from the Electronic Death Reporting System (EDRS).
- MCH Rapid Response Child Death Reporting form.
- Coroner report forms and coroner's CFR reports.
- Medical examiner reports.
- Sudden Unexplained Infant Death Investigation Reporting Form (SUIDIRF).
- Obituary scans.
- Substantiated cases of child abuse and neglect from the Department for Community Based Services (DCBS).

**Data Strengths:**

- Provides data on cause of death and circumstances surrounding the death, as well as recommendations for prevention, education and awareness.
- Statewide program with data analysis and reporting occurring on an annual basis.
- Data is updated monthly and is readily accessible by two full-time staff members in the MCH Division.
- Vital records are reviewed monthly.

**Data Limitations:**

- Data must be presented in aggregate form in resolutions larger than the county level due to small numbers when dealing with individual causes of death.
- Due to the nature of the data, there cannot be a standardized release of data to all requestors.
- Not all Kentucky resident deaths which occur out of state are being captured in the CFR.

**How is the system evaluated?**

- Data collection is monitored on a quarterly basis with review of the MCH Rapid Response Child Death Reporting forms and the coroner reporting forms to ensure proper agency (e.g., local health departments, law enforcement and the Department for Community Based Services) notification when a child death occurs.
- Death certificates from vital records are also reviewed to determine any discrepancies or omissions.

**Data Set Availability:**

- Data from 2000 to the present is available to certain requestors with approval from the Institutional Review Board (IRB).
- Staff reserves 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.

**Data Release Policy:**

- Kentucky CFR will only release a de-identified data set provided the requestor has received IRB approval and has been deemed to be HIPAA compliant.

**Data Publications:**

- Annual report that contains trend data on causes of death of children from birth to age 17.
- The report is produced in printed format as well as hosted on the CFR website.

**Suggested Citation:**

Kentucky Department for Public Health, Division of Maternal and Child Health, Child and Family Health Improvement Branch. Child Fatality Review Data. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, **[date year].**

**Contributing Author:**

Casey Reed, MPH, Kentucky Department for Public Health

# Drug Overdose Fatality Surveillance System (DOFSS)

**Coordinator:**
Dana Quesinberry, JD, DrPH
Assistant Professor, Department of Health Management and Policy
University of Kentucky College of Public Health
Associate Director, Kentucky Injury Prevention and Research Center
(859) 219-4919
dana.quesinberry@uky.edu

**State Website:** https://kiprc.uky.edu/programs/drug-overdose-surveillance

**Why is it used?**

- To enhance the state's analytical capacity to identify drug overdose fatalities using multiple data sources.
- DOFSS data is routinely analyzed and is used to inform stakeholders and the public of state drug overdose fatalities through:
    - Reports, presentations and briefs on findings.
    - Peer-reviewed publications.
    - Multi-state prevention efforts and data collaborations.
    - Data requests from external and internal agencies, organizations and associations.
    - Creation of prevention and education materials.

**What data is collected?**

Over 400 data fields are collected, including, but not limited to:

- Demographics.
- Place of injury and death.
- Cause of death.
- Drug paraphernalia found at scene.
- History of drug abuse or chronic pain.
- Mental illness or suicidal ideation.
- Known medical history.
- Significant contributing conditions.
- Pill counts from scene.
- Evidence of needle or track marks.
- Compliance with prescribed medications.
- Detected drugs and concentrations found in blood, urine, or vitreous fluid.

**How is data collected?**

Information is collected from:

- Vital statistics death certificates.
- Coroner investigation reports.
- Medical examiner autopsy reports.
- Emergency Medical Services (EMS) patient run reports.
- Post-mortem toxicology results.
- KASPER records.

**Data Strengths:**

- Bridges the gaps by inputting the data into one centralized database.
- Captures additional drug overdose fatalities and identifies emerging trends and patterns.
    - Identification of specific drug involvement has increased from 76% to 98%.

**Data Limitations:**

- Data may not be available for all decedents.
- Investigative and toxicological data are not available for decedents when the death certificate is completed out-of-state or when the death is not referred to the local coroner's office.

**How is the system evaluated?**

- Routinely evaluated based on CDC guidelines to ensure data quality and completeness, and to measure the program's efficiency.

**Data Set Availability:**

- DOFSS data utilizes information from many proprietary data sets. A limited de-identified dataset can be made available on consultation with coordinators.

**Data Release Policy:**

- Due to DOFSS data sets being derived from data sources maintained by other entities, data release inquiries must go through the primary custodians.

**Data Publications:**

- An annual report, specialized briefs, and peer-reviewed publications are produced and available on the KIPRC website.

**Suggested Citation:**

Kentucky Injury Prevention and Research Center (KIPRC). Kentucky Drug Overdose Fatality Surveillance System (DOFSS). Lexington, Kentucky: University of Kentucky **[data year].**

**Contributing Author:**

Sarah Hargrove, MS, Kentucky Injury Prevention and Research Center

# Kentucky Environmental Public Health Tracking (EPHT)

**Coordinator:**
Meagan Hurst, MPH
Program Manager, Epidemiologist III
Environmental Public Health Tracking
Kentucky Department for Public Health
(502) 229-9826
meagan.hurst@ky.gov
General Inbox: chfs.kyephtn@ky.gov

**State Website:** Environmental Public Health Tracking (ky.gov)
**National Website:** http://ephtracking.cdc.gov

**Why is it used?**

- Community level data for health assessments and health improvement planning.
- Compare environmental conditions, incidence and trends of chronic health conditions and environmental hazards between counties in Kentucky, as well as with other states.
- Generate hypotheses about possible associations between exposure to environmental hazards, social determinants of health and chronic health outcomes.
- Develop and evaluate plans for avoiding exposure to environmental hazards and mitigating the impacts of exposure.
- Design and implement public health actions specific to a community or jurisdiction.
- Identify opportunities to utilize data to improve health and racial equity and address environmental justice issues.

**What data is collected?**
Data is organized into a set of content areas defined by the CDC, which are reviewed and revised by the tracking program's content workgroup and include:

- Acute myocardial infarction.
- Air quality.
- Asthma.
- Birth defects.
- Cancer.
- Carbon monoxide poisoning.
- Childhood lead poisoning.
- Drinking water.
- Reproductive and birth outcomes.
- Climate and weather.
- COPD.
- Heart disease and stroke.
- Heat-related illness.
- Immunizations.
- Radon.

**How is data collected?**

- Data is collected from a variety of partners at national, state and local levels.

**Data Strengths:**

- Provides valid scientific information on environmental exposures and adverse health conditions and the possible spatial and temporal relationships between them.
- Allows data from census tract, county-level and/or state-level to be compared.
- It is currently the only surveillance system that organizes environmental and health data into a single source.
- Accessible to the public and researchers, decision-makers and public health professionals.
- Metadata further detailing the exact source of each content area is available on the national website listed at the top of the section.

**Data Limitations:**

- Statistical instability requiring spatial and temporal aggregation of data due to low numbers within small areas.
    - Data rates, proportions and percentages are checked for stability. Any rate or measure with a relative standard error (RSE) greater than or equal to 30% is flagged as unstable.
- Concerns regarding the release of sensitive information limit what data can be displayed for single years and small areas.
- CDC guidelines state that cell counts should be suppressed when the number of cases or underlying population is small.

**How is the system evaluated?**

- Data collection is routinely monitored utilizing CDC-developed quality control standards.
- Evaluation of quality is determined through monthly and annual reports of these performance standards.

**Data Set Availability:**

- Available at no cost through the national and state web portal.
- Users can obtain data based on area, indicator, geography, year and a number of other stratifying factors.
- Data can be viewed in map, table or graph form.
- National tracking program allows web-portal users to view and compare several data content areas or subsets side by side.

**Data Release Policy:**

- Requests for detailed data can be made to either the national tracking program or to individual grantee sites.

**Data Publications:**

- CDC has many peer-reviewed articles utilizing data from the tracking network that can be found on the publications page of the national tracking program website.

**Suggested Citation:**
Kentucky Tracking, Kentucky Department for Public Health, (content area and other details that were requested in query); Accessed From: healthtracking.ky.gov, **[data year(s)].**

**Contributing Author:**
Meagan Hurst, MPH, Kentucky Department for Public Health

# Fatality Assessment and Control Evaluation (FACE)

**Coordinator:**
Caitlin A. Northcutt (Pope), Ph.D.
Assistant Professor
University of Kentucky
Department of Epidemiology & Environmental Health
Kentucky Injury Prevention and Research Center
111 Washington Avenue, Suite 212
Lexington, KY, 40506
(859) 323-6222
Caitlin.pope@uky.edu

**State Website:** https://kiprc.uky.edu/programs/fatality-assessment-and-control-evaluation-face
**National Website:** http://www.cdc.gov/niosh/face

**What is FACE?**

- FACE has collected data and performed on-site investigations of traumatic fatal occupational injuries in Kentucky since 1994.
- Funded by the National Institute for Occupational Safety and Health to conduct surveillance of fatal occupational injuries, perform on-site investigations of work-related deaths, and disseminate prevention information to similar industries and occupations where workers died.
- FACE surveillance information is entered into a REDCap form that contains over 200 variables.

**What data is collected?**

Staff continue to add variables of importance to public health and research communities and include:

- Industry information, e.g., Standard Industrial Classification, North American Industry Classification Standards.
- Occupational classification codes.
- External cause of injury ICD-10 codes.
- Self-employment status.
- Health status such as diabetes, heart condition and/or weight.
- Specific questions related to motor vehicle collisions, farm incidents and interpersonal violence issues.

**How is data collected?**

- Coroner reports.
- State vital statistics records.
- Census of Fatal Occupational Injuries (CFOI) from the Kentucky Department of Labor.
- Kentucky CRASH datasets.
- Medical examiner reports.
- Mining Safety and Health Administration reports (MSHA).
- 24 state online newspapers.
- Radio and television reports.

**Data Strengths:**

- Provides timely, comprehensive multi-source surveillance and epidemiological analysis of worker fatalities to identify risk factors.
- Provides information used in case studies for employer/employee safety training and prevention strategies at the individual, company, and local or state levels by sector and across sectors.

**Data Limitations:**

- Out-of-state death certificates may not have all the data elements necessary if the injury took place in Kentucky, but the death occurred, and the death certificate was filed out-of-state.

**How is the system evaluated?**

- Evaluation is based on updated CDC guidelines to measure the program's impact on the reduction of occupational fatalities in Kentucky, the validity of its goals and the project's efficiency.
- FACE surveillance data is compared to CFOI, occupational safety and health fatality reports, and CRASH data monthly to verify and support information received though other sources, such as the newspaper.
    - At least two sources of information are used to confirm cases.

**Data Set Availability:**

- A public-use Kentucky FACE datasheet is not currently available.
- Aggregated data may be obtained in an Excel spreadsheet format at no charge by contacting the data coordinator.

**Data Release Policy:**

- Only aggregate data will be released upon request due to confidentiality concerns.

**Data Publications:**

- Publications available on the state FACE website include the annual FACE report, hazard alerts and fatality reports.

**Suggested Citation:**

Kentucky Injury Prevention and Research Center (KIPRC). Fatality Assessment and Control Evaluation (FACE) Program. Lexington, Kentucky: University of Kentucky **[data year]**.

**Contributing Author:**

Terry Bunn, PhD, Kentucky Injury Prevention and Research Center

# Health Facility and Services Data (HFSD)

**Coordinator:**
Michael Lawson, MSDA
Healthcare Data Administrator
Office of Data Analytics
Kentucky Cabinet for Health and Family Services
(859) 265-1888
MichaelC.Lawson@ky.gov

**State Website:** http://www.chfs.ky.gov/agencies/ohda/Pages/hfsd.aspx
**National Website:** http://www.hcup-us.ahrq.gov/

**Why is it used?**

- Inpatient hospitalization and outpatient services data is submitted annually to the Agency for Healthcare Research and Quality's (AHRQ) Healthcare Cost and Utilization Project (HCUP) for inclusion in the National Inpatient Sample and the National Emergency Department Sample.
- A subset of the hospitalization database plays a critical role in populating the Kentucky Birth Surveillance Registry.
- Data is used in preparing grant requests and status reports for KDPH programs in asthma, cardiovascular disease, diabetes and maternal and child health.
- Hospitalization data provide information for evaluating the health improvements of Kentuckians.
- Summaries of hospitalization data are key in developing and implementing Kentucky health care policies and decisions at the state level.
- Data is frequently requested by public health researchers, educators and consultants for a variety of individual projects.

**What data is collected?**

- Demographic data including gender, age group, state, county, race/ethnicity and zip code of residence. Personal identifying information is not included.
- Hospitalization fields including admission type and source, unique facility identifier, length of stay, diagnoses codes, procedure codes, discharge status and total charges.
- Grouping codes including Major Diagnostic Category and Medicare Severity - Diagnosis Related Group (MS-DRG).
- Procedure information for outpatient visitors via ICD and CPT codes.

**How is data collected?**

- Data is a collected under the requirements set forth in KRS 216.2920 - 216.2929 as the basis for regular reporting of cost, quality and outcome measures relative to hospital inpatient events and outpatient services utilization.
- Inpatient records describe a single inpatient stay in a Kentucky hospital.

- Outpatient records describe a single utilization of a service received at an ambulatory facility such as an ambulatory surgery or care center, a specialized medical technology services provider or a mobile health services provider, as specified for the dates below:
    - 2000 to 2007- an encounter where at least one of a list of CPT codes specified was performed.
    - 2008 to the present- the above with the addition of emergency department encounters.
    - 2015 to the present- all encounters for all specified ambulatory facilities and emergency departments, and not just the previous specified list of procedures.
    - 2019 to the present- HB 444 updated KRS 216.2927 to allow the Office of Data Analytics (ODA) to collect the necessary identifying information to assign a unique patient ID to each discharge.

**Data Strengths:**

- Allows detailed demographic, diagnostic and outcome analysis for public health reporting and research.
- Valuable in preparing documents such as chronic disease burden reports, grant proposals and justifications, resource utilization reports and ad-hoc studies about the health status of Kentucky citizens.
- The spatial components of this data can be used to illustrate regional hospitalization patterns and trends related to conditions and to show regional variation in hospital coverage and services.
- HFSD is included in the National Inpatient Sample, combined from hospitals in more than 45 states covering inpatient events in over 90% of U.S. hospitals.

**Data Limitations:**

- The records comprising these data files are constructed from claims submitted to the Kentucky Inpatient / Outpatient Data Collection System by hospitals and ambulatory facilities.
- The inpatient files contain all inpatient discharges from a given calendar year and must be used with caution in epidemiological analysis.
- Individual records represent single admit-through-discharge events.
    - Multiple admissions of an individual patient could not be definitively identified before 2019, so this data should not be used to directly measure the prevalence of a condition.
- State owned mental health facilities do not currently submit data.
- Charge amounts are the original amounts charged by the facility and do not reflect negotiated discounts for health insurance providers or the actual amount paid.
- The data cannot be linked with any other set at the line level.

**How is the system evaluated?**

- Data is verified as submitted, undergoing checks for presence and completeness of required fields, validity of submitted items, duplicate record checks and timeliness.
- Records with errors or omissions are returned to submitting hospitals and ambulatory facilities for correction and resubmission.

**Data Set Availability:**

- Data from 2000 to the present is available to the public only in calendar year data sets.
- Translation tables for coded data are included.
- Files containing the previous calendar year's data are available each July.
- Average yearly file size for inpatient records is 600,000 and 10,000,000 for outpatient records.
- Zip code is the smallest geographic level released for both inpatient and outpatient data.
- Data format is .csv files.
- Cost of data sets is $500 for non-profits, and $1500 for all others.

**Data Release Policy:**

- Requires a signed data user's agreement.
- Release of public use data sets is governed by 900 KAR 7:040.

**Data Publications:**

- Data is regularly summarized and published as a part of annual Administrative Claims Data Reports.
- Included in annual reports for programs in the Chronic Disease Prevention and Control Branch, data analysis provided by KIPRC, and in response to data requests from the public.

**Suggested Citation:**

Health Facility & Services Data, Frankfort, KY, [**year(s)**]: Cabinet for Health and Family Services, Office of Data Analytics.

**Contributing Author:**

Michael Lawson, MSDA, Kentucky Office of Data Analytics

# HIV Surveillance System

**Coordinator:**
Bob Ford, Surveillance Coordinator
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
(502) 564-8768
bob.ford@ky.gov

Manny Singh, MBBS, MPH, Senior Epidemiologist
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
(502) 564-6747
manny.singh@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/dehp/hab/Pages/default.aspx

**Why is it used?**

- Provides population level information about Kentucky's HIV/AIDS cases reported to KDPH.
- Provides data to create and evaluate prevention efforts and service initiatives for HIV/AIDS prevention specialists and community planning groups.
- Provides data for the evaluation of existing HIV/AIDS care and supportive services and the creation of new services to address unmet needs and service gaps.
- Provides data for grant applications for HIV/AIDS prevention and care services.
- To identify target populations that are disproportionately affected by HIV/AIDS.
- To assess Kentucky's progress regarding the National HIV/AIDS Strategy (NHAS), including information on the continuum of care, from diagnosis to viral suppression.

**What data is collected?**

Collected on standardized forms and includes:

- Demographics such as race and ethnicity, age groups and sex assigned at birth.
- Mode of exposure.
- Year of diagnosis.
- Year of report.
- Area Development District.
- County of residence.
- Laboratory and clinical information.

**How is data collected?**

There are several statutes that mandate HIV/AIDS related lab results go to the Cabinet for Health and Family Services (CHFS) and KDPH HIV/AIDS Branch and surveillance programs:

- KRS 211.180 calls for the creation of regulations specifying the information required and a minimum timeframe for reporting a sexually transmitted disease and establishes that the Cabinet requires cases of HIV to be reported by name and other relevant data.

  - KRS 311.282 states that licensed physicians will not be held civilly or criminally liable for disclosure of information to the Cabinet for HIV/AIDS reporting purposes.
- KRS 214.625 mandates that no person who has obtained or has knowledge of a test result shall disclose or be compelled to disclose the identity of any person upon whom a test is performed, or results of the test that permit the identification of the subject of the test, except to those with a legitimate need to know including the Cabinet in accordance with rules for reporting and controlling the spread of disease as required by law.
- 902 KAR 2:020, Section 16 states that physicians, hospitals, laboratories, counseling and testing sites and health professions licensed under KRS chapters 311-314 are required to report HIV and AIDS cases to KDPH. As of 7/15/2004, HIV cases are to be reported by name and no longer by a unique identifier.

**Data Strengths:**

- Data is collected from standardized forms.
- Data is managed using a series of standardized algorithms to decipher incoming data on previously existing cases or on new cases that need to be investigated.
- Surveillance performance standards and data quality are monitored at least monthly and laboratory data are imported into the registry routinely.

**Data Limitations:**

- HIV data is not always reported in a timely manner, which can lead to incomplete case numbers and may not be reliable in trend analyses.
- There are large percentages of infections without known modes of transmission that pose a barrier to provision of effective responses to the epidemic within the groups in question.

**How is the system evaluated?**

- HIV registry is evaluated annually utilizing quality control standards developed by the CDC.
- HIV data is not monitored monthly to evaluate the progress of these performance standards.

**Data Set Availability:**

- Raw data is not available for public use due to security and confidentiality restrictions.
- Aggregate data can be filled at the public's request with identified restrictions at no cost.

**Data Release Policy:**

- The data release policy is based on three main factors: the recipient of the data, population size of the data region and the timeframe.
- Under no circumstances will data be released if it is determined the data may compromise surveillance activities or affect public perception of the confidentiality of the surveillance system.
- A strict data release policy is necessary because release of certain types of data, even without names, could identify a case.
- You can request data by completing the request form: HIV Data Request Form

**Data Publications:**

- Annual surveillance report, continuum of care report and various category-based fact sheets.
- Integrated epidemiologic profile produced every five years with annual updates to epidemiologic data.
- Publications can be accessed on the HIV/AIDS website listed above.
- Additional resources including HIV prevention and care services data and external links to national HIV data are also available on our website.
- Interactive maps for national and state-level HIV data is also available at https://aidsvu.org/ and AtlasPlus

**Suggested Citation:**
HIV Surveillance. Frankfort, Kentucky: Cabinet for Family and Health Services, Kentucky Department for Public Health, **[data year].**

**Contributing Authors:**
Manny Singh, MBBS, MPH, Kentucky Department for Public Health
Bob Ford, MEd, Kentucky Department for Public Health

# Influenza Sentinel Surveillance System (ISSS)

**Coordinator:**
Carrie Tuggle
Influenza Surveillance Coordinator
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
Immunization Branch
(502) 564-3942
carrie.tuggle@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/Pages/RespiratoryDiseases.aspx
**National Website:** https://www.cdc.gov/flu/weekly/index.htm

**Why is it used?**

- To monitor influenza activity in the state.
- To promote influenza vaccination.
- Informs clinicians whether the circulating strain is a match for the current vaccine and if it is one that will respond to antiviral chemoprophylaxis and therapy.
- Laboratory information can be used to prepare for the possibility of responding to an influenza pandemic.
- To inform the public which strain is circulating, how influenza activity compares with other years and what populations are affected.

**What data is collected?**

The following is collected weekly from October through May by sentinel health care providers (HCP):

- Percentage of patients seen with influenza-like illness (ILI), defined as temperature <100$^{o}$F with a cough and/or a sore throat.
- Number of patient visits for respiratory illness and total number of patient visits by age group to calculate the percent of visits due to respiratory illness by age group.

**How is data collected?**

- ILI is reported by the sentinel HCP sites.
- Sentinel HCP sites report ILI to the CDC and obtain specimens for laboratory culture confirmation.

**Data Strengths:**

- System has done an excellent job of profiling the influenza activity at the end of each season, comparing its severity and pattern to other seasons and identifying the virus(es) responsible for the most activity during a particular season.
- Complements the systems of other states.
- Provides valuable input in the process of selecting strains for the following year's vaccine and to the strategy for annual vaccination campaigns.

**Data Limitations:**

- System relies on the accuracy and promptness of reporting by the sentinel HCP sites.

**How is the system evaluated?**

- Evaluated at the end of each influenza season.
- Summary information is evaluated by the state influenza coordinator, who determines how well the system provided answers to the frequently asked questions during the season.
- System has not been formally evaluated.

**Data Set Availability:**

- Kentucky requests information on all influenza-associated deaths for children less than 18 years of age or pregnant/postpartum women within three months of delivery.
- Sentinel surveillance depends on each HCP to report weekly.
- Cost of the data set includes the labor necessary to obtain the information.

**Data Release Policy:**

- This database is a restricted access system.

**Data Publications:**

- Reports are published weekly in the FluView on the CDC website.

**Suggested Citation:**

Kentucky Department for Public Health (KDPH). Influenza Sentinel Surveillance System Data. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, Kentucky Department for Public Health **[data year].**

**Contributing Authors:**
Carrie Tuggle, Kentucky Department for Public Health
Victoria Howell, MPH, Kentucky Department for Public Health

# Kentucky All Schedule Prescription Electronic Reporting (KASPER)

**Coordinator:**
Susan Harris
Division Director
Kentucky Cabinet for Health and Family Services
Office of Inspector General
SusanK.Harris@ky.gov

**State Website:** KASPER - Kentucky All Schedule Prescription Electronic Reporting - Cabinet for Health and Family Services

**What is KASPER?**
Kentucky's prescription drug monitoring program was established during the Kentucky General Assembly's 1998 Legislative Session. These provisions were then codified in KRS 218A.202. KASPER is a controlled substance prescription monitoring system designed to be a source of information to assist practitioners and pharmacists with providing medical and pharmaceutical care for patients using controlled substance medications. KASPER also provides an investigative tool for law enforcement and regulatory agencies to assist with authorized reviews and investigations. KASPER is not intended to prevent patients from receiving needed controlled substance medications.

**Why is it used?**

- Controlled substance prescription monitoring system.
- Source of information to assist practitioners and pharmacists with clinical decision making.
- Tool for monitoring compliance with KRS 218 Controlled Substance Act.
- Analysis and reporting of controlled substance trends in Kentucky.
- Law Enforcement tool for bona fide drug investigations.
- Data integration with electronic health records (EHRs) is available.
- For approved research.

**What data is collected?**
Collects data on Schedule II - V controlled substances dispensed in Kentucky:

- Patient's name, date of birth, gender, address and method of payment.
- Prescription information including the fill date, quantity, days' supply and prescription number.
- Prescriber's name, address and Drug Enforcement Administration (DEA) number.
- The drug name, strength and National Drug Code number.
- Information about the dispenser including their name, address, phone number and DEA number.
- Information about non-fatal overdoses, overlapping prescriptions, KY Find Help Now resources, prescriber report cards and drug conviction data is also collected.

**How is data collected?**

- Per 902 KAR 55:110 (3), the data shall be transmitted no later than close of business on the business day immediately following dispensing unless the cabinet grants an extension.
- A data use agreement between the Administrative Office of the Courts and OIG provides the connection for drug conviction data.
- An agreement with the Kentucky Health Information Exchange (KHIE) provides information regarding non-fatal overdoses received from hospitals/emergency departments.

**Data Strengths:**

- Helps health care providers identify patients who may be at risk for prescription drug abuse.
- Used by law enforcement and regulatory officials during bona fide investigations and other appropriate reviews.
- Data is standardized utilizing the Prescription Drug Monitoring Information Exchange (PMIX) and American Society for Automation in Pharmacy (ASAP) standards.

**Data Limitations:**

- KASPER data can only be disclosed to authorized entities under KRS 218A.202.
- KASPER data must be de-identified and cannot identify any individual prescriber, dispenser or patient.

**Who can query the KASPER system?**

- Licensing boards to investigate potential inappropriate prescribing by a licensee.
- Practitioners and pharmacists to review a current bona fide patient's controlled substance prescription history for medical or pharmaceutical treatment.
- Medical examiners engaged in a death investigation.
- A judge, probation officer or a parole officer to help ensure adherence to drug diversion or probation program guidelines.
- Law enforcement officers, OIG employees, Commonwealth attorneys and county attorneys to review an individual's-controlled substance prescription history as part of a bona fide drug investigation or drug prosecution.
- Medicaid to screen members for potential abuse of pharmacy benefits and to determine lock-in, and to screen providers for adherence to prescribing guidelines for Medicaid patients.

**Limits to usage:**

- CHFS may disclose KASPER data only to authorized entities, and only for the purposes specified under KRS 218A.202. KASPER data may be used by CHFS for investigations, research, statistical analysis, educational purposes and to proactively identify trends in controlled substance usage and other potential problem areas.
- Under KRS 218A.240, trend reports are established, and changes must be approved. KRS 218A.240, 7 (b) provides guidance on how trend reports are to be created and shall not identify any individual prescriber, dispenser or patient.
- Per record retention schedule, data is maintained for 15 years.

**How is the system evaluated?**
Regular data analysis is conducted by resource management analysts, IT staff and drug enforcement staff which includes:

- Failures and data corrections pursued from the dispensaries.
- KASPER querying compliance with 218A.
- KASPER account registration compliance.
- Data quality reviews.
- Education with providers, end users and researchers regarding system functionality.
- Ongoing modernization efforts.
- Regular meetings at the national level with other prescription drug monitoring programs and the Prescription Drug Monitoring Program Training and Technical Assistance Center at the Institute for Intergovernmental Research for system evaluations, trends and data discussion.
- Required feedback loop with research agencies and collaborative partners regarding outcomes which provides insight into the system, usage and improvement or areas for focus.

**Data Set Availability:**

- Authorized users have online access to KASPER data for 2 full years plus the current year.
- Data is maintained for 15 years.
- All data sets provided for research purposes will be completely de-identified.
- Average annual controlled substance prescription records reported to KASPER between 2010 and 2016 is 11,144,862.
- County level data is the smallest geographic level released.
- All non-zero counts less than ten are suppressed.
- Formatted in an Excel spreadsheet.
- No cost for the data.

**Data Release Policy:**

- Requires completion of a KASPER External Request form for those outside of CHFS/KASPER, or an Internal Request form for those from CHFS agencies.
- Requests will be reviewed on a case-by-case basis.
- Each request must identify the requesting organization, state the purpose of the research, explain the proposed methodology to be used and describe the publication plan, including:
    - Minimum necessary data elements to complete research.
    - Training on KASPER data.
    - Review with ODA to determine value to the Cabinet, other research cross-over and support.
    - Review with inspector general.

**Contributing Author:**
Office of Inspector General, Kentucky Cabinet for Health and Family Services

# Kentucky Birth Surveillance Registry (KBSR)

**Coordinator:**
Emily Ferrell, DrPH, CPH
Kentucky Department for Public Health
Division of Maternal and Child Health Program Support Branch
(502) 564-2521
emily.ferrell@ky.gov

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

**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.

**Suggested Citation:**

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

**Contributing Author:**

Emily Ferrell, DrPH CPH, Kentucky Department for Public Health

# Kentucky Cancer Registry (KCR)

**Coordinator:**
Eric B. Durbin, DrPH, MS
Director of Cancer Informatics
Kentucky Cancer Registry
(859) 218-3182
ericd@kcr.uky.edu

Jaclyn McDowell, DrPH
Epidemiologist
Kentucky Cancer Registry
(859) 218-2228
jaclyn.mcdowell@uky.edu

**State Website:** https://www.kcr.uky.edu/

**Why is it used?**

- Provides data used to calculate cancer incidence by age, race, gender and place of residence.
- Provides cancer incidence statistics for a variety of purposes and state programs for cancer prevention and control efforts.
- Provides data to government agencies and other health care researchers to assess the cancer burden in Kentucky.
- Provides data to the National Cancer Institute, the CDC and the North American Association of Central Cancer Registries (NAACCR) for estimating the cancer burden in the United States.

**What data is collected?**

- Over 400 data elements for each case of cancer diagnosed in Kentucky.
- Information about the first course of treatment.
- Place of residence, including geocode, for each cancer diagnosis.
- Detailed pathology information as well as certain biomarkers.

**How is data collected?**

- From hospitals, outpatient facilities, pathology laboratories and doctor's offices.
- From freestanding diagnosis and treatment facilities and multi-specialty clinics.
- From next generation sequencing reports.
- KCR can also obtain information on Kentucky residents with cancer who are treated in contiguous states.
- KCR links registry data with Kentucky death certificates to identify any cancer diagnosis made upon death that was not previously reported to the registry.

**Data Strengths:**

- Population-based rather than relying on a sampling strategy.
- Electronic data have been maintained in a consistent format since 1991.
- From 1999 - 2021, KCR received gold certification, the highest level of NAACCR certification available.
- KCR data has been included in the Cancer in North America (CINA) publication, which has strict standards for submissions that KCR was able to meet.

**Data Limitations:**

- Due to the network of outpatient facilities where patients may receive care, information about some non-surgical treatments may be incomplete.
- KCR only captures the first course of treatment.
- Timeliness:
    - Facilities are allowed 6 months from date of initial contact with a patient before cancer report is required to be sent to KCR. This allows time for collection of complete or nearly complete records.
    - Time must also be spent collecting out-of-state and death certificate records to complete a final edit of the data.
    - There is currently a delay of two years in establishing a complete annual database.
    - KCR must rely on other agencies for population estimates, which also may contribute to a delay.

**How is the system evaluated?**

- Collection protocols and formats follow national standards set by the National Cancer Institute's Surveillance, Epidemiology and End Results Program (SEER), CDC's National Program of Cancer Registries (NPCR), the American College of Surgeons' Commission on Cancer, and the NAACCR.
- Data has been submitted to NAACR for an objective evaluation of completeness, accuracy and timeliness each year since a formal certification program was established in 1997.

**Data Set Availability:**

KCR recognizes four categories, levels, or types of data that can be released for cancer surveillance and research purposes:

- Reports of aggregate data stratified by non-confidential data fields like case counts by race, sex and county.
- Data files containing individual, record-level data with no personal identifiers.
    - Zip code and county of residence can be included.
- Data files containing individual, record-level data with personal identifiers to be used for purposes of record linkage, either electronic or manual, but not direct patient contact.
    - Upon record linkage completion, personal identifiers will be removed.
- Files containing individual, record-level data with personal identifiers, to be used for research purposes involving direct patient or family contact.

**Data Release Policy:**

- Investigators who wish to use registry data for research purposes must complete the appropriate application for review by the KCR review panel.
    - The application must include a description of the proposed study, justification for the necessity of the research, and assurances of upholding confidentiality.
    - Requestor must have documented IRB approval for level two through four data.
- The KCR website provides the public with user-friendly access to cancer data, including cancer incidence and mortality data by cancer site, sex, race, geography and year of diagnosis.
    - Case counts are suppressed if fewer than five cases were reported in a specific category.

**Data Publications:**

- Cancer incidence and mortality data for the state is updated annually.
- Data for the years 1995 - 2021 are currently available at http://www.kcr.uky.edu/

**Suggested Citation:**
Kentucky Cancer Registry. (**[date updated]**). Cancer Incidence/Mortality Rates in Kentucky. Retrieved **[date]** from: http://www.kcr.uky.edu/.

**Contributing Authors:**
Eric Durbin, DrPH, MS, University of Kentucky
Jaclyn McDowell, DrPH, University of Kentucky

# Kentucky Childhood Lead Poisoning Prevention Program Data System (KCLPPP)

**Coordinator:**
James Cousett, MPH
Kentucky Department for Public Health
Maternal and Child Health Division
Child and Family Health Improvement Branch
(502) 564-2561
james.cousett@ky.gov

**State Website:** https://chfs.ky.gov/agencies/dph/dmch/cfhib/Pages/clppp.aspx
**National Website:** http://www.cdc.gov/nceh/

**Why is it used?**

- To ensure timely local health department intervention for elevated blood lead levels (EBLL).
- To track EBLL case history to help identify and prevent further access to potential and identified lead hazards.
- For determination of follow-up and decrease in EBLL.
- For submission of quarterly reports to the CDC for data reporting.
- For completion of performance evaluations.
- For fulfillment of open records requests.
- To estimate a populations' risk of lead poisoning based on their specific demographic and address information.
- Utilized by the CDC to assemble a national surveillance database.

**What data is collected?**

- Information regarding any Kentucky resident tested for lead.
- Comprehensive patient information is entered into the Healthy Homes and Lead Poisoning Surveillance System (HHLPSS), and the Childhood Lead Poisoning and Prevention Network Application (CLPPPNet).
- HHLPSS also contains results from on-site environmental lead inspections and risk assessments.
    - The risk assessment section of HHLPSS stores all environmental measurements taken during the lead inspection and risk assessment such as samples sent for lead testing.

**How is data collected?**

- Data is collected from any physician, nurse, hospital administrator, director of clinical laboratory, commercial laboratory or public health officer who receives information of a possible lead poisoning incident.

**Data Strengths:**

- Data is received in a timely manner which allows for accurate reporting.
- Current electronic data submission rates are above 95%.
- There is minimum manual data entry from outside labs.
- Current system is population-based rather than relying on a sampling strategy.

**Data Limitations:**

- Out-of-state laboratories that voluntarily report blood lead levels on Kentucky residents must enter them manually.
- Can be incomplete because patient records with incomplete or incorrect data fields are held for manual review and due to a lack of blood lead screening tests and reporting.
- It can be difficult to analyze data because county and zip code are often missing, making geographical analysis inaccurate, and data can contain duplicates which must be removed prior to analysis.
- Blood lead data for years 2015 – 2022 is missing required data fields such as address and source of specimen. Corrected data must be entered into the child's HHLPSS record.

**How is the system evaluated?**

- Data collection is based on CDC and National Institute for Occupational Safety and Health (NIOSH) guidelines.
- Data are subject to manual edits when entered.

**Data Set Availability:**

- Data set is only available in aggregate form and completely de-identified unless otherwise legally approved.

**Data Release Policy:**

- Data from 2015 to 2022 are available to requestors once IRB approval has been obtained.
- KCLPPP staff reserve the right to deny any data request that would violate state and/or federal laws governing the data set.
- Data requests should be submitted to the coordinator with the proper approvals (IRB, open records request, etc.) for release.

**Data Publications:**

- Reports on child blood lead levels and environmental data are sent to the CDC on a quarterly basis: CDC Childhood Blood Level Surveillance: State Data
- Additional reports can be found on the state website.

**Suggested Citation:**

Childhood Lead Poisoning Prevention Data. [**Year**]; Kentucky Cabinet for Health and Family Services, Kentucky Department for Public Health, Division of Maternal and Child Health.

**Contributing Author:**

James Cousett, MPH, Kentucky Department for Public Health

# Kentucky Colon Cancer Screening Program (KCCSP)

**Coordinator:**
Summer Amador
Data Quality Specialist
Kentucky Department for Public Health
(502) 564-4356
summer.amador@ky.gov

Shelby VanAlstine
Health Program Administrator
Kentucky Department for Public Health
(502) 564-6633
shelby.vanalstine@ky.gov

**State Website:** KY Colon Cancer Screening Program

**Why is it used?**

- State mandated program through KRS 214.540-544.
- To track program participation.
- Ensure patients are qualified for program.
- To track diagnosis and treatment of patients.
- Compile data into policy mandated annual report.
- Identify opportunities to improve health equity.
- Identify gaps in program outreach and promotion.

**What data is collected?**

- Eligibility and program enrollment information such as gender, race, ethnicity, DOB, SS, age, county of residence, insurance status, individual annual income and self-reported risk factors for colorectal cancer.
- Provider detailed data from the colonoscopy abstraction tool including the type of screening service and location, polyp removal information such as size and number of polyps, final diagnosis and cancer treatment status.
- Cologuard test results and any follow-up screening service recommended by Exact Sciences Laboratory.

**How is data collected?**

- Eligibility and enrollment forms completed by Kentucky Cancer Link with patient provided information.
- Abstraction tool from gastroenterologist/operating physician.
- Results from Exact Sciences Laboratory.

**Data Strengths:**

- Complied into annual report and sent to several governmental agencies as well as the Governor's Office and KDPH Commissioner's Office to advocate for colon cancer screening efforts.
- Uniform reporting tools across all screening locations.
- Displayed in a variety of forms including maps, tables, graphs and text.

**Data Limitations:**

- Information provided by patient thus we must rely on the patient to report accurate information and to recount risk factors to the full extent of their knowledge.
- We rely on Kentucky Cancer Link to send all information to us monthly.
- Limited to patient population and screening availability which ranges year to year.
- Treatment and staging for cancer diagnosis is not typically reported.
- Provider's quality measure standards vary from provider to provider.

**How is the system evaluated?**

- Internal evaluation of REDCap system by team.
- Data quality specialist enters, maintains and reviews data for quality standards monthly, quarterly and annually.
- Advisory committee reviews data every other month and annually.
- KDPH Commissioner's Office reviews annual report and provides feedback.

**Data Set Availability:**

- Data set is not available to the public.
- Data report is released to the public on the KCCSP website.

**Data Release Policy:**

- Data is compiled into annual report and must be approved by KDPH Commissioner's Office.
    - Once approval is received, the report is released to the public via the KCCSP website.

**Suggested Citation:**

For previous annual report: Kentucky Colon Cancer Screening and Prevention Program Advisory Committee. The Kentucky Colon Cancer Screening and Prevention Program Implementation and Outcomes Report. Frankfort, KY: Kentucky Cabinet for Public Health and Family Services, Department for Public Health Colon Cancer Screening Program, **[Year]**.

**Contributing Author:**

Summer Amador, Kentucky Colon Cancer Screening Program

# Kentucky COVID-19 Data

**Coordinator:**
Mandy Fannin
Epidemiology Process Coordinator
Kentucky Department for Public Health
amanda.fannin@ky.gov

**State Website:** Respiratory Viruses - Cabinet for Health and Family Services (ky.gov)

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**Why is it used?**

- To analyze trends including disease burden across the state.
- To help support public health surveillance activities and actions to control outbreaks and prevent further spread of disease or other health threats.

**What data is collected?**

- From 2020 through 2023, COVID-19 case investigation and laboratory report data were collected.
- October 2023 to present: COVID-19 hospital, death, and electronic laboratory reporting (ELR) surveillance data is currently published on the Kentucky's Respiratory Virus webpage.
- Data collected includes:
    - Patient demographics like age, gender, race and ethnicity.
    - County of residence.
    - Date of COVID-19 test.
    - Test result.
    - Clinical data such as symptoms, medical history and outcomes including hospitalization or death.

**How is data collected?**

Case data was collected and reported through a standardized case reporting form, i.e., the Person Under Investigation (PUI) form, electronic cases reports, ELR, and health information exchanges from a network of reporting providers across the state. In fall 2023, COVID-19 reporting expanded to include additional data sources such as:

- Hospitalizations and Emergency Department Visits.
    - Data from the National Syndromic Surveillance Program's (NSSP) platform, the Electronic Surveillance System for the Early Notification of Community-Based Epidemics (ESSENCE), is used to describe hospitalization trends.
    - Both inpatient admissions and Emergency Department visits for respiratory illnesses are described by weekly counts. These indicators describe trends in severe outcomes due to respiratory diseases.

- Outpatient ILI activity.
    - The U.S. Outpatient Influenza-like Illness Surveillance Network (ILINet) monitors outpatient visits for respiratory illness referred to as influenza-like illness (ILI), not laboratory-confirmed influenza.
    - This system might capture respiratory illness visits due to infection with any pathogen that can present with similar symptoms, including influenza, COVID-19 and RSV.
- Deaths due to respiratory diseases.
    - Death certificate data provided by the Office of Vital Statistics is used to describe overall mortality due to COVID-19 and influenza by week of death.
    - Pediatric deaths identified through provider reporting or death certificate searches are displayed in aggregate counts.
        - Pediatric deaths due to COVID-19 or influenza are reportable and reviewed by subject matter experts before being added to official counts.

**Data Strengths:**

- Describing overall COVID-19 levels and trends over time helps us understand the epidemiology of COVID-19 and implement prevention measures to avoid strain on the health care system and further protect those at increased risk of severe outcomes.
- Using a multidisciplinary approach to understand COVID-19 trends allows for a flexible and adaptable surveillance system.

**Data Limitations:**

- The COVID-19 pandemic strained public health systems and that led to reporting challenges.
    - As a result, case reports might be missing data including clinical signs and symptoms.
    - COVID-19 cases might have been underreported due to passive reporting systems.
- Since 2020, testing access has expanded to include the use of home test kits, which are not reportable to KDPH, leading to reduced utility of case report data to estimate disease burden.

**How is the system evaluated?**

- Case and ELR data are collected using the National Electronic Disease Surveillance System (NEDSS) that follows standards developed by CDC.
- Internally, KDPH epidemiologists routinely perform data quality assurance (i.e., ongoing updates to address data errors such as updating specimen collection dates, jurisdiction information, etc.).

**Data Set Availability:**

- Current COVID-19 trend information can be found here: Respiratory Viruses - Cabinet for Health and Family Services (ky.gov).
- Archived COVID-19 data can be found here: COVID-19 Reports - Cabinet for Health and Family Services (ky.gov).

**Data Release Policy:**

- Non-public data can be requested using the Open Records Request form found here: Records Center - Cabinet for Health and Family Services (govqa.us).
- Depending on the intended use of the data, the requestor may have to go through the IRB approval process with the Cabinet for Health and Family Services. Information on the IRB approval process can be found here: Institutional Review Board (CHFS IRB) - Cabinet for Health and Family Services (ky.gov).

**Contributing Authors:**
Lucy Ingaiza, MPH, Kentucky Department for Public Health
Amanda Pettinger, MPH, CDC Foundation
Carolyn Adam, MPH, CDC Foundation

# Kentucky Immunization Registry (KYIR)

**Coordinator:**
Laura Barrett
Registry Manager
Kentucky Immunization Branch
274 E. Main Street HS2WD
Frankfort, KY 40621
(502) 892-9101
Laurae.barrett@ky.gov

**Help Desk Contact:**
KYIR Help Desk
275 E. Main Street HS2WD
Frankfort, KY 40621
(502) 564-0038 (phone)
(502) 564-4760 (fax)
kyirhelpdesk@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/dehp/idb/Pages/kyir.aspx

**What is the KYIR?**

- System to monitor the immunization status of children and adults.
- Securely shares immunization information among health care professionals.
- Helps ensure adequate immunization levels and avoid unnecessary immunizations.
    - Can recommend to providers the vaccinations needed by any child or adult.
- Promotes compliance with state laws on immunization requirements for individuals.
- Identifies geographic areas at high risk due to low immunization rates.
- Documents and assesses vaccination coverage during disease outbreaks.
- Continuous enrollment of providers will ultimately result in readily accessible and complete immunization health records for all Kentucky residents.
- Includes a vaccine inventory management system that allows providers to maintain an accurate, adequate and viable vaccine inventory.

**What data is collected?**

- Immunization and demographic data.

**How is data collected?**

- CHFS Vital Records, local health departments, private health care providers, and hospitals across the Commonwealth.

**Data Strengths:**

- Contains immunization and demographic data that is maintained and updated over the life of each patient from birth to death.
- Easy to update vaccination records from any county within or outside of Kentucky.

**Data Limitations:**

- Reporting to the state immunization registry is not required.

**Data Release Policy:**

- The KYIR website provides clinical staff with user-friendly access to immunization related data in Kentucky.
- These records are not available to the public.
    - Due to the sensitive nature of the data and laws designed to protect the individual, fully identified records are subject to a strict confidentiality policy.
    - Non-patient specific reports may be made available to enrolled providers and possibly to qualified researchers who have submitted a written application to KYIR and have been approved.

**Data Publications**

- Kentucky Immunization Registry information, enrollment forms for providers, and additional program information are available on the website: https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/kyir.aspx
- Immunization rates are pulled annually from KYIR and are available on the website: Kentucky Immunization Registry

**Contributing Author:**
Jody Schweitzer, MPH, Kentucky Immunization Registry

# Kentucky Incentives for Prevention Student Survey (KIP)

**Coordinator:**
Paula Brown
Branch Manager
Prevention & Promotion
Division of Substance Use Disorder
Department for Behavioral Health, Developmental & Intellectual Disabilities
Kentucky Cabinet for Health and Family Services
(502) 782-7384
paulab@ky.gov

**Data Contact:**
Lisa Crabtree, MA, KIP Survey Project Director
REACH Evaluation
501 Park Ave.
Louisville, KY 40208
(502) 585-1911
lisa@reacheval.com

**State Web Site:** https://www.kipsurvey.com/

**Why is it used?**

- Enables schools to obtain valuable information about alcohol, tobacco and other drugs (ATOD), and school safety issues that can be used in prevention activities.
- Allows statewide planners to obtain a picture of the prevalence and consequences of ATOD issues to allocate resources and support communities.
- Can be used by government agencies to monitor Healthy Kentuckians goals pertaining to substance misuse.
- Useful in designing and evaluating substance misuse prevention initiatives and meeting federal reporting requirements related to ATOD.

**What data is collected?**
Using student-reported surveys, data about the following topics is collected:

- Student demographics, consumption patterns and consequences of ATOD use.
- Accessibility of ATOD for students.
- Personal and parental values.
- School safety, bullying, and sleep.
- Race-based experiences and concerns.
- Grades and mental health.

**How is data collected?**

- Self-reported surveys, distributed to students in grades 6, 8, 10, and 12 throughout Kentucky.
- In 2021 the survey transitioned to a fully web-based administration.
- Participation is optional and at the discretion of each school district.

**Data Strengths:**

- Provides easy-to-interpret, presentation-ready reports to each participating district.
- Creates trend graphs for districts that have participated in at least two KIP surveys.
- Each district is issued a unique username and password to access their KIP Survey results and archived KIP data.
- Graphs are provided depicting each district's Government Performance and Results Act (GPRA) data, which are the required outcome measures for the drug-free communities (DFC) grant program and may be useful for other government-issued grants as well.
- Significant efforts go into protecting the anonymity of responses, thereby reducing the risks associated with self-reporting.
- REACH searches for implausible responses during the data cleaning process and eliminates those surveys from the tallied results.

**Data Limitations:**

- Each individual school district decides what part of its report to make public, possibly limiting the use of local-level data.
- The anonymity of the responses greatly reduces the risks associated with answering the questions honestly, though some limitations associated with self-reported data are inevitable.
- Due to COVID-19, the 2021 data carry a distinct set of limitations due to several factors:
    - The 2021 sample represents fewer participants than prior years.
    - 2021 survey represents a new cohort of students not represented in prior years.
    - Wording of questions was revised, and new questions added, while others were deleted.
    - The pandemic itself had substantial impact on many behaviors measured by the survey, therefore comparisons to 2021 KIP data are not recommended.

**How is the system evaluated?**

- Following each biennial administration, analysis begins with data cleaning to ensure that any problems with the data set are discovered and resolved.
- Analyses are then conducted to assure the data are psychometrically sound.
- To find inconsistencies, pairs of answers are compared.
- To find exaggerations, REACH statisticians create summary variables that combine groups of individual variables.
- Data is then cross tabulated for each school district or group of school districts and can be related with past data to produce multi-year charts and graphs.

**Data Set Availability:**

- KIP statewide and regional reports, summary infographics and interactive data tools are available to the public free of charge and can be accessed on the REACH Evaluation KIP website at: https://www.kipsurvey.com/.

**Data Release Policy:**

- Since KIP survey data are the property of the schools, written permission from the school district is required to access district-specific results. Persons wishing to request district-specific data may contact the KIP Coordinator or the KIP Survey Project Director.

**Suggested Citation:**

- REACH Evaluation. KIP Survey 2021: Statewide Trends Related to Youth Substance Use, Mental Health, & School Safety (2012-2021: Sourcebook. Louisville, KY: REACH Evaluation, **[2021]**.

**Contributing Authors:**
Lisa Crabtree, M.A., REACH Evaluation
Dr. Daniel Sanders Jr., REACH Evaluation

# Kentucky Occupational Safety and Health Surveillance (KOSHS)

**Coordinator:**
Caitlin A. Northcutt (Pope), Ph.D.
Assistant Professor, University of Kentucky
Department of Epidemiology & Environmental Health
Kentucky Injury Prevention and Research Center
111 Washington Avenue, Suite 212
Lexington, KY, 40506
(859) 323-6222
Caitlin.pope@uky.edu

**State Website:** https://kiprc.uky.edu/programs/kentucky-occupational-safety-and-health-surveillance-koshs-program

**What is KOSHS?**

- Conducts surveillance of 25 fatal and nonfatal occupational injuries and illness indicators.
- Funded by NIOSH.
- Performs epidemiological analysis of fatality data.
- Uses surveillance data to determine priorities for development of interventions to promote occupational health and safety.
- Produces and disseminates occupational injury prevention information to industries and occupations.

**What data is collected?**

- Information regarding work-related injuries and fatalities occurring in Kentucky while performing work-related tasks.
    - Victim and employer names are not identified.
- Information is collected for both fatal and non-fatal injuries.

**How is data collected?**

Data is collected from:

- Bureau of Labor Statistics (BLS) Survey of Occupational Injuries and Illnesses.
- BLS Current Population Survey (CPS).
- Year 2000 US standard population data.
- US Census state population data.
- National Academy of Social Insurance.
- Census of Fatal Occupational Injuries.
- Bureau of Census County Business Patterns.
- OSHA annual reports.
- BLS data on covered employers and wages.
- Professional trade organization data.
- Kentucky Cancer Registry.
- Hospital discharge information.
- National Academy of Social Insurance.
- Office of Workers' Claims (OWC).

**Data Strengths:**

- Provides epidemiological analysis of fatal and nonfatal work-related injuries to identify risk factors.
- Continues to build a solid foundation of surveillance, epidemiological studies and innovative prevention strategies for translation of research into practice (R2P) for use by employers and policymakers.
    - R2P initiatives are promoted through effective dissemination of occupational injury and illness data, results and materials to occupational safety and health stakeholders.
- Timely and comprehensive multi-source surveillance.

**Data Limitations:**

- Not all occupational injuries and illnesses are being captured through the surveillance system.
- Increases in temporary workforce, self-employment status and lack of worker's compensation coverage leads to undercounting and underreporting of workplace injuries and illnesses.
- Despite limitations, KOSHS provides an accurate and comparable indication of the scope of occupational injuries and illnesses in Kentucky.

**How is the system evaluated?**

- Evaluation began in June 2005.
- System evaluation is based on updated CDC guidelines to measure the program's impact on the reduction of occupational injuries in Kentucky, the validity of its goals and the project's efficiency.
- Evaluation also includes indicators, and prevention and dissemination processes.

**Data Set Availability:**

- KOSHS data utilizes data from several proprietary and public data sets.
    - For proprietary data sets, the user will be required to request the data set from the appropriate data custodian.
    - For public data sets, the user should contact the Kentucky Injury Prevention and Research Center.

**Data Release Policy:**

- Due to the multi-source nature of the system, for proprietary data sets, requests should be made to the appropriate data custodian.

**Data Publications:**

- Annual KOSHS reports, hazard alerts, and peer-viewed publications are available on the state KOSHS website.

**Suggested Citation:**

Kentucky Injury Prevention and Research Center (KIPRC). Kentucky Occupational Safety and Health Surveillance (KOSHS) program. Lexington, Kentucky: University of Kentucky [**data year**].

**Contributing Author:**

Terry Bunn, PhD, Kentucky Injury Prevention and Research Center

# KY State Ambulance Reporting System (KStARS)

**Coordinator:**
Douglas Taylor
EMS Data Manager
Kentucky Board of Emergency Medical Services
Douglas.taylor@ky.gov
(502) 764-1507

**State Website:** https://kbems.ky.gov/KSTARS/Pages/default.aspx
**National Website:** http://www.nemsis.org

**Why is it used?**

- National Emergency Medical Services Information System (NEMSIS) data provides consistent definitions for elements used in EMS and prehospital care settings.
- Impacts all EMS clinicians and agencies across the continental United States and associated territories.
- To evaluate and improve patient care.
- To help improve EMS curriculums.
- Provides data for all EMS incident responses, including natural disasters and mass casualty events.

**What data is collected?**

NEMSIS-based prehospital patient care report data associated with EMS calls, including:

- Demographics.
- Injury severity.
- Vital signs.
- Treatments provided.
- Medications administered.
- Location.
- Destination.

**How is data collected?**

- Collected by Kentucky-certified and/or licensed EMS practitioners on behalf of licensed EMS agencies.
- Data is based on the NEMSIS Version 3 standard and collected in certified-compliant software packages, and then submitted to the KStars database using web services or direct entry methods.
- All licensed EMS agencies are required by 202 KAR 7:540 to submit to KStars using the latest state-adopted version of NEMSIS within 120 hours of incident completion.

**Data Strengths:**

- The current, state-wide, average incident submission timeliness is approximately 33 hours, and the state-wide median incident submission timeliness is approximately 3 hours, an improvement over years past.

**Data Limitations:**

- Some agencies have much slower than average data submission timeliness, making state-wide real-time use and data analytics less than ideal.
- Reports limited to flat file formats like CSV and XML.
- Elements with multiple values (e.g., vital signs) cause a repeating row in the report that makes one incident appear across multiple rows.
- Validation rules exist to improve data quality but complete and accurate adoption of the validation rules amongst the various patient care report software vendors can be difficult to ensure.

**How is the system evaluated?**

- Validation rules are used to enforce mandatory and recommended data element collection, but patient care reports may still be submitted without the desired 100-point validation scores.

**Data Set Availability:**

- Collected data is part of a national standard with comprehensive data dictionaries at the NEMSIS website.
- Fully identified data sets are not available to the public.
- Portions of the data set can be shared and identified data can be made available to research organizations provided the requestor enters into a data sharing agreement with the Kentucky Board of Emergency Medical Services and the request gains approval from any associated Human Subjects Review Board and/or IRB.

**Data Release Policy:**

- Any data released to the public will be de-identified.
- Requests are accepted through the open records procedure at KY Board of EMS Legal Services.

**Data Publications:**

- The Kentucky Board of Emergency Medical Services strives to publish an annual report with a variety of interesting topics, available at kbems.ky.gov

**Data Citation:**

Kentucky Board of Emergency Medical Services, Kentucky State Ambulance Reporting System, Frankfort, Kentucky, **[data year]**.

**Contributing Author:**
Douglas Taylor, Kentucky Board of EMS

# Kentucky Trauma Data Bank (KTDB)

**Coordinator:**
Julia Costich, JD, PhD
Kentucky Injury Prevention and Research Center
University of Kentucky, College of Public Health
(859) 257-6712
Julia.costich@uky.edu

**State Website:** https://kiprc.uky.edu/programs/kentucky-trauma-data-bank

**What is the KTDB?**

- In 2012, 902 KAR 28:040 established a single statewide Kentucky Trauma Registry (KTR) with KIPRC designated as the statewide repository for trauma data.
    - It was renamed the Kentucky Trauma Data Bank in 2023 to reflect the fact that is not a true registry and to be consistent with the nomenclature of the American College of Surgeons' (ACOS) National Trauma Data Bank.
- Funded by the National Highway Traffic Safety Administration through the Kentucky Transportation Cabinet to support annual and ad-hoc reports using registry data and reporting system activation for new trauma facilities.
- There are 24 Kentucky hospitals designated and verified or in the process of designation as trauma centers in Kentucky.
    - Please see Appendix C for a list of designated trauma centers.

**Why is it used?**

- Trauma system planning.
- To Inform legislative initiatives.
- Identification of areas in which additional activity is necessary.

**What data is collected?**

- Hospital name and if relevant, the referring hospital.
- Patient gender, date of birth and race.
- Country of injury, residence and zip code.
- Date and time of injury, arrival, and discharge.
- External cause of injury code, or E-code.
- Injury Severity Score (ISS), Glasgow Coma Score (GCS) and trauma score when relevant.
- Revised Probability of Survival (RPS).
- Blood Alcohol Level (ETOH).
- ICD-10 codes.
- Length of stay and number of ICU days.
- Disposition.

**How is data collected?**

- Data is submitted from various designated trauma centers that are listed in Appendix C.

**Data Strengths:**

- Provides a robust database that includes Kentuckians who incur serious traumatic injury that are cared for in the state's verified facilities.
- Supports the identification of areas in which the state deviates from national norms regarding traumatic injury incidence, characteristics and care.

**Data Limitations:**

- KTDB only includes data from facilities that are either ACOS-verified, state-verified Level IV centers, or those preparing for initial verification.
    - There are other centers that provide trauma care that are not represented in KTDB.
- Data must be de-identified, so repeat visits by the same patient are not identifiable.
- Some Kentucky residents living on state borders seek out-of-state treatment due to location, and KTDB has no way of obtaining that data.

**How is the system evaluated?**

- Data collection is routinely monitored utilizing quality control standards developed by the CDC and National Highway Traffic Safety Administration (NHTSA).
- Evaluation of quality is determined through monthly and annual reports of performance standards.

**Data Set Availability:**

- Raw data is not available to the public.
- Spreadsheet versions of KTDB data are available upon request from KIPRC.

**Data Release Policy:**

- KIPRC reviews data requests on a case-by-case basis and obtains additional information as needed.
- KIPRC and the research team will discuss and agree on a collaboration plan which will include schedule, methods, analysis, reporting and publication of the study.
- Reports using KTDB data cannot identify any individual patient or hospital.

**Data Publications**

- Detailed reports profiling the traumatic injuries treated in Kentucky trauma facilities are available at the website listed above.

**Suggested Citation:**

Costich JF, Murphy A. Kentucky Trauma Registry 2022 Annual Report. Kentucky Injury Prevention & Research Center, December 2023.

**Contributing Author:**

Julia Costich, JD, PhD, KIPRC, University of Kentucky

# KY Violent Death Reporting System (KVDRS)

**Coordinator:**
Sabrina Brown, DrPH
Associate Professor, Department of Epidemiology
University of Kentucky, College of Public Health
Kentucky Injury Prevention and Research Center
(859) 285-7271
Sabrina.brown@uky.edu

**State Website:** https://kiprc.uky.edu/programs/kentucky-violent-death-reporting-system

**Why is it used?**

- Used in peer-review publications, reports, briefs for advocacy groups, preventing suicide, intimate partner violence, veteran suicide, child abuse and responding to media requests.
- Used to develop proposals for National Institute of Health funding and National Institute of Justice funding.

**What data is collected?**

In the past, information related to homicides, suicides, and firearm-related deaths has been inaccessible and unreliable but by integrating multiple data sources to form the KVDRS, the following information can be compiled and analyzed:

- Information related to homicides, suicides and firearm-related deaths.
- Death certificates, coroner and medical examiner reports, forensic crime laboratory and toxicology reports and Kentucky State Police reports.

**How is data collected?**

- Electronic Death Certificates are imported into an internal database, linked with other investigative reporting sources, which are primarily manually abstracted, and hand entered.
- Data is then imported into the National Violent Death Reporting System, housed at the CDC.
- PII is removed before the national import.

**Data Strengths:**

- The Coroner Investigation Reporting System (CIRS) was designed, developed, and distributed to improve coroner reporting.
- CIRS is expanding to the Death Scene Investigation (DSI) system with users being any death investigator.

**Data Limitations:**

- Only deaths occurring in Kentucky are included.
    - Deaths of Kentucky residents that occur out-of-state are not included.
- Reporting may differ from the Office of Vital Statistics and the National Center for Health Statistics, who report on Kentucky residents regardless of where the death occurred.

**How is the system evaluated?**

- Data collection is routinely monitored utilizing CDC-developed quality control standards.
- Evaluation of quality is determined through monthly and annual reports of these performance standards.

**Data Set Availability:**

- Data set includes over 600 variables and circumstantial data such as events leading to the violent death, demographics and information about the weapon.
- National data are also available following the approval of a data sharing agreement (DSA) with the CDC.
- Data with cell counts less than five will be reported as <5. Average yearly sample size is 1000 - 1300.
- Smallest geographic level released is the county.

**Data Release Policy:**

Statewide and county-level aggregate summary data can be provided upon request through the website listed at the top of this section. If you would like to request data, please provide the following information:

- Name and organization.
- Intended use of the data.
- What years of data are needed.
- Geographic level needed.
- It is not necessary, but we would greatly appreciate a return email specifying in what capacity the data was used such as a citation from a presentation, grant application, or report.

**Data Publications**

- For a full list of publications, visit the state website listed at the top of this section.

**Suggested Citation:**

Brown SV, Seals J. Kentucky Injury Prevention and Research Center, a bona fide agent for the Kentucky Department for Public Health. Kentucky Violent Death Reporting System Data. Lexington, Kentucky: University of Kentucky, College of Public Health, **[data year]**.

**Contributing Author:**

Sabrina Brown, DrPH, Department of Epidemiology, University of Kentucky

# Kentucky Women's Cancer Screening Program (KWCSP)

**Program Director:**
Ellen Barnard
Program Coordinator
Kentucky Department for Public Health
Division of Women's Health
(502) 564-5024
ellen.barnard@ky.gov

**Coordinator:**
Sivaram "Ram" Maratha, M.Sc, MPA
Data Manager and Epidemiologist
Kentucky Department for Public Health
Division of Women's Health
(502) 564-5071
sivaramr.maratha@ky.gov

**State Website:** **KWCSP Website**
**National Website:** National Breast & Cervical Cancer Early Detection Program

**Why is it used?**

- Breast and cervical cancer screening services for low-income, age appropriate and uninsured women throughout the state
- Minimum data elements (MDE) are standardized data variables designed to ensure complete cycles of care occur, barriers are resolved, and disparities and quality issues are identified.
- MDE are the data set required by our grantor, CDC's National Breast & Cervical Cancer Early Detection Program, to be collected on all those eligible for KWCSP.

**What data is collected?**

- Patient demographics.
- Screening services including tests and diagnostic procedures.
- Results of screening services.
- Results of diagnostic services.
- Treatment if needed.

**How is data collected?**

- MDE are completed for each screening service provided to eligible women using program funds.
    - Each MDE record describes a screening cycle that starts with a screening test and tracks women through any immediate follow-up of abnormal findings needed to complete diagnostic evaluation and initiate treatment.
- Every contracted provider and participating local health department collects the MDEs and submits monthly and/or quarterly to KWCSP via secured email channels.

**Data Strengths:**

- MDE are accurate, complete and timely, used to establish strategies, activities and target populations of focus.
- Data at present is 99% complete and core performance indicators have been met for over 20 years.
- Screening data is available after 3.5 months and diagnostic data is available after 9.5 months from the MDE report cut off dates.

**Data Limitations:**

- Data is only collected on women over 21 who are at or below 250% poverty level and have no health insurance.

**How is the system evaluated?**

- Routinely monitored utilizing quality control standards developed by the CDC.
- Semiannual data reports are submitted to the CDC National Breast and Cervical Cancer Early Detection Program twice a year, and follow-up data calls are conducted to discuss findings.

**Data Set Availability:**

- MDE are available on the national website.
- Average yearly sample size is 3500 records.
- Smallest geographic level released is the county.
- Data format includes SPSS, text and access format.
- There is no cost for the data set.

**Data Release Policy:**

- MDE data set may be obtained by making requests through the open records process.

**Data Publications:**

- The KWCSP annually produces an internal Report of Breast & Cervical Cancer Screening, utilizing MDE analysis to produce this report.

**Suggested Citation:**

Kentucky Department for Public Health (KDPH), Kentucky Women's Cancer Screening, Frankfort, Kentucky: Cabinet for Health and Family Services; [**data year(s)**].

**Contributing Author:**

Sivaram 'Ram' Maratha, M.Sc, MPA, Kentucky Department for Public Health

# Neonatal Abstinence Syndrome (NAS) Surveillance System

**Coordinator:**
Emily Ferrell, DrPH, CPH
Kentucky Department for Public Health
Division of Maternal and Child Health
(502) 564-4830
emily.ferrell@ky.gov

**State Website:** https://chfs.ky.gov/agencies/dph/dmch/Pages/default.aspx
**National Website:** https://www.marchofdimes.org/complications/neonatal-abstinence-syndrome-(nas).aspx

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**Why is it used?**

- Provides population level information about Kentucky's NAS cases reported to KDPH, Division of MCH.
- Provides data to create and evaluate prevention efforts and service initiatives for NAS cases.
- Used to identify target populations that are disproportionately affected by NAS.
- Used to generate annual reports, fact sheets, data briefs and presentations.

**What data is collected?**

- Demographic information for mother and infant.
- Clinical symptoms displayed by infant.
- Maternal history of substance abuse, maternal toxicology and infant toxicology.
    - All are substance specific.
- Maternal prescriptions.
- Treatment and medication.
- Factors at discharge including disposition, breastfeeding and involvement with DCBS.

**How is data collected?**

- Mandated reporting (KRS 211.676) from hospitals of all Kentucky resident children with signs and symptoms of NAS and a supporting history.
    - Hospitals may report at birth, transfer, or readmission.
- Clinical staff complete a REDCap reporting form.

**Data Strengths:**

- Provides a population-based dataset of NAS cases in Kentucky based on clinical reports.
- Data are collected on a standardized form.
- Collection of mother and baby identifiers facilitate data linkage to birth certificates and other data sources.
- Reporting is ongoing, with timeliness encouraged.

**Data Limitations:**

- Due to the sensitive nature of the data collected and to ensure the confidentiality and security of the information, data will only be reported in aggregate fashion.
- Passive surveillance system relies on accurate, timely and complete reporting by hospitals.

**How is the system evaluated?**

- Surveillance performance standards and data quality are monitored at least monthly.
- Technical assistance to reporting facilities is conducted on an as-needed basis.

**Data Set Availability:**

- Due to security and confidentiality restrictions, raw NAS datasets are not available for public use.
- Interested researchers may contact the program to go through the data request process.

**Data Release Policy:**

- Data may be disseminated in aggregate fashion at the discretion of the MCH division director upon completion of the approval process.
    - IRB review and approval, in addition to MOU, are often required for these requests.
    - Aggregate data can be filled at the public's request with restrictions at no cost.

**Data Publications:**

- Mandatory publication (KRS 211.678) of an annual report containing de-identified statistical data on the number of reports made under KRS 211.676 related to a diagnosis of NAS is available on the website.
- Hospitals receive annual fact sheets on their reporting data, which are not distributed beyond those reporting contacts.

**Suggested Citation:**
Kentucky Department for Public Health, Division of Maternal and Child Health, Neonatal Abstinence Syndrome Surveillance System data; **[data year(s)]**.

**Contributing Author:**
Casey Gill, MPH, Kentucky Department for Public Health

# Perinatal Hepatitis B Screening

**Coordinator:**
Roberta Butler RN, MSN
Perinatal Hepatitis B Coordinator
Kentucky Department for Public Health
Vaccine Preventable Disease/Immunizations
275 East Main Street
Frankfort, KY 40621
(502) 562-3938
(606) 202-1228
roberta.butler@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/dehp/idb/Pages/perinatal-hepatitis-b.aspx

**Why is it used?**

- To identify and provide case management for hepatitis B surface antigen (HBsAg) positive pregnant women and their babies.
- Track changes in the overall epidemiological characteristics of hepatitis B.
- Assure that infants at risk of perinatal transmission receive hepatitis B immune globulin (HBIG) and hepatitis B vaccine series follow with post vaccination serology testing.
- To monitor for vaccine failures in infants born to hepatitis B positive mothers who receive the preventative regimen.

**What data is collected?**

- Reports of HBsAG tests on all prenatal patients.
- Demographic and clinical information.
- Dates of HBIG administration and hepatitis B vaccine series administration after birth.
- Date and results of post-vaccination serology testing including both HBsAg and hepatitis B surface antibodies.

**How is data collected?**

- Following mandatory HBsAg screening for all pregnant women, positive results reported by LHDs or obstetrical provider using EPID 394.
- Birthing hospitals complete EPID 399 (infant exposure to HBsAg positive mother) forms and send via secure fax or email to LHD or the state coordinator.
- Electronic lab submissions and vital record search.
- Internet Information Services (IIS) query to identify infants who have received HBIG.

**Data Strengths:**

- Provides surveillance and monitoring of known cases of children born to hepatitis B positive mothers.

**Data Limitations:**

- Information is limited to what is provided by LHDs, obstetrical providers, pediatricians, primary care providers and birthing hospitals. Data is also received from commercial labs and vital statistics.
- Access to the data is limited and inconsistent.
- Providers buy in to report via electronic medical records.
- Providers inconsistently testing and reporting results to LHDs and state coordinator.

**How is the system evaluated?**

Evaluated annually through a report submitted to the CDC containing:

- The number of births to HBsAg positive mothers.
- Vaccination completion rates.
- Post-vaccination testing rates.

**Data Set Availability:**

- Current registry is a restricted access database housed on a server in Frankfort, Kentucky.

**Data Release Policy:**

- Kentucky follows the integrated security and confidentiality guidelines for HIV, STD, viral hepatitis and TB surveillance programs mandated by the CDC.

**Data Publications:**

- Data are released to the CDC for publication in the Morbidity and Mortality Weekly Report (MMWR).
- The Department for Health and Human Services (HHS) uses these data for its viral hepatitis and perinatal hepatitis B programs.

**Suggested Citation:**

- Kentucky Department for Public Health (KDPH). Perinatal Hepatitis B Screening Data. Frankfort, KY: Cabinet for Health and Family Services, Kentucky Department for Public Health, **[data year].**

**Contributing Author:**

Roberta Butler, Kentucky Department for Public Health

# Pregnancy Risk Assessment Monitoring System (PRAMS)

**Coordinator:**
Nick Conley, MPH
Kentucky Department for Public Health
Division of Maternal and Child Health
(502) 564-4830
nick.conley@ky.gov

**State Website:** PRAMS (ky.gov)
**National Website:** http://www.cdc.gov/PRAMS

**Why is it used?**

- To increase understanding of maternal behaviors and experiences and their relationship to adverse pregnancy outcomes.
- To develop new maternal and child health programs and modify existing programs.
- To influence public health policy.
- To help health professionals incorporate the latest research findings into their standards of practice.
- To monitor progress toward local, state and national health objectives and goals.
- To provide data not available from other sources about pregnancy and the first few months after birth.
- To capture and investigate emerging maternal and child health issues.
- To evaluate health disparities.

**What data is collected?**

- State-specific, population-based data on maternal attitudes and experiences before, during and shortly after pregnancy.
- Data on perinatal maternal behavior and experiences that may be associated with adverse birth outcomes like smoking and oral health.
- Data is collected on a variety of topics including:
    - Demographics including race, age, education level, income and marital status.
    - Information about the mother's access to prenatal care, employment status, insurance status and quality of prenatal care.
    - Medical problems during pregnancy.
    - Information about the birth, infant sleeping position and whether breastfeeding or bottle-fed.

**How is data collected?**

- Mixed mode system of mail, telephone and web surveys.
- Survey distribution cycle is conducted over a period of three to six months with participant samples drawn each month.
    - The samples are derived from the live birth certificate files and are randomly generated to include women who gave birth three to six months prior to sample selection.

- Three types of questions available for use include core questions that are asked by all states, standardized questions that states may choose to use, and state-added questions related to the health needs of a particular state.

**Data Strengths:**

- Designed to supplement vital records data.
- Provides state-specific data on maternal behaviors and experiences to be used for planning and assessing perinatal health programs.
- Uses standardized collection methods.
- Provides data on health indicators not collected by other surveillance systems such as information about preterm births, low birth weight, infant mortality, breastfeeding and pregnancy intent.

**Data Limitations:**

- It is possible that recall bias may impact the accuracy of the data due to the mother's ability to recall the past events.
    - To alleviate this bias, calendars are included with survey mailings to help the mother develop a timeline of events during her pregnancy.
- Surveys are mailed based on address information collected from birth certificate files which can create non-response bias.
- Transient populations and non-English speaking populations are more difficult to reach, also creating response bias.
- It is possible that the results between non-response and respondent populations could be different.
- Only 50-60% of the approximately 150 women that are selected to participate each month respond so the sample size is small.

**How is the system evaluated?**

- Data collection follows the CDC model surveillance protocol to ensure consistent and valid sampling techniques and survey monitoring.

**Data Set Availability**

- Data will be made available once the program has one full calendar year of weighted data.
- Data will be available in SAS and comma-delimited format.
- A weighting variable will be included in the data sets so that prevalence estimates can be generalized to the state-wide population.
- Average yearly sample size is 1200.
- The data is provided at no cost.

**Data Release Policy**

- Data requests should be addressed to the PRAMS data coordinator, and data release policies will be discussed at that time.
- National data is available on the CDC PRAMS website.

**Data Publications:**

- PRAMS program will produce a statewide summary for each survey year. Once completed and approved, summary materials will be made available on the website.

**Suggested Citation:**

Kentucky Department for Public Health (KDPH). Pregnancy Risk Assessment Monitoring System Data. Frankfort, Kentucky: Division of Maternal and Child Health, **[Data year]**.

**Contributing Author:**

Nick Conley, MPH, Kentucky Department for Public Health
Tracey Jewell, MPH, Kentucky Department for Public Health
James Cousett, MPH, Kentucky Department for Public Health

# Reportable Disease Surveillance System (NEDSS)

**Coordinator:**
Courtney Marshall, MPH
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
Informatics Epidemiologist/NEDSS Coordinator
(502) 234-4568
courtney.marshall@ky.gov

**State Website:** https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/default.aspx
**National Website:** https://www.cdc.gov/nndss/about/nedss.html

**Why is it used?**

- To monitor disease trends in the state.
- Provides data to create and evaluate prevention and treatment initiatives.
- To provide data to the CDC for national reportable disease statistics.
- Provides data for grant applications related to reportable diseases in Kentucky.
- To monitor and evaluate geographic and/or spatial characteristics of disease.
- To monitor and evaluate outbreaks of disease.

**What data is collected?**

- Demographic information including gender, age, race, ethnicity and place of residence.
- Clinical symptoms.
- Risk factors.
- Outbreak associations.
- Laboratory information.
- Vaccine information.

**How is data collected?**

Disease reporting by health care providers, hospitals, clinics and laboratories is mandated by the Kentucky Disease Surveillance Administrative Regulation 902 KAR 2:020. Data collection tools include:

- EPID 200 Reportable Disease form.
- CDC disease-specific supplemental forms.
- Electronic case reports from hospital electronic health record systems.
- Clinical laboratory reports.

Data is submitted via fax, mail, or electronically through KHIE by:

- Hospitals and clinics.
- Local health departments.
- Private practice physicians.
- Commercial laboratories.
- State public health laboratory.

**Data Strengths:**

- Provides an estimate of communicable disease incidence and trends across the state.
- Works toward one of the ten essential public health services - to monitor health status to identify and solve community health problems.

**Data Limitations:**

- Data on the EPID200 form and in NEDSS investigations is often incomplete.
- Follow-up is difficult and may not result in obtaining the needed information.
- Data are often sent to the state or LHD weeks and sometimes months after the reportable event, which makes follow-up even more difficult.
- Due to large volumes of data in the system, extracting data can be cumbersome and typically needs to be done by reportable disease staff or regional epidemiologist.
- NEDSS is a passive system and thus data availability is dependent on reporting by health care providers and laboratories.

**How is the system evaluated?**

- Data collection is routinely monitored utilizing quality control standards developed by the CDC.
- Reportable Disease staff at KDPH review individual cases before initial submission to the CDC.
- Data are reviewed annually; any discrepancies between Kentucky and the CDC are reconciled before data are finalized.
- Informatics staff review incoming lab and case data daily for errors.

**Data Set Availability:**

- Fully identified data is not available to the public.
- Most data are released as an Excel file; other formats or connection types are available on request.

**Data Release Policy:**

- Portions of the data set may be shared, and identified data can be made available to research organizations if the requestor signs a confidentiality / security agreement with KDPH.
- Approval by the IRB is occasionally necessary.
- Any data released to the public will be de-identified.
- All requests should include a project justification, variables of interest, time of interest and anticipated deadline.

**Data Publications:**

- The Reportable Disease Section produces a 5-year and 10-year statewide reportable disease summary, which is available at: https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/diseasesummary.aspx
- The most recent 5-year report includes data from 2017-2021.
- The most recent 10-year report contains data from 2006-2015.

**Suggested Citation:**

Kentucky Department for Public Health Reportable Disease File. Frankfort, Kentucky. Cabinet for Health and Family Services, Department for Public Health **[data year]**.

**Contributing Author:**

Carrell Rush, MPH, Kentucky Department for Public Health

# Stroke Encounter Quality Improvement Project (SEQIP)

**Coordinator:**
Lonna Boisseau
Program Manager
Heart Disease and Stroke Prevention Program
Division of Prevention and Quality Improvement
Kentucky Department for Public Health
(502) 564-0646
lonna.boisseau@ky.gov

**State Website:** https://www.chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/heartdiseasestroke.aspx
**National Website:** CDC Division for Heart Disease and Stroke

**Why is it used?**

- SEQIP was created in 2009 as a statewide voluntary stroke quality improvement initiative of the Kentucky Heart Disease and Stroke Prevention Task Force - Cardiovascular Health (CVH) Delivery Systems Subcommittee and the American Heart Association/ American Stroke Association (AHA/ASA).
- To identify demographic variables associated with stroke prevalence to improve program or policy decision making.
- Data on standardized evidence-based measures help SEQIP hospitals monitor and improve acute stroke care processes and clinical outcomes.
- To ensure SEQIP hospitals are achieving greater than 85% on the Get With the Guidelines® performance measures.

**What data is collected?**

- Demographic information including gender, age, race, ethnicity and place of residence.
- Complete information regarding type of stroke.
- Complete information on clinical measures related to stroke care from hospital admission to discharge.
- A few pre-hospital and post-hospital discharge points.

**How is data collected?**

- Hospitals enter data into the Get With the Guidelines® -Stroke database maintained by IQVIA, a health information technology and clinical research organization.
    - All certified stroke centers in Kentucky are required to participate in the SEQIP data registry per KRS 211.575.

**Data Strengths**

- Allows for a thorough understanding of stroke types and severity.
- Contains detailed information on clinically relevant measures.
- Stores information regarding medical management strategies from hospital arrival to discharge, facilitating quality improvement at hospitals.

**Data Limitations:**

- Pre-hospital and post-hospital discharge information is limited.
- Stroke data from hospitals that do not use the Get With the Guidelines® database is not included.
- Many patient records have incomplete information.

**How is the system evaluated?**

- Data collection is routinely monitored utilizing quality control standards developed by the American Heart Association.

**Data Set Availability:**

- Fully identified data set is not available to the public.

**Data Release Policy:**

- Requests for specific analyses can be made to the program manager / data contact.

**Data Publications:**

- The Heart Disease and Stroke Prevention Program produces an annual statewide summary and can be found at the website listed above.

**Suggested Citation**

Kentucky Cabinet for Health and Family Services. The SEQIP Stroke Registry **[year]** Annual Report. Frankfort, KY: KY Cabinet for Health and Family Services, Department for Public Health Heart Disease and Stroke Prevention Program, Stroke Encounter Quality Improvement Project, **[year]**.

**Contributing Authors:**

Samantha Albuquerque, DrPH, MS, Kentucky Department for Public Health
Adam Berrones, PhD, Kentucky Department for Public Health

# Syndromic Surveillance (SYS)

**Coordinator:**
John Prather, MBA
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
(502) 564-4478 ext. 4264
john.prather@ky.gov

**National Website:** https://www.cdc.gov/nssp/index.html

**Why is it used?**

- Large event surveillance.
- Population health surveillance.
- Chronic disease surveillance.
- Surveillance of health issues related to the environment.
- Opioid surveillance projects with KIPRC.

**What data is collected?**

- Information about the patient including age, address and gender.
- Information about the event including date and time, facility name, chief complaints, triage notes and diagnosis codes and patient and event types.

**How is data collected?**

- Data is collected using the personal health information number (PHIN) messaging guide for syndromic surveillance HL7 Version 2.5.1.
- The data is provided through a collaborative working partnership between KDPH, KHIE and the NSSP.
- KDPH also has access to this data utilizing ESSENCE.

**Data Strengths:**

- Data and surrounding events are as real-time as possible.

**Data Limitations:**

- Lack of data completeness across facilities.
- Data is de-identified, making it hard to cross reference data between applications.
- Sending inconsistencies with facilities, e.g., data feeds can drop off at any time.
- Hospital exit data can take three to six months before it is finalized and released.
- CDC ESSENCE environment is controlled by KHIE.

**How is the system evaluated?**

- Evaluated daily utilizing data dashboards looking at facility connectivity and data completeness.

**Data Set Availability:**

- ESSENCE access is available on request and issued by the Kentucky Syndromic Surveillance Administrator, John Prather.

**Contributing Author:**

John Prather, MBA, Kentucky Department for Public Health

# Kentucky Harm Reduction Services

**Coordinator:**
Chase Barnes, MPH
Harm Reduction Program Manager
Kentucky Department for Public Health
Division of Public Health Protection & Safety
(502) 229-5870
chase.barnes@ky.gov

**State Website:** Syringe Services Programs- Cabinet for Health and Family Services (ky.gov) and Harm Reduction Program - Cabinet for Health and Family Services (ky.gov)

**Why is it used?**

- To evaluate the status of unique participants and total participant visits.
- To make referrals to substance use, mental health and infectious disease treatment, or other social services, including HIV and hepatitis C testing.
- To distribute harm reduction and overdose prevention supplies, e.g., Fentanyl test strips and Naloxone.
- To distribute syringes and evaluate the syringe return rate.
- To provide educational materials.

**What data is collected?**

Non-identifiable demographics including:

- Age.
- Race.
- Sexual orientation.
- Insurance status.
- Gender.
- Ethnicity.
- Housing status.
- Employment.

**How is data collected?**

- Through a REDCap Survey.
    - The participant receives a nonidentifiable ID consisting of the 1st two letters of their first name, the 1st two letters of their last name, the last two digits of their birth year and the last two digits of their social security number, e.g., FNLN9803.

**Data Strengths:**

- Data is received in a timely manner and each client has a record.
- Allows data from county-level and district-level to be compared.
- Currently the only harm reduction data collection tool that collects data from multiple LHD jurisdictions.

**Data Limitations:**

- Not every LHD offering harm reduction services throughout the state is utilizing this data collection tool.
- Data is de-identified.
- Unable to confirm acceptance and/or completion of treatment.

**How is this system evaluated?**

- Data collection is monitored on a quarterly basis.
- REDCap Survey will be reviewed on an annual basis.

**Data Set Availability:**

- Data from 2015 to the present has been collected.
- Data is not available for public use.
    - LHD directors and harm reduction coordinators have access to an internal dashboard.
- Through publication of internal annual reports.
- Not available for external research purposes.

**Data Release Policy:**

- LHDs can request Harm Reduction Services REDCap data by completing the request form: Kentucky Harm Reduction Program (readyop.com)

**Contributing Author:**

Chase Barnes, MPH, Kentucky Department for Public Health

# Vital Statistics Program

**Registrar:**
Jeffrey E. Sparks
Branch Manager and State Registrar
502-564-4937
JeffreyE.Sparks@ky.gov

**Coordinator:**
Claudia Valdivieso, MPH, MS, MLS
Epidemiologist III/Epi Lead
502-564-4948
OVS.epi@ky.gov

Courtney Walker, PhD
Population Health Data Unit Manager
502-234-8581
Courtney.Walker@ky.gov
Kentucky Department for Public Health
Division of Epidemiology and Health Planning

**State Website:** The Office of Vital Statistics
**National Website:** http://www.cdc.gov/nchs/nvss.htm

**What is it?**
The Office of Vital Statistics (OVS) administers the vital statistics program, which collects vital records for registration. The system of vital statistics preserves and protects the collection of all vital events. These vital records are the major life events for individuals and include births, fetal deaths (stillbirths), deaths, marriages, divorces (dissolution of marriages) and abortions. The Vital Statistics Program maintains and operates as the Commonwealth's only official vital statistics system. OVS performs four distinct core functions: vital records, public requests, protection, and collaboration.

**Why is it used?**
- Essential for identifying and measuring health patterns and for assessment of public health achievements.
- Supports nationwide statistics by integrating into the National Vital Statistics System (NVSS) through NCHS at CDC.
- Contributes to the assessment of the prevalence and distribution of many diseases and conditions.
- Identifies populations at risk for certain medical problems and diseases.
- Aids in the evaluation of the effectiveness of public health programs statewide.
- Supports the study of maternal and child health and infant morbidity and mortality, e.g., crude birth rates by geographic region, percent of births by age of mother, age specific birth rates, live births by birth weight, preterm births rates and fertility rates, among others.
- Helps to identify morbidity and mortality trends within communities.

- Calculates the estimate of death indicators such as crude death rate by geographic region, age and cause-specific death rates.
- Source of information for percent of underage marriage, marriage rates, and divorce rate estimates.
- Supports planning and allocation of resources by government agencies.
- Tracks the occurrence and characteristics of vital events in the state.

**What data is collected?**

Vital records resulting from vital registrations that take place in Kentucky are gathered by OVS, which also receives data about out-of-state occurrences for Kentucky residents. The completed paper or electronic forms that record significant events make up the collection of these vital records. Standard certificates are used to gather essential data prepared in a way that complies with NCHS standards. This data includes:

- Demographic information on the individuals associated with the vital event.
- Characteristics of the vital event.
- Some information on behavioral risk factors.
- Please see table in Appendix D for more information.

**How is data collected?**

- OVS is centrally located and is responsible for civil registration and certification of all vital record occurrences in the Commonwealth.
- Events that take place out-of-state for Kentucky residents are gathered with the collaboration of 57 other nationwide state jurisdictions.
- Information originates from birth, death, stillbirth, marriage, divorce and abortion certificates and forms collected and maintained by OVS.
- Please see Appendix D for more detail.

**Data Strengths:**

- OVS is the only agency that collects vital events data and holds over 15 million unique records.
- Registration of vital events is required by law, assuring that virtually 100% of events that occur in the state are reported.
- Vital statistics data have been maintained in reasonably consistent formats since 1990.
- Population-based rather than relying on a sampling strategy.
- Electronic collection protocols and formats are similar among states.
    - Data collected over time is for the most part comparable within the state as well as across the country.
- Since OVS data is integrated to the NVSS through NCHS/CDC, it is used to estimate the vital statistics for Kentucky at the national level and to compare nationwide, therefore OVS data is used for national statistics for Kentucky. National web source: CDC WONDER.

**Data Limitations:**

- Each state registers vital events that occur within its jurisdiction, therefore, data on out of state events may be limited due to how other states collect vital event information and what data is shared with the Kentucky OVS.
- Data on marriages and divorces are often incomplete because the collection method relies on mailed forms from county clerk offices.

- Due to the time it takes to collect and complete records, available data is typically 8-10 months behind the current year.

**How is this system evaluated?**

- Data are subject to computerized edit checks when entered.
- Corrections and amendments are made to the database on an on-going basis.
- The NCHS requires the state to maintain an error rate of no more than 2% for birth and death data.
- OVS conducts a final check of the files prior to establishing the official annual database.
- Any anomalies are checked against the actual certificates.

**Data Set Availability:**

- You can request data by completing this request form: https://wkf.ms/3Qyj8VY
- Data is released in an Excel workbook, Excel-csv, or text file. The most common ways to distribute data are via email, encrypted files via email, or transfer files through the state secure site MOVEitFTP.
- For requesters inside the cabinet, data transferring to network-attached storage in One Drive folders is another common method. Sometimes external drives may be used when multiples files for indexes/lists are provided.
- Depending on the complexity of the data request and the time it takes to process the request, there may be a fee. See Appendix D for more information.
- Data is released in the following formats:
    - Aggregate data reports.
    - Individual level data.
        - Data elements for births and deaths available as open records in an index or a list. Please see Appendix D for more information.
        - Individual level data that is not open as a public record is released through a data sharing agreement. IRB approval may be needed if PII or Protected Health Information (PHI) are included.

**Data Release Policy:**

- OVS adheres to the KDPH Data Release Policy, but it applies additional and specific restrictions due to internal regulations and policy within the OVS.
- There are two types of criteria: strict and minimum.
    - Program-specific regulations enforce stringent standards contingent on the degree of data sensitivity but both criteria are recommended for any particular use or situation.
- All data will be released if the population group under study is ≥ 1000. If the population count is < 1000, then any cell <5 will be suppressed.
    - OVS will suppress cells with fewer than five cases if the population count is less than 1000 and the comment < 5 shall be inserted.
- A combination of aggregate years of data (3-5 years) can be released for highly stratified data, to accommodate for low cell counts for specific cause or variable(s).
- Most data requests are released upon discretion of the epidemiologist in OVS however, depending on the case or type of data or request, state registrar and/or Office of Legal Services may provide the final approval for data release.

- Individual level data that includes PIIs and/or PHIs would have to follow the requirements for a data sharing agreement, and IRB approval (as needed) would have to be obtained before data is released. Assistance will be provided to requestors if IRB approval is needed.
- It is prohibited by law for anyone to permit the inspection of vital records, to disclose information contained in them, or to copy or issue a copy of any record, unless specifically authorized by KRS 213, by regulation, or an order of a court with competent jurisdiction. This is to ensure the integrity of vital records, their proper use, and the effective and proper administration of the system of vital statistics. Adopted regulations by the cabinet must guarantee sufficient levels of vital record security and confidentiality.

**Data Publications:**

- Kentucky Annual Vital Statistics Reports from 1997 - 2005 are available on the KDPH website: https://chfs.ky.gov/agencies/dph/dehp/vsb/Pages/reports.aspx.
- This manuscript is no longer published, but tables can be requested for release if the data requested meets the data release policy.

**Suggested Citation:**

Office of Vital Statistics - Kentucky Department for Public Health (KDPH). Birth (or Death or Marriage or Divorce) Certificate Files. Frankfort, Kentucky: Cabinet for Health and Family Services, 2024

**Contributing Authors:**

Jeffrey E. Sparks, State Registrar, Kentucky Department for Public Health

Claudia Valdivieso, MPH, MS, Lead Epidemiologist, Kentucky Department for Public Health

Courtney Walker, PhD, Population Health Data Unit Manager, Kentucky Department for Public Health

# Youth Risk Behavior Surveillance System (YRBSS)

**Coordinator:**
Ashley Bush
2365 Harrodsburg Road, Suite B340
Lexington, KY 40504
ashleybush@uky.edu

**State Website:** https://www.education.ky.gov/curriculum/WSCC/data/Pages/Youth-Risk-Behavior-Survey-(YRBS).aspx
**National Website:** https://www.cdc.gov/healthyyouth/data/yrbs/index.htm?scid=hy-homepage-002

**Why is it used?**

- Used to monitor priority health-risk behaviors of youth that contribute substantially to the leading causes of death, disability, and social problems among youth and adults.
- To determine the prevalence and co-occurrence of health risk behaviors among middle and high school students.
- To assess whether health risk behaviors increase, decrease or stay the same over time.
- Provides comparable data among subpopulations of youth.

**What Data is Collected?**

Information about the prevalence of health-risk behaviors among middle and high school students including:

- Tobacco, alcohol and other drug use.
- Sexual behavior.
- Dietary behavior / eating habits.
- Physical activity.
- Items related to unintentional injury, violence and suicide.

**How is data collected?**

- Biennial survey administered to representative samples of students in grades 9 – 12 during the spring of odd-numbered years.
    - Personal identifying information, such as name and address are not collected.
- Kentucky also administers a middle school YRBS for grades 6-8.
- Schools participating in the survey are selected randomly and participation is voluntary.

**Data Strengths:**

- The schools utilizing the YRBSS are selected using double random sample selection.
- In two test-retest reliability studies of the YRBSS questionnaire done by the CDC, a majority of the prevalence estimates were not significantly different.
- The 2003, and 2007-2023 YRBSS had an overall combined school and classroom response rate of over 70%, making this data statistically representative of students in typical public high schools throughout Kentucky.
- The middle school data was statistically representative in 2009-2023.
- The YRBSS has been conducted in Kentucky since 1991.

**Data Limitations:**

- Data are self-reported, and the extent of over-reporting or underreporting behaviors cannot be determined.
- The data apply only to youth who attend school and are not representative of all persons in this age group.
- Parental permission procedures are not consistent throughout the state.
    - Due to the passage of SB 150 in 2023, active parental permission will not be required in all schools.
- There is no federal or Kentucky mandate that requires data collection.

**How is the system evaluated?**

- Before each biennial survey, sites (states and districts) and the CDC work together to revise the YRBSS questionnaire to reflect site and national priorities.

**Data Set Availability:**

- YRBSS data from 2005 - 2023 for high schools, and 2009 - 2023 data for middle schools are available to the public.
- The data is available in SPSS and comma delimited formats.
- In 2021 the sample size included 1,925 high school students and 1,481 middle school students.
- Contact the YRBSS coordinator if requesting raw data sets.
- Visit the state web site for data reports and data request forms.
- Smallest geographic level released is the state.
- There is no cost for the data.

**Data Release Policy:**

- Due to confidentiality, the names of participating schools are not available.

**Data Publications:**

- Once surveys are complete, the CDC includes results for all states that conduct the YRBSS in the MMWR.
- The 2021 Kentucky YRBSS results are highlighted in the latest report and can be found on the YRBSS website: http://www.cdc.gov/healthyyouth/yrbs/index.htm.
- The website also includes a tool called Youth Online that can analyze and create tables and graphs and perform statistical tests on high school and middle school results from 2001-2023 by site and health topic.

**Suggested Citation:**

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**Contributing Author:**
Stephanie Bunge, M.Ed.
Kentucky Department of Education

# Appendix A: Additional Resources

The public health data sources presented in this guide are valuable to public health research and decision making. However, in many instances the research conducted is most effective when supplemented with additional population data as well as data pertaining to various social and economic indicators. Listed below are links to various national and state websites that will provide population and economic related data. Specific sites that include county level data are also included.

**Economic Data**
Statistical Abstract of the United States:
https://www.census.gov/library/publications/2011/compendia/statab/131ed.html
This document produced by the U.S. Census Bureau is a source for various social and economic indicators.

U.S. Department of Labor, Bureau of Labor Statistics: http://www.bls.gov
This is a link to a source for data pertaining to employment, wages, and productivity.

U.S. Department of Commerce, Bureau of Economic Analysis: http://www.bea.gov
This site contains information on various economic indicators including personal income by county, state, and Metropolitan Statistical Area (MSA) level.

**Population**
U.S. Census Bureau: http://www.census.gov
This is the main source for all population data. The most recent complete census was conducted in 2010.

Kentucky State Data Center: http://ksdc.louisville.edu/
The Kentucky State Data Center website contains Kentucky related census data as well as population estimates for most recent years. Population data by county and Area Development District (ADD) are included.

**State and Regional Data**
National Center for HIV/AIDS, Viral Hepatitis, STD and Tuberculosis Prevention (NHHSTP) Atlas:
http://gis.cdc.gov/GRASP/NCHHSTPAtlas/main.html
The atlas includes HIV/AIDS, Viral Hepatitis, STD and Tuberculosis data submitted to the CDC by state and local health departments.

**State and County Level Data**
CDC Wonder: https://wonder.cdc.gov/
This website includes a broad range of Public Health Information which can be beneficial to public health professionals and the public at large.

Community Commons: http://www.communitycommons.org/
Mapping Section: https://www.communitycommons.org/collections/Maps-and-Data
Community Commons is an interactive GIS mapping information system that provides data related to communities, economics, environment, food, health etc. on thousands of mappable geographic regions.

County Health Rankings: http://www.countyhealthrankings.org
The County Health Rankings help community leaders see that where we live, learn, work and play influences how healthy we are and how long we live. The Robert Wood Johnson Foundation is collaborating with the University of Wisconsin Population Health Institute to develop these rankings for the counties in each state.

Health Landscape: http://healthlandscape.org/
The health landscape is an interactive web-based atlas that enables health professionals and other policymakers to analyze their data and produce results that can be easily comprehended.

Interactive Atlas of Diabetes, Obesity and Physical Activity: CDC US Diabetes Surveillance System
The CDC website includes national, state and county level data on diabetes, obesity and leisure time physical inactivity.

Kentucky's Data Warehouse for Substance Abuse Prevention: http://sig.reachoflouisville.com/
This site allows program managers and prevention staff throughout Kentucky to have access to comprehensive data to inform their decisions and bring about a more cost-effective utilization of resources in the prevention of substance abuse.

Kentucky Health Facts: http://kentuckyhealthfacts.org/
The goal of Kentucky Health Facts is to provide readily accessible key health data for Kentucky communities. Communities can use this data to identify local needs, to motivate change, to guide planning efforts and to take meaningful, positive action toward improved health.

Policy Map: http://www.policymap.com/
The GIS mapping system offers data from over 15,000 indicators related to demographics, real estate, city crime rates, health, schools, housing affordability, employment, energy and public investments.

# Appendix B: Acronyms List and Page Numbers

# Appendix C: Kentucky Trauma Data Registry – Designated/Verified Trauma Facilities

**Designated/Verified Trauma Facilities (21 of 24):**

- Level 1 Adult Trauma Centers:
  - University of Kentucky, Chandler Medical Center (Lexington)
  - University of Louisville Hospital (Louisville)
- Level 1 Pediatric Trauma Centers:
  - University of Kentucky, Kentucky Children's Hospital (Lexington)
  - Norton Children's Hospital (Louisville)
- Level 2 Trauma Centers:
  - Pikeville Medical Center (Pikeville)
- Level 3 Trauma Centers:
  - Ephraim McDowell Regional Medical Center (Danville)
  - Frankfort Regional Medical Center
  - Owensboro Medical Center
- Level 4 Trauma Centers:
  - Ephraim McDowell Ft. Logan (Stanford)
  - Harlan ARH
  - Hazard ARH
  - Ephraim McDowell James B. Haggin Memorial Hospital (Harrodsburg)
  - Livingston County Hospital (Salem)
  - Mercy Health Marcum & Wallace Hospital (Irvine)
  - McDowell ARH
  - Deaconess Union County Hospital (Morganfield)
  - Morgan County ARH (West Liberty)
  - Tug Valley ARH (South Williamson)

**Facilities in the Process of Designation/Verification (3 of 24):**

- St. Joseph London
- The Medical Center at Bowling Green
- Twin Lakes Regional Medical Center

# Appendix D: Vital Events Datasets

**The following applications are used to collect vital records information:**

- Kentucky Child Hearing Immunization Lab Data (KY-CHILD)
  - Birth Record and Fetal Death Record (Stillbirth)
- Kentucky Electronic Death Registration System (KY-EDRS)
  - Death Record
- Marriage Records Management System (MRMS)
  - Marriage Record
- Divorce Records Management System (DRMS)
  - Divorce Record
- OVS - Abortion and Prescription Reporting
- State and Territorial Exchange of Vital Events (STEVE)
  - Transfer of vital events data from and to other states and NCHS

| **Data** | **Years Available**<br>**NF: New Format**<br>**OF: Old Format** | **Summary of data** |
|---|---|---|
| Birth* | Electronic:<br>• NF: 2004-present<br>• OF: 1990-2003 (out of state data until 2013)<br>Paper: 1911-present | Approximately 98% of the data collected for the live births is coming from birthing facilities through KY-CHILD. Currently there are 57 questions on the certificate of live birth. Birth data collected includes demographic information about the newborn and parents such as address, age, race, ethnicity, educational level; medical and health information such as previous pregnancy history, birth weight, plurality, characteristics of the birth, obstetric procedures, abnormal conditions of the newborn; and medical risk factors such as tobacco and alcohol use are included, among others. |
| Death* | Electronic:<br>• NF: 2010 mid-year-Present<br>• OF: 1990-2010<br>Paper: 1911-present | Death data is submitted by medical certifiers (coroners, medical examiners, physicians, APRNs and DOs) and funeral directors through EDRS. There are 52 questions in the certificate of death. Death data includes demographics such as address, age, sex, race, ethnicity and occupation; circumstances of the death, including date and place; the underlying cause of death (leading cause of death), and up to 20 supplemental causes, and significant contributing factors to death. Additional questions associated with injury deaths are included such as type of injury, how the injury occurred and geographic area where death occurred, among others. |

| Data | Years available | Summary of data |
|---|---|---|
| Stillbirth* | Electronic:<br>• NF: 2004 - present<br>• OF: 1990 - 2004 partial<br><br>Print: Scattered 1922 - 1939; 1940 - present | Stillbirth certificates contain 40 questions from both the birth and death certificates. Maternal and paternal demographic information, pregnancy and birth characteristics, medical and health information, and cause of death for the stillbirths are some of the information collected. Reporting of fetal deaths or stillbirths is mandatory when a stillbirth occurs after 20 weeks gestation or the fetus weighs 350g or more. Data is collected only for stillbirths occurring in Kentucky. |
| Marriage | Electronic: 2000 - present<br>Paper: 1958 - present | Information collected on marriage records includes names, dates of birth, and parents of the two parties involved, as well as basic demographic data (age, sex), location of marriage ceremony, and history of previous marriages. Marriages are only recorded for those that occur within the state, regardless of residence. |
| Divorce | Electronic: 2000 - present<br>Paper: 1958 - present | Information collected on the divorce form includes the two parties involved such as basic demographic data: sex and age; and history of previous marriages. Information is only recorded for divorces that occur within the state. |
| Abortion/Induced termination of pregnancy (ITOP) | | A person or institution responsible for completing an abortion report shall submit the report by completing the VS-913 form or by submitting electronically through the Abortion Portal. Some of the information collected includes facility information, patient demographics, to include race, age, and ethnicity, and previous live births and abortions. All abortions performed in Kentucky are required to be reported to the Vital Statistics Branch. |

* Vital event forms are updated by the NCHS/CDC to enhance data quality or improve our ability to assess trends and relevant factors associated with pressing health issues. This is important to keep in mind when interpreting these data from historical to current years. Electronic information in OVS is currently available upon request in one of two formats. The first data collected electronically is referred to as the "Old Format" of the certificate, and the most recent and currently used form is referred to as the "New Format". Form updates for all births, deaths, and stillbirths occurred in different years, please refer to the notes for each form for the year ranges relevant to that dataset. Guidance will be provided and the proper data dictionary, to guide data interpretation for each case.

**Indexes/Lists files**
Per KRS 213.131, OVS prepares lists that include all Kentucky occurrence births and deaths. The lists are subject to inspection by the public upon request. The difference between lists and indexes includes the type and number of data elements listed, and the years for which each type of file was made available to the public. Lists became the mandatory files available to the public in 1990 for all births and deaths occurring in Kentucky.

The information contained in those files includes:
**Births**
*Lists*: Child's name, mother's maiden name, date and county of birth.
*Indexes*: Child's name, mother's maiden name, date of birth, county of birth, certificate number, sex and file date.
**Deaths**
*Lists*: Name of deceased, date and county of death.
*Indexes*: Name of deceased, age of deceased, county of death, date of death, county of residence and certificate number.

**Residence and Occurrence Data**
**Occurrence data** indicates data for vital events occurring in Kentucky, regardless of persons state of residence.
**Residence data** refers to data for vital events based on Kentucky being the state of residence for the individual, regardless of where the event occurred.

Data may either be tabulated by residence or by occurrence. For instance, a woman who lived in Lexington, KY (Fayette Co) but had her baby in Cincinnati, OH (Hamilton Co) would be counted in Fayette Co (KY) on a residence table and in Hamilton Co (OH) on an occurrence table. Some users may be tempted to add residence and occurrence figures together to get a total for an area, but that would be inaccurate. There is a great deal of overlap between these two, as most residents of a county also have babies or die in the same county. Other users try to subtract residence and occurrence data to figure out how many residents are born or die outside of their county, but this is also incorrect. The only way to determine where county residents are having babies or dying is to tabulate births or deaths by place of residence relative to place of occurrence. Rates for these estimates are to be calculated based on residence information as population data used for denominators are based on residence of subgroups in a specified geographic area as well.

**Fees, Reports, Certified Copies, and Records Search**
A search of the files or records, certified copies of the certificates or records, copies of the information provided for administrative, statistical, or research purposes, and file searches may all incur fees. Certified copies of certificates and records, searches of the files and records when necessary, and copies and information supplied for administrative, statistical, or research reasons are all subject to fees. Copies or data from the system of vital statistics may be provided for statistical or administrative purposes upon request to federal, state, local, and other public or private agencies, subject to certain terms and conditions.

References: KRS 213.016, KRS 213.131, KRS 213.136, and KRS 213.141