

Kentucky Public Health Data Resource Guide 2018



Division of Epidemiology and Health Planning

Kentucky Public Health Data Resource Guide 2018 Edition

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Kentucky Public Health

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2018

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Introduction

Providing easy access to data resources is essential for effective public health decision making and research. The Kentucky Public Health Data Resource Guide was first published in 2005 and included twenty publicly available data-based resources. Since the original publication, new editions of the guide have added several new resources. The 2011 edition added four new resources, and the 2013 and 2015 editions each added two new resources.

The 2018 edition of the Kentucky Public Health Data Resource Guide updates the 2015 edition and provides information five new resources — the Drug Overdose Fatality Surveillance System, Kentucky State Ambulance Reporting System, Stroke Encounter Quality Improvement Project, Syndromic Surveillance, and the United States Zika Pregnancy Registry. Additionally, the 2018 edition is adding back information on the Pregnancy Risk Assessment Monitoring System, which was featured in the 2013 edition.

A variety of Kentucky specific health-related surveys, surveillance systems, and registries are described in this guide. The types of data collected are included, along with the strengths and limitations of each data source. Contact information is provided for every resource, and most sources contain web links for easy access to publicly available data.

The Kentucky Department for Public Health Data User's 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 follow the Health Insurance Portability and Accountability Act (HIPAA) guidelines when disseminating data. As a result, full data sets may not be available for all data sources presented. However, data summaries and reports should be available for most sources.

This guide is a valuable resource for public health research, monitoring public health goals or objectives, evaluating initiatives, and exploring Kentucky-related resources about population health. To recommend other useful data resources for inclusion in future editions, please contact Sara Robeson, Division of Epidemiology and Health Planning at (502) 564-3418 ext. 4311 or sara.robesson@ky.gov. Additional suggestions to make this guide more useful are welcome.

Behavioral Risk Factor Surveillance System (BRFSS)



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

Sources of Information for the Database

The Behavioral Risk Factor Surveillance System (BRFSS) is a cross-sectional telephone health survey co-sponsored by the Centers for Disease Control and Prevention (CDC) and the Kentucky Department for Public Health. The survey is randomly administered to non-institutionalized civilian adults aged 18 or older who are living in a household with a telephone. Participation in the survey is strictly voluntary. Personal identifying information, such as name or address, is not collected. BRFSS field operations are managed by state health departments that follow guidelines provided by the CDC. State health departments participate in developing the survey instrument and conduct the interviews either in house or by using contractors. In Kentucky, BRFSS is known as KyBRFS (Kentucky Behavioral Risk Factor Surveillance). The KyBRFS has been conducted continuously since 1985 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Prevention and Quality Improvement, Chronic Disease Prevention Branch. The surveillance is funded through a federal grant received from the CDC.

Description of the Data Collected

The BRFSS is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. Some topics included in this survey are tobacco use, alcohol consumption, influenza, immunization, diabetes prevalence, asthma prevalence, hypertension awareness, HIV/AIDS, colorectal cancer screening, breast cancer screening, cervical cancer screening and weight control. Demographic data collected include gender, age, race, ethnicity, income, education level, employment status, zip code and county of residence. The survey has three types of questions: Core, Optional Modules, and State-Added. Core questions are asked by all states.

Optional Module questions are groups of questions on particular topics developed by the CDC that states may select to include on the questionnaire. State added questions are questions that states may develop or obtain that relate to the public health needs of their state.

Strengths of the Data

The BRFSS provides data on risk behaviors, preventive health practices, and chronic disease prevalence that are not collected by other surveillance systems. For many states, the BRFSS is the only available source of timely, accurate data on health-related behaviors. In Kentucky, the KyBRFS sample size is large enough to provide yearly prevalence estimates by Area Development Districts (ADD). Data are usually available within six months of the collection year. For example, data from survey year 2010 were available by May 2011. The survey is conducted by all states, Washington D.C., Puerto Rico, U.S. Virgin Islands, and Guam; therefore, data from Kentucky may be compared to other states.

Data Limitations

There are two main limitations to BRFSS data: non-coverage bias and self-report bias. These limitations should not hinder the use of BRFSS data, but should be considered.

Non-Coverage Bias:

- Since the BRFSS is a telephone survey, adults who live in households without a telephone (landline or cell phone) are not included in the sample. Households without a telephone tend to be of lower income and could have socio-economic differences from the survey population.
- The BRFSS only surveys adults living in households. Therefore, individuals living in a group setting, such as a nursing home, the military, or prison are not surveyed.

Self-Report Bias:

- The BRFSS survey relies on self-reporting. That means that the prevalence estimates are strictly based on each respondent's answers to the questions. Therefore, the tendency to report a healthier lifestyle may occur.

Specific Uses of BRFSS Data

- Collect data on Adverse Childhood Experiences (ACEs) and provide data to stakeholders as fact sheets.
- Collect data on preconception health (contraception and health practices) in order to help prepare Kentuckians for any Zika virus outbreak response.
- Provide data to develop a baseline measure of Healthy Kentuckians 2030 objectives.
- Provide data to measure the goals/objectives stated in Healthy Kentuckians 2020 and Healthy People 2020.
- Collect data about health indicators of minority populations such as African Americans, Hispanics and lesbian, gay, bisexual, and transgender (LGBT) populations.
- Create a Kentucky State Health Assessment report in preparation for accreditation of the Kentucky Department for Public Health.
- To show prevalence of chronic conditions among adults with a diagnosed depressive disorder in each of the 8 Medicaid Managed Care Organization regions in Kentucky.
- Identify and address barriers to colorectal cancer screening to improve rates.
- Create a State Plan for Coordinated Chronic Disease Prevention and Health Promotion.

BRFSS

- Determine the prevalence of both Chronic Obstructive Pulmonary Disease (COPD) and its comorbidities and, the risk differences of COPD comorbidities and risk differences of COPD comorbidities across Area Development Districts (ADDs).
- To identify characteristics of women of reproductive age (18-50 years old) that may influence the type of contraceptive use.

Provide data for reports such as:

- Creating Health Equity Map Series (by the Northern Kentucky Health Department).
- Health Disparities in the Commonwealth, A Report on Race and Ethnicity and Health in Kentucky, 2016 (by The Foundation for a Healthy Kentucky).
- Kentucky Diabetes Report, 2015 (Report to the LRC on diabetes-related efforts in the Department for Medicaid Services, the Department for Public Health and the Office of Health Policy within the Cabinet for Health and Family Services, and 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 KY Asthma Program).

System Evaluation

The data collection process is routinely monitored utilizing quality control standards developed by CDC. The data collection process is also monitored remotely by the project coordinator. Evaluation of quality is determined through monthly and annual reports of these performance standards.

Changes in BRFSS Protocol

In 2011, two major changes were made in BRFSS Protocol:

- The incorporation of cell phone interviews.
- The adoption of a more advanced weighting method called iterative proportional fitting or raking (Beginning with the 2011 dataset, raking replaced post-stratification as the BRFSS statistical weighting method).

Due to these significant changes, estimates of prevalence from 2011 forward cannot be directly compared to estimates from previous years. Comparing 2011 BRFSS data with BRFSS data from previous years may cause misinterpretation of trend line shifts in prevalence estimates.

Data collected in 2011 is the new baseline for BRFSS prevalence data collected in subsequent years.

These changes in BRFSS protocol are discussed in detail in the June 8, 2012, MMWR Policy Note "Methodologic Changes in the Behavioral Risk Factor Surveillance System in 2011 and Potential Effects on Prevalence Estimates." This note is available online at the CDC Surveillance Resource Center:

<https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6122a3.htm>

Additionally, the Kentucky BRFSS program released a report tailored to the changes seen in Kentucky data. It is entitled "Effect of Changes in BRFSS Protocols on 2011 Behavioral Risk Factor Surveillance Data in Kentucky" and can be obtained from the Kentucky BRFSS website:

<https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/brfss.aspx>.

Data Set Availability

KyBRFS data from 1985 to the present are available to the public in yearly data sets. The statewide data are available in both SAS and SPSS. A weighting variable is included in the data sets so that prevalence estimates can be generalized to the statewide population. National data are available on the national CDC BRFSS web site. Contact the KyBRFS coordinator if requesting Kentucky aggregated data or raw data sets. There are two data request forms (see Appendices C and D) available on the KyBRFS website cited earlier. One is to request a data set and the other is to request analyzed data. Anyone requesting data should complete the data request form and send it to the KyBRFS epidemiologist/coordinator via e-mail or fax. 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.

- **Average Yearly Sample Size (Landline: Cell Phone):** 4,200: 2,800 (60:40)
- **2015 AAPOR* Response Rate (Landline: Cell Phone: combined):** 62.1%: 51.6%: 59%
- **2015 AAPOR Cooperation Rate (Combined):** 81.3%
- **Smallest Geographic Level Released:** Area Development District (ADD)
- **Data Format:** SAS, SPSS, asci
- **Cost of Data Set:** No Charge

AAPOR* = American Association of Public Opinion Research
Response rates for BRFSS are calculated using standards set by AAPOR Response Rate

Formula #4

https://www.cdc.gov/brfss/annual_data/2015/pdf/2015-sdqr.pdf
https://www.cdc.gov/brfss/annual_data/2015/2015_responserates.html

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:

- Area Development District (ADD) Profiles: a summary of selected prevalence estimates for each of the 15 Kentucky Area Development Districts with comparisons to statewide and national prevalence estimates.
- KyBRFS Annual Report: a report featuring prevalence data stratified by gender, race, age, education, and household income; this report also includes a section with ArcGIS maps showing prevalence estimates at the ADD level.

The reports can be found on the KyBRFS website: <https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/brfss.aspx>

Data Release Policy

The program does not release data for small sample sizes (i.e. county level), since estimates produced from fewer than 50 un-weighted records are not considered by the CDC to meet standards of statistical reliability. There is also a possibility of the identification of individual respondents if the sample size is very small. If data sets are released to requestors from out of state, then information about county identifiers is suppressed. It is highly recommended that 95% Confidence Intervals or standard errors be reported for all estimates produced using BRFSS data.

BRFSS

Suggested Data 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].

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Central Nervous System Injury (CNSI) Surveillance System



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State Web Site:	http://www.mc.uky.edu/kiprc/programs/tbi-surveillance.html
National Web Site:	http://www.cdc.gov/ncipc/tbi/TBI.htm

Sources of Information for the Database

The Central Nervous System Injury (CNSI) Surveillance Project is funded by the Kentucky Traumatic Brain Injury Trust Fund Board under the Cabinet for Health and Family Services' Department of Aging and Independent Living. The purpose is to track cases of traumatic brain injury, spinal cord injury, acquired brain injury, and stroke as defined by the Centers for Disease Control and Prevention (CDC) and the Kentucky Revised Statutes (KRS 211.470). Cases are taken from two sources: inpatient hospital records and emergency department visits for CNSI are ascertained using the Kentucky Hospital Discharge Database (HDD). Fatalities are obtained from the National Center for Health Statistics' annual Multiple Cause of Death (MCO) files. When reported on jointly, these sources are linked to resolve duplication of cases across databases, using a probabilistic methodology based upon research by Fellegi and Sunter (1969) and Jaro (1985, 1995).

Description of the Data Collected

Data are collected on the injured person's demographics (age, gender, county of residence), cause of injury (mechanism, manner, and external cause of injury code) injury severity (fatality indicator, injury severity score, length of stay in hospital, and discharge), and diagnoses, as well as the hospital name, payers billed, and total charges billed for those who were hospitalized.

Strengths of the Data

The MCODE and HDD files are population-based rather than relying on a sampling strategy. The CDC's Central Nervous System Injury Data Submission Standards – 2002 are followed. This is a widely accepted standard, meaning that Kentucky's results are comparable to those of many other states who conduct CNSI surveillance.

Data Limitations

There are two main limitations to the CNSI data:

- **Incompleteness of residence data:** Because the MCODE files are based on cases collected under Kentucky's Vital Statistics Surveillance System, data collected on fatal CNSI cases can sometimes be incomplete. Also, the HDD does not capture Kentucky residents who are treated in out-of-state hospitals, including those treated for CNSI.
- **Lack of identifying information:** Without being able to identify individuals within the HDD database, it is impossible to ascertain whether the visit is for a new, first time brain or spinal cord injury or a repeat visit with a new injury or complication of an old injury.

Specific Uses of Information

- Annual CNSI surveillance report
- Ad-hoc data requests and reporting

System Evaluation

The MCODE files are based on death certificate files provided to the National Center for Health Statistics (NCHS) by the Kentucky Vital Statistics Surveillance System (KVSSS). Therefore, evaluation measures described under the KVSSS entry apply to this system as well. Computerized edit checks are also in place by the collecting source for the HDD as well.

Data Set Availability

The Kentucky Injury Prevention and Research Center's (KIPRC's) data use agreements for the hospital discharge and MCODE databases do not permit the release of case-level data from the CNSI database. Aggregated (tabular) data may be requested by contacting Shannon Beaven at KIPRC.

Data Release Policy

The Central Nervous System Injury Surveillance database is not made generally available. Ad-hoc data requests are filled by way of summary data, with suppression of counts less than 5 in areas where confidentiality may be threatened.

Data Publications

Since 1998, KIPRC has published an annual report of the Traumatic Brain Injury and Spinal Cord Injury Project. The fiscal year 2017 report describes injuries that occurred in 2016 (calendar year) and will be available on the website:

<http://www.mc.uky.edu/kiprc/programs/tbi-surveillance/reports.html>, once finalized.

Suggested Data Citation

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

References

- Fellegi IP, Sunter AB. A theory for record linkage. *Journal of the American Statistical Association*, 1969; 64(328):1183-1210.
- Jaro M. Advances in record linkage methodology as applied to matching the 1985 census of Tampa, Florida. *Journal of the American Statistical Association*, 1989; 84(406):16-21.
- Jaro M. Probabilistic linkage of large public health data files. *Statistics in Medicine*, 1995; 14:491-498.

Contributing Author

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Child Fatality Review (CFR)

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State Web Site:

[https://chfs.ky.gov/agencies/dph/dmch/cfhib/
Pages/child-fatality.aspx](https://chfs.ky.gov/agencies/dph/dmch/cfhib/Pages/child-fatality.aspx)

Sources of Information for the Database

The Child Fatality Review (CFR) program is a passive surveillance system that reviews all child deaths from birth to the age of seventeen years in Kentucky. The system is designed to provide information on incidence, prevalence, and trends of causes of death of Kentucky's children. The CFR is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Maternal and Child Health (MCH), Child and Family Health Improvement Branch. The Child Fatality Review and Injury Prevention Program is funded by the MCH Title V Block Grant. KRS 211.680 established in 1996 was created to establish 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.

Description of the Data Collected

The CFR collects information from vital records, the MCH Rapid Response Child Death Reporting Form, and coroner report forms on all Kentucky resident children from birth to seventeen years of age who die of any cause of death. Supplemental information pertaining to childhood deaths is obtained from Coroner's CFR Reports, Medical Examiner Reports, Sudden Unexplained Infant Death Investigation Reporting Form (SUIDIRF), and obituary scans. Data are also provided to the CFR from the Department for Community Based Services regarding substantiated cases of child abuse and neglect to Kentucky's children. Vital records are accessed on a weekly basis from the Electronic Death Reporting System (EDRS) and coroner report forms are mailed in as soon as they are completed and subsequently entered into the CFR database. Personal identifying information, cause of death codes, and circumstances surrounding the death are collected by CFR. Thus, CFR is considered a highly confidential database. Due to the sensitive nature of the data and laws designed to protect the individual, no personal identifying information is released from CFR, and data are only presented or released in aggregate fashion. The lowest demographic level of information that can

be provided by CFR is the Area Development District level; county level data are **not** available.

Strengths of the Data

The CFR provides data on causes of death and circumstances surrounding the death as well as recommendations for prevention education and awareness. The CFR is a statewide program with data analysis and reporting occurring on an annual basis. Data are readily accessible only by two full-time staff members in the MCH Division and are updated on a monthly basis. Data provided to the CFR occurs in a relatively timely fashion, with coroner report forms being submitted as soon as the investigation is complete and vital records being reviewed on a monthly basis.

Data Limitations

There is one main limitation to CFR data: small numbers when dealing with individual causes of death. As a result, data must be presented in an aggregate fashion and cannot be provided by county level. Also, the sensitive nature of the data plays a role in what can and cannot be released to data requestors. This limitation should not hinder the use of CFR data, but should be considered. Another limitation that CFR is working to correct involves capturing deaths of Kentucky residents that occur out-of-state. Not all out-of-state cases are being captured in CFR.

Specific Uses of Information

- Monitor Healthy *Kentuckians 2020 Goals*.
- Monitor KIDS NOW Initiatives on Early Childhood Development.
- Provide data for use in various projects.
- Provide data for the Annual Child Fatality Review Report.
- Monitor select performance measures for the Title V Federal Maternal and Child Health Block Grants.
- Evaluate health disparities.
- Monitor trends of child deaths among specific populations, geographical areas, and the state as a whole and to monitor any cluster of specific causes of death.

System Evaluation

Data collection for CFR 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 (i.e. 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

CFR data from 2000 to present are available to certain individuals, provided an Institutional Review Board (IRB) approval to access the data has been obtained. CFR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and no identifying information will be released to any requestor under any circumstances.

Data Release Policy

Kentucky CFR will only release a de-identified data set provided that the request has received Institutional Review Board (IRB) approval and has been deemed to be Health Insurance Portability and Accountability Act (HIPAA) compliant.

Data Publications

The CFR produces an annual report that contains trend data on causes of death of children from birth to age seventeen. The data are broken out by cause of death, age, sex, and race. The report is produced in printed format as well as placed on the CFR web site.

Suggested Data 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, [**data year**].

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Crash Outcome Data Evaluation System (CODES)



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National Web Site: <https://crashstats.nhtsa.dot.gov/#/PublicationList/27>

Sources of Information for the Database

The Crash Outcome Data Evaluation System (CODES) was a program funded by the National Highway Traffic Safety Administration (NHTSA) from 1992 through 2013. The purpose of the CODES program was to support state linkage of state motor vehicle traffic crash report databases to administratively unrelated databases containing medical and economic information pertaining to persons involved in crashes. At the center of this effort is the Kentucky motor vehicle traffic crash reporting system, called Collision Reporting and Analysis for Safer Highways (CRASH). To date, CRASH has been linked with the state inpatient Hospital Discharge Database (HDD) for years 2000 through 2016, and with both inpatient and outpatient databases for years 2008 through 2016. The linkage is accomplished using a probabilistic methodology based upon research by Fellegi and Sunter (1969) and Jaro (1985, 1995), using the LinSolv software package (Strategic Matching, Inc). This linked database enables the discovery of relationships between crash characteristics and injury outcomes for persons hospitalized as a result of motor vehicle crashes, and the assessment of the inpatient acute care charges associated with their treatment. There is no federal or state mandate requiring that this surveillance be conducted.

Although CODES is no longer a NHTSA-funded program, integration of CRASH, injury, and other state traffic records data systems has continued to be pursued through KIPIC's Traffic Injury Research and Prevention Program (TIRPP). That work is made possible by support of the Kentucky Office of Highest Safety, the Governor's Executive Committee on Highway Safety, and Kentucky Traffic Records Coordinating Committee.

CODES

Description of the Data Collected

CRASH reports are mandated in Kentucky for crashes occurring on public roadways involving an injury or property damage in the amount of \$500 or more. Officers collect information on all persons involved in the crash, including: data on individuals (age, gender, date of birth, seating position, safety belt and helmet use, human contributing factors, and more); vehicles (type, make, model, Vehicle Information Number, extent of damage, vehicular contributing factors, and more); crash event (date, time, and location of crash, manner of collision, first and second collision events, most harmful event, and more); and environment (weather, light conditions, roadway conditions and characteristics, environmental contributing factors, and more).\

Hospital discharge reports are mandatory for all discharges of inpatients and emergency department (ED) patients from hospitals operating in Kentucky. The HDD database includes personal and medical information for each patient, including demographics, diagnosis and procedure codes, external cause of injury, monetary charges and payment sources billed, and more.

Strengths of the Data

The combination of these three population-based data sources through probabilistic linkage yields a data source on persons hospitalized or treated in EDs as a result of crashes on Kentucky's roadways. Thus, it enables analyses that would be impossible using either source alone. Crash reports lack reliable information about the type, severity, cost, and treatment of injuries to crash participants. Hospital discharge data lack information about the many factors and circumstances that led to the crash and influenced its severity, and about the use of safety devices. Using the CODES linked database, we can discover relationships between risk and protective factors and medical outcomes.

Data Limitations

There are two main limitations of the CODES data:

- **Representativeness:** Some persons who are involved in crashes in Kentucky are hospitalized outside of Kentucky, and some who crash outside of Kentucky are hospitalized in Kentucky. Our data sources do not capture out-of-state events, therefore such cases will not be represented in our linked database. As a result, it is a significant challenge to determine how well the CODES database represents the population of all persons hospitalized as a result of crashes that occur in Kentucky. A more tractable question is how well the data represents the population of persons who both crashed and are hospitalized in Kentucky, since they are the cases covered by our data source. The question has been the focus of the CODES evaluation efforts.
- **Misclassification:** Some data elements on the CRASH reports are inherently difficult to capture reliably. For example, from comparing the reported seat belt use rate on CRASH with results of observational studies, we know that the latter is significantly over reported. This is because the vast majority of persons involved in crashes are not severely injured. By the time police arrive on the scene, it is usually impossible to know whether such occupants were wearing seat belts, so the officer has to rely on self-reporting. The more severe the injury, the more likely the officer can directly observe belt use.

Specific Uses of Information

- Fact sheets on motor vehicle traffic safety topics.
- Peer-reviewed research on traffic safety and injury prevention.
- Data requests from NHTSA and from state and local users.

System Evaluation

Both the CRASH and HDD systems perform computerized edit checks at the time reports are entered. Our evaluation efforts have focused on the positive predictive value (PPV) and sensitivity of the linkage process. We conducted an evaluation of the linked CODES database among persons hospitalized at the University of Kentucky Chandler Medical Center (UKMC) in order to determine the percentage of UKMC patients admitted for motor vehicle crash-related injuries who were matched incorrectly to a CRASH record. We found this type of error in less than 5% of cases. Our conclusion is that the linkage process has a very high PPV for persons who were hospitalized in Kentucky. A second study estimated the system sensitivity. This was accomplished by reviewing medical records for persons admitted to UKMC with an external cause of injury code indicating involvement in a motor vehicle crash, but whom we were unable to link to a CRASH record with a high degree of certainty. We estimate that about 15% of persons who crashed and were hospitalized in Kentucky are not represented in the CODES database, for a variety of reasons including crashes not being reported to police or failure of record linkage.

Data Set Availability

A public-use Kentucky CODES data set is not currently available. Aggregated (tabular) data may be requested by contacting the project coordinator. Requests from researchers for access to the linked database will be referred to data-owning agencies for case-by-case consideration.

Data Publications

CODES publications from NHTSA can be found at:
<https://crashstats.nhtsa.dot.gov/#/PublicationList/27>.

Suggested Data Citation

Kentucky Injury Prevention and Research Center (KIPRC). *Crash Outcome Data Evaluation System*. Lexington, Kentucky: University of Kentucky [**data year**].

References

- Fellegi IP, Sunter AB. *A theory for record linkage*. Journal of the American Statistical Association, 1969; 64(328):1183-1210.
- Jaro M. *Advances in record linkage methodology as applied to matching the 1985 census of Tampa, Florida*. Journal of the American Statistical Association, 1989; 84(406):16-21.
- Jaro M. *Probabilistic linkage of large public health data files*. Statistics in Medicine, 1995; 14:491-498.

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Drug Overdose Fatality Surveillance System (DOFSS)

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Sources of Information for DOFSS

The Drug Overdose Fatality Surveillance System (DOFSS) is funded by the Centers for Disease Control and Prevention (CDC) to enhance the state's analytical capacity to identify drug overdose fatalities using multiple data sources.

Since 2013, DOFSS has collected surveillance data on fatal drug overdose fatalities in the state of Kentucky. Sources include:

- Vital statistics death certificates (with NCHS ICD-10 coding).
- Medical examiner autopsy reports.
- Coroner investigation reports.
- Post-mortem toxicology reports.
- Kentucky All Schedule Prescription Electronic Reporting (KASPER) records.

Description of Data Collected

DOFSS includes over 400 individual data fields including, but not limited to: death certificate information (demographics, place of injury and death, causes of death literal text, significant contributing conditions text, ICD-10 coded underlying and multiple causes of death); coroner reports (e.g., drug paraphernalia found at scene, history of drug abuse, chronic pain, mental illness, or suicidal ideations, known medical history, compliance with prescribed medications, pill counts from scene, coroner narrative text); autopsy reports (e.g., body mass index, evidence of needle or track marks, internal organ weights, pills identified in stomach, causes of death per ME's opinions); post-mortem toxicology results (e.g., detected drugs and concentrations found in decedent's system in blood, urine, or vitreous fluid at time of death); and KASPER data (drug names, drug doses, date filled, pharmacy where prescription was filled, etc.)

Strengths of the Data

Without a centralized death investigation system, Kentucky drug overdose fatality data are not collected by a single agency. DOFSS is bridging the gaps by inputting the above data into one, centralized database. A comprehensive multi-source database is able to capture additional drug overdose fatalities and identify emerging trends and patterns of use and abuse that may not be readily identified through a single source. For example, identification of specific drugs involved in drug overdose deaths in Kentucky increased from 76% using a single data source to 98% using multiple data sources.

Data Limitations

All data elements within DOFSS may not be available for all decedents. Investigative and toxicological data is not available for decedents where the death certificate is completed out-of-state or where the death is not referred to the local coroner's office.

Specific Uses of Information

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.

System Evaluation

DOFSS is routinely evaluated based on CDC guidelines to ensure data quality, completeness, and measure the program's efficiency and validity of goals.

Data Set Availability

DOFSS data utilizes data from a number of proprietary data sets. The user will be required to request the original, identified data set from the appropriate data custodian.

Data Release Policy

DOFSS program data is derived from data sets maintained by other entities. Data release inquiries should be directed to the primary custodians of the data sets.

Data Publications

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

Suggested Data Citation

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

Contributing Author

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Environmental Health Management Information System (EHMIS)



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Sources of Information for the Database

The Environmental Health Management Information System (EHMIS) is a comprehensive data management system designed to collect data for all the environmental health program areas. Custom Data Processing (CDP) designed and maintains the EHMIS system and stores the data for the state. The EHMIS system is a web based application allowing for remote access and real time data entry and retrieval. The system currently consists of nine major components or modules including: Activities, Accounts Receivable, Certifications, Establishments, Inspections, Onsite Sewage, Requests for Service, Report Viewers, and Water Sample modules. These different modules allow for state and local personnel to manage data and responsibilities across more than thirty Environmental Health programs.

The Division of Public Health and Safety's Environmental Health Programs regulate over 90,000 facilities or individuals, provide over 330,000 services, and collect associated fees for the permitting and inspection of these facilities and services. The Environmental Health Programs are conducted in large part at the local level with the help of local health department personnel. Inspections of facilities occur at food service and retail food establishments, bed and breakfasts, farmers markets, food processing and storage facilities, hotels, boarding homes, mobile home and RV parks, public buildings and recreational facilities, tattoo studios, schools, septic tank pumping and disposal companies, ear and body piercing studios, state owned confinement facilities, youth camps, onsite sewage systems, public beaches and public swimming and bathing facilities. Results of these inspections are entered in the EHMIS system. In addition to routine inspections, other services provided and documented in the EHMIS include accounts receivable for regulated establishments and certifications, public health complaints, rabies investigations, water sampling, public building inspections and plan review. Individuals with certifications that are regulated and entered into the EHMIS system include septic system installers, tattoo artists, ear and body piercers, lead hazard detection and abatement professionals, and food handlers and managers. Currently, the EHMIS system is supported primarily through agency funds, which are procured through state environmental fees. Although this system is not mandated

specifically, there are mandates that require the collection of onsite sewage data, as well as accounts receivable information, in an electronic database. Legal requirements for data collection are included in KRS 211.350, KRS 212:240, and 902 KAR 8:165.

Description of the Data Collected

The data is collected by local and state environmentalists and entered into the system locally. Collected data includes relevant information of establishments, as well as inspection data based on health and safety criteria. Establishment record, inspection results, enforcement actions, billing and accounts receivable, permit issuance, individual certification, request for service, animal bite records, and all non-site specific environmental service activity are the categorical headings for data collection.

Strengths of the Data

- **Comprehensive Data:** The system has a comprehensive list of all regulated facilities along with information such as number of seats, square feet of retail space, gallons of water in a pool, etc. In addition, the system details inspection and violation history, accounts receivable and owner/operator information.
- **Geocoding:** The system has latitude and longitude coordinates for use in GIS and mapping analyses.
- **Timeliness:** The data are entered on a daily basis and updated to the mainframe on a weekly basis.

Data Limitations

There are three main limitations:

- **Record Retention:** Information has been collected since the mid 1980's, but is only available live, on the website, for one year beyond the hard-copy record retention schedule.
- **Data System:** Occasional bugs and glitches may occur within the system and are continually being processed and repaired. Because of this, data should be examined and analyzed for errors.
- **Coding:** Coding/definition disparities occur across the state along with different coding standards among the local health departments which enter the information. Due to these inconsistencies, data cannot be uniformly compared across Kentucky or to other states.

Specific Uses of Information

The data is presently used to evaluate the status of environmentalist workload, fee allocation based on services, failed septic systems, quarantine of food items, animal bites, and complaint investigations. In addition, the system serves to document and retain inspection records for regulated establishments.

System Evaluation

Data is saved with CDP in real time and backed up on servers at a different location nightly. This process ensures proper data retention and integrity.

Data Set Availability

Standard reports are available through the Report Viewer. These reports include, but are not limited to, financial and accounts receivable, inspection history and status, agency and inspector performance, and work load analysis reports.

EHMIS

In addition, ad-hoc queries and data reports may be accessed from the system by using Oracle Discoverer. Additional data requests and reports are available through CDP as needed.

- **Average Yearly Sample Size:** 30,000 Records
- **Smallest Geographic Level Released:** Address level
- **Data Format:** The system is web-based with export capabilities to Excel, Adobe PDF, and Word.
- **Cost of Data Set:** Cost is determined by annual CDP contract pricing.

Data Release Policy

All Environmental Program data is considered public record and is thus eligible to be released with a formal open records request. However, personal information is restricted for rabies and foodborne illness investigations, as well as complaint investigations.

Suggested Data Citation

None suggested at this time.

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EnviroHealthLink KY's Environmental Public Health Tracking Network



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State Web Site: envirohealthlink.org

National Web Site: <http://ephtracking.cdc.gov>

Sources of Information for the Database

The Environmental Public Health Tracking Network (EPHTN) is an integrated, web-based portal system funded by the Centers for Disease Control and Prevention (CDC) to collect data on environmental hazards, exposures, and related health conditions for display in a format accessible to the general public. The data on the network comes from a variety of national, state, and local sources. Currently, the national Environmental Public Health Tracking Program is made up of 26 contributing members in state health departments and in New York City. Kentucky and Michigan were selected to become the newest members of the tracking program in August 2014. Each grantee site is required to build its own web-based portal with the same data content as in the national portal. CDC does however encourage grantees to customize their portals with state specific information. Kentucky launched its web-based portal, titled "EnviroHealthLink" in December 2016.

Description of the Data Collected

The states funded by the tracking program are required to collect and submit National-ly Consistent Data and Measures (NCDMs) to the national network for display on the national tracking portal. The data are organized into a set of content areas defined by the CDC, which are reviewed and revised by the tracking program's Content Workgroup.

EnviroHealthLink

The currently required content areas include: Acute Myocardial Infarction, Air Quality, Asthma, Birth Defects, Cancer, Carbon Monoxide Poisoning, Childhood Lead Poisoning, Drinking Water, and Reproductive Health Outcomes. Kentucky has also added optional state specific indicators, such as radon, as well as created interactive maps on our website to increase data utilization and communication of information. Other optional content areas that have recently been added to the network include Climate Indicators, Community Design, Developmental Disabilities, and Health Behaviors. In 2010, Kentucky was paired with Florida by the Association of State and Territorial Health Officials (ASTHO) as part of its mentorship program. The outcomes of this mentorship included two pilot projects examining the link between the environment and respiratory health outcomes, especially asthma. In the fall of 2014, Kentucky was one of four members of the ASTHO program to submit hospital discharge data to the tracking network. Birth Defect content area was recently submitted to the national tracking network in spring 2017. This means that all Nationally Consistent Data and Measures will be available for Kentucky on both the state and national tracking portals.

Strengths of the Data

The EPHTN provides valid scientific information on environmental exposures and adverse health conditions as well as the possible spatial and temporal relations between them. The network allows data from counties within states to be compared, as well as data between states. The EPHTN is the only surveillance system that organizes both environmental and health data into a single source, accessible to the general public, as well as researchers, decision makers, and public health professionals. The data is displayed in map, graph, or chart form and can be downloaded into CSV files. Metadata describing the exact source and details about each content area are available on the website.

Data Limitations

Limitations of tracking data for Kentucky include statistical instability requiring spatial and temporal aggregation of data due to low numbers within small areas. Each data content area has specific limitations on the smallest number that can be displayed per data cell, the time period for which the data is available, and the geographic resolution. Concerns about the release of sensitive information frequently limit the data that can be displayed for single years and small areas, especially for rare conditions such as cancer and birth defects. States or counties where there are no health outcome cases or no measured occurrences of an environmental hazard are labeled as “no events”. For example, some counties do not have air monitors, and some community water systems do not sample or test for every contaminant during every reporting period. Rates, proportions, and percentages of data are checked for their stability. Any rate or measure with a relative standard error (RSE) greater than or equal to 30 percent is flagged as unstable, or in the case of cancer data, suppressed (not shown). In accordance with CDC guidelines, cell counts are suppressed when the number of cases or the underlying population is small. In general, non-zero counts of less than 6 are suppressed for counties with a total population of less than 100,000 people.

Specific Uses of Information

- Community level data for health assessments and health improvement planning.
- Compare environmental conditions and the incidence of chronic health conditions between counties in Kentucky, as well as with other states.
- Identify trends in chronic health conditions and environmental hazards.

- Monitor the levels of environmental hazards over time and place.
- 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 impact of exposure.
- Design and implement public health actions specific to a community or jurisdiction.

System Evaluation

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

Data Set Availability

The data on the Environmental Public Health Tracking Network is available to the public at no cost through both the national web portal located at ephtracking.cdc.gov and the EnviroHealthLink portal located at envirohealthlink.org. Users may select content area, indicator, geography, year, and a number of other stratifying factors. Once a user has made a selection, the data can be viewed in map, table or graph form. The data is also available for download from both the national and state portals. The national tracking program has recently developed an advanced option for the web portal that will allow the user to view several data content areas or subsets side-by-side. Public web portals for other grantee sites can be accessed through the national EPHTN website.

Data Release Policy

The data on the National Environmental Public Health Tracking web portal are available to the general public without restrictions. Requests for more detailed data than displayed on the public portal can be made either to the national tracking program or to individual grantee sites.

Data Publications

The Centers for Disease Control and Prevention has many peer-reviewed articles published based on data utilized from the tracking network. These articles can be found on the Publications page of the national tracking program website.

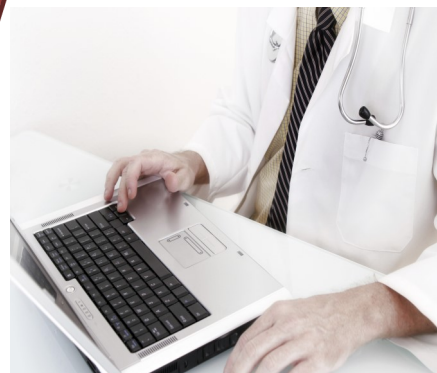
Suggested Data Citation

Each data citation should begin with EnviroHealthLink, Kentucky Department for Public Health, (content area and other details that were requested in query); Accessed From: envirohealthlink.org - Accessed on: (Insert Date). After running a query, the user is provided with a date/time stamp and can choose to load or save the query definition, or output the data to an Excel file.

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Fatality Assessment and Control Evaluation (FACE)

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State Web Site:

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National Web Site:

<http://www.cdc.gov/niosh/face/>

Sources of Information for the FACE Program

The Fatality Assessment and Control Evaluation (FACE) program is 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. Since 1994, the Kentucky FACE program has collected data and performed on-site investigations of traumatic fatal occupational injuries. A work-related fatality is included in the Kentucky FACE dataset if the occupational injury occurred in Kentucky and the decedent was performing work tasks. Multiple sources of information for identification of cases include death certificates, Department of Labor reports, Occupational Safety and Health Administration (OSHA) reports, the Collision Reporting Analysis for Safer Highways (CRASH) reports, coroner reports, interviews, news media reports, Mining Safety and Health Administration (MSHA) reports and others. There is no Kentucky mandate that requires collection of occupational fatality data.

Description of Data Collected

Sources utilized to identify potential cases include 24 state online newspapers, radio and television reports, coroner reports, state vital statistics records, the Census of Fatal Occupational Injuries (CFOI) program located in the Kentucky Department of Labor, the Kentucky CRASH dataset, medical examiner reports, and Mining Safety and Health Administration (MSHA) reports. FACE surveillance data is compared to CFOI, occupational safety and health fatality reports, and CRASH data monthly to verify and support information received through other sources, such as the newspaper. At least two sources of information are used to confirm cases. Authority to use the state and national agency resources is based on verbal agreements.

FACE surveillance information is entered into a first report form in the FACE dataset (EpiInfo v. 6.0) that contains 205 data variables. Staff continue to add variables that are of importance to both public health and research communities. These include industry (Standard Industrial Classification, North American Industry Classification Standards), occupation (Occupational Classification Codes), external cause of injury (ICD-10 codes), self-employed status, health status (e.g., diabetes, heart condition, weight), and specific questions related to motor vehicle collisions, farm incidents, and interpersonal violence issues. Data are updated and edited as new information is obtained on a case.

FACE data are analyzed with descriptive and, as necessary, advanced statistics using EpiInfo, Microsoft Excel, and SAS®. Basic descriptive analysis on all data variables is performed to assess data quality and validity, and to describe cases. Frequencies are determined for the dataset to account for any missing variables. Routine cross-tabulations are performed to assess relationships between selected variables. Continuous variables are recoded to categorical variables (i.e., e-code, Standard Industrial Classification (SIC) system, Occupational Classification Codes (OCC), age groups, etc.) and frequency analysis is completed. Results are utilized for quarterly summary reports, annual reports, newsletters, Hazard Alerts, data requests, peer-reviewed and non-peer reviewed articles and other dissemination avenues.

Strengths of the Data

The FACE program provides timely, comprehensive multi-source surveillance and epidemiologic analysis of worker fatalities to identify risk factors. On-site investigations of motor vehicle collision and logging fatalities produce case studies for employer/employee safety training at the individual, company, local, and state levels, by sector and across sectors. Prevention strategies are developed and disseminated to target populations of workers/employers.

Data Limitations

All data elements in the dataset may not be available for some workers who incurred a fatal occupational injury in Kentucky but died out of state because their death certificates were filed out-of-state. Other sources of information may be available to complete the data elements for these few cases.

Specific Uses of Information

Hazard alerts on specific types of occupational injuries
Peer-reviewed publications on occupational injuries and illnesses
Case fatality reports for use by employers for safety training purposes
Data requests from external and internal agencies, organizations, and associations
Production of prevention materials to educate legislators.

System Evaluation

Evaluation of the FACE program is based on updated Centers for Disease Control and Prevention (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. Since the FACE program was initiated in 1994, it is primarily a process and outcome evaluation

FACE

Data Set Availability

As of July 1, 2011, the FACE database currently contains information on 2,100 fatality cases. A public-use Kentucky FACE dataset 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

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

Data Publications

An annual FACE report, hazard alerts, and fatality reports are produced and available on the state FACE website.

Suggested Data Citation

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

References

- Hallman EM, Gelberg KH, Hallisey JL. The NIOSH Fatality Assessment and Control Evaluation (FACE) program: a New York case study illustrating the impact of a farm manure pump PTO entanglement. *J Agromedicine*. 2005;10(3):57-64.
- Higgins DN, Tierney J, Hanrahan L. Preventing young worker fatalities. The Fatality Assessment and Control Evaluation (FACE) Program. *AAOHN J*. 2002 Nov;50(11):508-14.
- Higgins DN, Casini VJ, Bost P, Johnson W, Rautiainen R. The Fatality Assessment and Control Evaluation program's role in the prevention of occupational fatalities. *Inj Prev*. 2001 Sep;7 Suppl 1:i27-33.

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HIV / AIDS Surveillance System



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Data Contact:	Julie Kauzlarich, MPH Kentucky Department for Public Health Division of Epidemiology and Health Planning (502) 564-6539 ext. 4271 julie.kauzlarich@ky.gov
State Web Site:	https://chfs.ky.gov/agencies/dph/dehp/hab/Pages/default.aspx
National Web Site:	https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html

Sources of Information for the Surveillance System

There are several statutes which pertain to the reporting of HIV/AIDS related lab results to the Cabinet for Health and Family Services, Department for Public Health, HIV/AIDS Branch, HIV/AIDS surveillance program. Below are listed some of the most comprehensive statutes and regulations.

1. KRS 211.180 Section (1) (b) states the Cabinet shall adopt regulations specifying the information required in and a minimum time period for reporting a sexually transmitted disease. It also establishes that the Cabinet requires cases of HIV to be reported by name and other relevant data.
2. KRS 311.282 states physicians licensed shall not be civilly or criminally liable for disclosure of information to the Cabinet for HIV/AIDS reporting purposes.
3. KRS 214.625 states 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.

HIV / AIDS

4. According to state regulation 902 KAR 2:020, Section 13, 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 the Kentucky Department for Public Health. New HIV reporting regulations were adopted on July 15, 2004. The regulations require HIV cases to be reported by name and no longer by a 'Unique Identifier.' AIDS cases have always been reported by name.

The surveillance branch is funded entirely from a federal grant through the Centers for Disease Control and Prevention (CDC) to conduct HIV surveillance and epidemiological activities.

Description of the Data Collected

HIV/AIDS data available to the public includes demographic information including race/ethnicity, sex, age at diagnosis, county of residence/area development district (ADD), modes of exposure to infection, year of diagnosis, and year of report for adults/adolescents and pediatric cases.

Strengths of the Data

The HIV/AIDS registry provides a population data set of reported HIV infections in Kentucky from mandatory lab reporting and medical record abstractions. Data are collected on standardized forms and include demographics (race/ethnicity, age groups and sex), mode of exposure, year of diagnosis, year of report, area development district (ADD), county of residence, laboratory and clinical information. The program processes clinical and immunologic lab data in a systematic manner which makes the registry robust. Data are 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 lab data are imported into the registry routinely.

Data Limitations

HIV data are not always reported in a timely manner. As a result of reporting delays, case numbers for the most recent years of diagnosis may not be complete and therefore, not reliable for use in trend analyses. HIV/AIDS data provided by the Kentucky Department for Public Health are not adjusted for reporting delays. Another limitation of HIV/AIDS data includes the number of cases reported with undetermined mode of exposure information. The existence of large percentages of infections without known modes of transmission poses a barrier to provision of effective responses to the epidemic within the groups in question. Enhanced surveillance activities have been implemented to attempt to resolve case reports with missing mode of exposure information.

Specific Uses of Information

- Provides population level information of Kentucky's HIV/AIDS cases reported to the Department for Public Health.
- 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.
- Identify target populations that are disproportionately affected by HIV/AIDS.
- Used to assess Kentucky's progress regarding the National HIV/AIDS Strategy (NHAS), including information on the continuum of care— from diagnosis to viral suppression.

System Evaluation

The HIV registry is evaluated annually utilizing quality control standards developed by the CDC. Additionally, HIV data are monitored on a monthly basis to evaluate the progress of these performance standards.

Data Set Availability

Kentucky HIV/AIDS raw data are not available for public use due to security and confidentiality restrictions. Aggregate data requests can be filled at the public's request with identified restrictions at no cost. A copy of the data request form can be found in the appendix. For requests, please contact Bob Ford at bob.ford@ky.gov or (502) 564-6539 ext. 4285 or Julie Kauzlarich at julie.kauzlarich@ky.gov.

Data Release Policy

An integral part of public health surveillance is the dissemination of data to public health agencies, case providers, and the general public. Surveillance data are needed in order to analyze emerging and prevalent trends at the state and local level, as well as to effectively plan and evaluate prevention and care programs.

Key Components of Data Release:

- The data release policy of the Kentucky HIV/AIDS Program is based on three main factors: (1) the recipient of the data, (2) population size of the data region, and (3) time period. In no circumstances shall data be released if it is determined that the data may compromise surveillance activities or affect the public perception of confidentiality of the surveillance system.
- HIV/AIDS data are released in aggregate to ensure the security and confidentiality of reported cases. Data release policies exist for HIV/AIDS data release of any nature. A strict data release policy is necessary because release of certain types of data, even without names, could identify a case. Those individuals granted access to data must sign confidentiality agreements, with the understanding that the data are to be used only for those purposes listed in the agreements.

Data Publications

The HIV/AIDS program publishes data through an annual surveillance report, an integrated epidemiologic profile produced every 5 years with annual updates to the epidemiologic data, factsheets of selected populations or regions and supplemental reports. The program's publications can be accessed at the HIV/AIDS Web site: <https://chfs.ky.gov/agencies/dph/dehp/hab/Pages/reports-stats.aspx>. A host of additional resources including HIV prevention and care services data and external internet links to national HIV data are also available on our web site. Interactive maps for national and state level HIV data are also available at <https://aidsvu.org/> and <https://www.cdc.gov/nchhstp/atlas/index.htm>.

Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *HIV/AIDS Surveillance*. Frankfort, Kentucky: Cabinet for Family and Health Services, Kentucky Department for Public Health, [**data year**].

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Hospital Inpatient Discharge & Outpatient Services Databases (HIDOSD)



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State Web Site: <https://chfs.ky.gov/agencies/ohda/Pages/data-requests.aspx>

National Web Site: <http://www.hcup-us.ahrq.gov/>

Sources of Information for the Database

The Kentucky Hospital Inpatient Discharge Database is a collection of records each of which describes a single inpatient stay in a Kentucky hospital. The Kentucky Outpatient Services Database is a collection of records each of which describes a single utilization of a service received at an Ambulatory Facility (Ambulatory Surgery Center, Ambulatory Care Center, Specialized Medical Technology Services provider, or a Mobile Health Services provider) as specified for the dates below:

- 2000 – 2007: An encounter where at least one of a list of Current Procedural Terminology (CPT) procedure codes specified was performed.
- 2008 – Current: The above with the addition of Emergency Department encounters.
- 2015 – Current: All encounters for all specified Ambulatory Facilities and Emergency Departments (not just the previous specified list of procedures).

Each Outpatient Services record represents a visit where the patient is not admitted to the hospital. These data are collected under the requirements set forth in KRS 216.2920 — 216.2947 as the basis for regular reporting of cost, quality, and outcomes measures relative to hospital inpatient events and outpatient services utilization. Actual data collection, verification, and storage is performed on a quarterly basis by an external contractor through a cooperative agreement with the Cabinet for Health and Family Services and the Kentucky Hospital Association (KHA). The Cabinet and KHA have collaborated in this effort since 2000.

Description of the Data Collected

Each record in a hospital discharge data set includes demographic fields (gender, age group, state, county, race, ethnicity, and ZIP code of residence), a unique hospital identifier, hospital stay fields (admission type and source, length of stay, diagnoses codes, procedure codes, discharge status, and total charges), and grouping codes (Major Diagnostic Category, Medicare Severity - Diagnosis Related Group (MS-DRG)). Personal identifying information, such as name, address, and social security number, are not collected and therefore not included in these data. Each record in an outpatient services data set includes demographic fields (gender, age group, state, county, race and ethnicity), a unique facility identifier, and procedure information (ICD-9 codes and CPT procedure codes).

Strengths of the Data

The included data items are sufficient to allow detailed demographic, diagnostic, and outcome analysis for public health reporting and research. These data are valuable in preparing chronic disease burden documents, grant proposals and justifications, resource utilization reports, and ad-hoc studies of the health status of Kentuckians. The spatial components of these data can be used to illustrate regional hospitalization patterns and trends related to conditions such as influenza, asthma, and diabetes and to show regional variation in hospital coverage and services. These data are also included in the National Inpatient Sample (NIS), a combined sample 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 built from hospital-submitted or ambulatory facility-submitted claims to payers, commonly known as UB-92, 837 file format records, or HCFA-1500. The inpatient files contain all inpatient discharges from a given calendar year and must be used with caution in epidemiological analysis. Furthermore, individual records represent single admit-through-discharge events; multiple admissions of an individual patient cannot be definitively identified. For this reason, these data should not be used to directly measure the prevalence of a condition in the general population. The outpatient files prior to 2008 contain only data related to ambulatory surgery provided by hospital-related ambulatory surgery centers. Hospitals began submitting emergency department data in 2008. In 2009, other ambulatory facilities began submitting outpatient data for records that contained specific CPT codes. In 2015, facilities began submitting all of their encounter data, no matter what procedure codes might be included. 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 and/or the actual amount paid.

Specific Uses of Information

- Inpatient hospitalization and outpatient services data are submitted annually to the Agency for Healthcare Research and Quality's Health Care Utilization Project (HCUP) for inclusion in the National Inpatient Sample and the Nationwide Emergency Department Sample.
- A subset of the hospitalization database plays a critical role in populating the Kentucky Birth Surveillance Registry.

HIDOSD

- Hospitalization data and emergency department data are used in preparing grant requests and status reports for Kentucky Department for Public Health's programs in asthma, cardiovascular disease, diabetes, and maternal and child health.
- Hospitalization data provide information for evaluating the improvement of health of the citizens of the commonwealth as detailed in Healthy Kentuckians 2020.
- Summaries of hospitalization data are instrumental in developing and implementing Kentucky health care policies and decisions at the state level.
- Hospitalization data and emergency department data are frequently requested by public health researchers, educators, and consultants for a variety of individual projects.

System Evaluation

Data are 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

Kentucky inpatient hospitalization data and outpatient services data from 2000 to the present are available to the public only in calendar year data sets. Data files come with translation tables for coded data. Data users are required to sign a Data User's Agreement before data files are transferred. Files containing the previous calendar year's data are available each July.

- **Average Yearly File Size:** *Inpatient:* 600,000 records.
Outpatient: Prior to 2008, the average is 700,000.
After 2008, the average is 4,000,000.
After 2015, the average is 10,000,000.
- **Hospital Compliance Rate:** >99%
- **Smallest Geographic Level Released:** *Inpatient:* ZIP
Outpatient: ZIP
- **Data Format:** .txt files
- **Cost of Data Sets:** \$8 per yearly file
- **Other Requirements:** Signed Data User's Agreement

Data Release Policy

Release of Public Use data sets is governed by 900 KAR 7:040.

Data Publications

Kentucky inpatient hospitalization data and Kentucky outpatient services data are regularly summarized and published as a part of annual Administrative Claims Data Reports. Inpatient hospitalization data are used to produce inpatient hospitalization days by facility and payer, and leading 25 MS-DRGs by Area Development District of hospital. The outpatient services data are used to produce emergency department utilization reports by facility and payer and leading 25 primary diagnoses for emergency department visits. Both the inpatient hospitalization data and the outpatient services data are used to produce the number of diagnostic and therapeutic cardiac catheterizations by facility. The data are also included in annual reports for programs in the Chronic Disease Prevention and Control Branch (e.g. asthma, diabetes, cardiovascular health and etc.), data analysis provided by the Kentucky Injury Prevention and Research Center (KIPRC) as well as in responses to data requests from the public.

Suggested Data Citation

Inpatient: Kentucky Inpatient Hospitalization Claims Files, Frankfort, KY, [year(s)]; Cabinet for Health and Family Services, Office of Health Policy.

Outpatient Services: Kentucky Outpatient Services Claims Files, Frankfort, KY, [year(s)]; Cabinet for Health and Family Services, Office of Health Policy.

Contributing Authors

Kentucky Office of Health Data and Analytics

Influenza Sentinel Surveillance System (ISSS)



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State Web Site:	https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/influenza.aspx
National Web Site:	http://cdc.gov/flu/weekly/fluactivitysurv.htm National Influenza Activity

Sources of Information for the Database

Influenza Like Illness (ILI) is reported by sentinel Local Health Department (LHD) sites. All sites survey absenteeism in a school district, or schools representative of grades K-12, for one day each week. Every site is requested to also survey a nursing home for ILI. LHD sites also survey healthcare providers and hospitals.

Sentinel Health Care Provider (HCP) sites report ILI to the Centers for Disease Control and Prevention (CDC), and obtain specimens for laboratory culture confirmation.

Mandatory reporting of culture confirmed cases within one week is required of laboratories to LHDs. The data obtained are subsequently entered into a database by each LHD.

Long-term care facilities are required by law (KAR 902 KAR 2:065) to report outbreaks of two or more ILIs that occur within a one-week period of time to the LHD immediately. Nationally, the CDC requires notification of all pediatric deaths. Kentucky's Reportable Disease Surveillance law (902 KAR 2:020) requires all influenza-associated deaths be reported, both pediatric and adult. The influenza surveillance system is funded by the federal immunization grant.

Description of the Data Collected

Beginning in October and continuing through May, LHD sentinel sites fax, phone or email weekly reports of ILI counts received from medical practices, nursing homes and hospitals; absenteeism for schools is collected on Tuesdays. The numbers and types of influenza virus isolates from the state public health laboratory are maintained in a

database and reported to CDC. HCP sentinel sites send information about ILI by age group to CDC through an automated online system, or by fax. The state influenza coordinator has access to the computer data. Laboratory confirmed cases, ILI reports from sentinel LHD sites and HCP sentinel sites are considered in determining the state's activity code for each week. This code is reported to the CDC. The information is also compared to previous weeks of the current season and to previous influenza seasons.

In the fall, information on ILIs and absentees for a six week period are used to determine outbreak baseline numbers for LHD sentinel site participants. The baseline for HCPs and hospitals is three ILI occurrences during the six-week period. The nursing home outbreak baseline number is two occurrences during the six-week period. School absentees for six weeks are added together, divided by six and multiplied by two to obtain an outbreak baseline number for each participating school district. Outbreak baseline numbers are used to compare the levels of ILI. The state influenza coordinator uses all the information to make a subjective determination regarding the influenza activity rating for the State Epidemiologist's report each week. Activity levels and definitions are:

- No Activity - No laboratory-confirmed cases of influenza and no reported increase in the number of cases of ILI.
- Sporadic Small - Numbers of laboratory-confirmed influenza cases or a single laboratory-confirmed influenza outbreak has been reported, but there is no increase of cases of ILI.
- Local Outbreak - Outbreaks of influenza or increases in ILI and recent laboratory-confirmed influenza in a single region of the state.
- Regional - Outbreaks of influenza or increases in ILI and recent laboratory-confirmed influenza in at least two but less than half the regions of the state with recent laboratory evidence of influenza in those regions.
- Widespread - Outbreaks of influenza or increases in ILI cases and recent laboratory-confirmed influenza in at least half the regions of the state with recent laboratory evidence of influenza in the state.
 1. Lab confirmed case is a case confirmed by culture, or PCR. (At the beginning of the season, the State Epidemiologist may report No Activity until there is evidence of culture-confirmed cases in the state, regardless of rapid antigen reports.)
 2. Institutions include: nursing homes, hospitals, correctional facilities, schools, etc. ILI activity can be assessed using a variety of data sources including sentinel providers, school/workplace absenteeism, and other surveillance systems that monitor influenza-like illness.
 3. Region-Geographical subdivision of a state defined by the department of health (DOH). 15 Area Development Districts and 2 Geographical subdivisions are used. The identity of specific isolates from Kentucky and nearby states, information on the age of the person tested and collection date are used to interpret whether outbreaks of ILI's in the state actually represent influenza, and if so, what type and whether the strain is thought to be a close match to the content of the currently available vaccine.

Strengths of the Data

The current 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 in identifying the virus or viruses responsible for most of the activity for each particular season. This system complements those of other states and provides valuable input to the process of selecting strains for the following year's vaccine, and to the strategy for annual vaccination campaigns.

Data Limitations

One of the limitations of the ISSS is that the system relies on the accuracy and promptness of reporting by the sentinel sites.

Specific Use of Information

The activity information can be used to promote influenza immunization, let clinicians know whether the circulating strain is a match for the current vaccine, and whether it is one which will respond to antiviral chemoprophylaxis and therapy. In addition, laboratory information can be used to prepare for the possibility of responding to an influenza pandemic. The public can be informed about which influenza strain is circulating, how influenza activity compares with other years, and what populations are affected. The state influenza coordinator sends a weekly activity report to the Cabinet's Communications Office and the infection control list serve for release to the media.

System Evaluation

The system is informally evaluated at the end of each influenza season. Summary information is evaluated by the State Influenza Coordinator, and the coordinator determines how well the system provided answers to the frequently asked questions during the season. The system has not been formally evaluated.

Data Set Availability

Only lab-confirmed cases are entered into the system. Lab-confirmed cases are only a fraction of the influenza cases in the general population. The data submission is not mandatory. Kentucky requests information on all influenza-associated pediatric and adult deaths, influenza in pregnant women and individuals with risk factors. Sentinel surveillance depends on each provider or LHD 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 FLU VIEW on the CDC website.

Suggested Data 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, [2018].

Contributing Authors

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Kentucky All Schedule Prescription Electronic Reporting (KASPER)

**Coordinator:**

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David.mcmahan@ky.gov

State Web Site:

www.chfs.ky.gov/KASPER

Sources of Information for the Database

The Kentucky All Schedule Prescription Electronic Reporting (KASPER) system is Kentucky's Prescription Drug Monitoring Program (PDMP). Responsibility for KASPER lies with the Cabinet for Health and Family Services (CHFS), Office of Inspector General. KASPER tracks most Schedule II–V controlled substance prescriptions dispensed in Kentucky. Under Kentucky Revised Statute (KRS) 218A.202 practitioners and dispensers are required to report daily to CHFS the Schedule II – V controlled substances they have administered or dispensed.

Description of the Data Collected

KASPER collects data on Schedule II – V controlled substances dispensed in Kentucky. Data maintained in KASPER include the following:

- Patient Information: name, date of birth, gender, address, and method of payment.
- Prescription Information: fill date, quantity, days supply, and prescription number.
- Prescriber Information: name, address, and Drug Enforcement Administration (DEA) number.
- Drug Information: drug name, strength, and National Drug Code (NDC) number.
- Dispenser Information: name, address, phone number, and DEA number.

Strength of the Data

KASPER supports improved public health and safety in Kentucky by providing data for health care providers to help identify patients who may be at risk for prescription drug abuse and to verify compliance with a treatment regimen established by the patient's health care team. KASPER is also used as a tool for law enforcement and regulatory officials during bona fide investigations and other appropriate reviews.

Information regarding authorized users of KASPER is utilized to select representative stratified samples for periodic approved KASPER user surveys. User survey results are used to identify user requested program improvements and system enhancements, along with desired user training.

Data Limitations

CHFS may disclose KASPER data only to entities authorized, and for the purposes specified under KRS 218A.202. KASPER data may also 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. However, under KRS 218A.240, studies and trend reports prepared using KASPER data cannot identify any individual prescriber, dispenser, or patient.

Specific Uses of Information

- Analysis and reporting of controlled substance usage trends in Kentucky.
- Data integration and analysis projects performed by approved partners. For example, controlled substance usage and public health and safety related issues such as drug related accidents, drug-related deaths, drug-related crime activity, etc.
- Monitor patient activity (by authorized health care providers to determine patients who may be at risk for prescription drug abuse),
- Monitor provider activity (by authorized regulatory officials during bona fide investigations and other appropriate reviews).
- Monitor patient and provider activity (by authorized law enforcement officials during bona fide drug investigations).
- Gather KASPER user feedback and evaluate KASPER user satisfaction.

System Evaluation

The data collected are reviewed to eliminate duplicate record transmissions, to validate specific data elements including Drug Enforcement Administration (DEA) numbers and National Drug Control (NDC) numbers, and to perform basic field format edits on remaining data elements.

Data Set Availability

Authorized users have online access to KASPER data for two full years plus the current year. Remaining data from inception of the KASPER program in 1999 are available from archival records for research purposes. Data sets provided for research purposes will not identify any individual prescriber, dispenser or patient.

- **Average Annual Controlled Substance Prescription Records Reported to KASPER 2010 – 2016:** 11,144,862
- **Smallest Geographic Level Released:** County
- **Data Format:** Excel Spreadsheet
- **Cost of Data Set:** No Cost

Data Release Policy

Spreadsheet versions of the KASPER controlled substance prescribing and usage data are available upon request from the Office of Inspector General (OIG) data contact. Additional KASPER data can be made available to appropriate research agencies through submission of a formal request to the OIG data contact. Each request should identify the requesting organization, purpose of research, proposed methodology to be employed, and publication plan. On a case-by-case basis, the OIG reviews the request and obtains additional information as needed. The OIG and the research team agree upon a collaboration plan documenting the study – schedule, methods, analysis, reporting, and publication. Upon review and agreement of the study plan, the OIG may approve the request for data, subject to approval by the CHFS Institutional Review Board. However, under KRS 218A.240, studies and trend reports prepared using KASPER data cannot identify any individual prescriber, dispenser, or patient.

Data Publications

According to KRS 218A.240, the Cabinet shall, on a quarterly basis, publish trend reports from the data obtained by KASPER. The quarterly KASPER Trend Reports along with a series of quarterly KASPER Threshold Reports produced in collaboration with the Kentucky Injury Prevention and Research Center are publically available on the KASPER web site at www.chfs.ky.gov/KASPER. The quarterly trend and threshold reports contain information regarding controlled substances reported to KASPER, KASPER usage statistics and prescribing and usage patterns by age, gender, and geographic area in Kentucky. The reports are available to download in PDF format. KASPER trend and threshold reports do not identify any individual prescriber, dispenser or patient. The trend reports utilize geographic information systems (GIS) software to provide graphical representation of the prescribing and usage data by geography.

Suggested Data Citation

Kentucky All Schedule Prescription Electronic Reporting (KASPER) System. Frankfort, Kentucky: Cabinet for Health and Family Services, Office of Inspector General, [**data extraction years**].

<p style="text-align: center;">Contributing Author</p>

<p style="text-align: center;">David R. Hopkins, Kentucky Office of Inspector General</p>

Kentucky Birth Surveillance Registry (KBSR)



Coordinator:	Monica Clouse, MPH Kentucky Department for Public Health Division of Maternal and Child Health (502) 564-4830 ext. 4394 monica.clouse@ky.gov
State Web Site:	https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/kbsr.aspx
National Web Site:	http://www.nbdpn.org

Sources of Information for the Database

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

Description of the Data Collected

KBSR collects information from vital records, acute care and birthing hospitals, laboratory reporting, and voluntary outpatient reporting on all children from birth to five years of age who are diagnosed with any structural, functional, or biochemical abnormality determined genetically or induced during gestation. Medical records of the child are reviewed on an ongoing basis to verify a physician diagnosis of major structural anomalies. Hospital discharge data and laboratory reporting are received on a quarterly basis, and the information is prepared for medical record abstraction. Vital records including live births, stillbirths, and deaths are reported to KBSR on a monthly basis. Personal identifying information and diagnostic codes are collected by KBSR, and as such, it is considered a highly confidential database. Due to the sensitive nature of the data and laws designed to protect the individual, no personal identifying information is released from KBSR and data are only presented or released in aggregate fashion. The lowest demographic level of information that can be provided by KBSR is the Area Development District (ADD) level; county level data are not available.

Strengths of the Data

KBSR provides data on certain birth defects, genetic and disabling conditions, pregnancy outcomes, and maternal risk factors that are not collected by other surveillance systems. KBSR is a statewide mandated system; therefore, reporting entities are required by law to provide the data as described under KRS 211.651-670. Data provided to KBSR occurs in a timely fashion with all birthing hospitals in the state currently submitting data through a vendor on a quarterly basis. Medical records abstraction is consistently conducted on an ongoing schedule and data from 1998-2014 have been verified.

Data Limitations

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

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

Specific Uses of Information

- Provide data for use in various projects by the Folic Acid Partnership of Kentucky, the March of Dimes Kentucky chapter, the Spina Bifida Association of Kentucky, and the National Birth Defects Prevention Network.
- Data on specific abnormalities are currently being used for a National Birth Defects Prevention Network study.
- Data are used annually for the preparation of the grant application "Cooperative Agreements for Population-Based Surveillance of Birth and Data Utilization for Public Health Action."
- Data are used annually to monitor trends of birth defects among specific populations, geographical areas, and the state as a whole and to monitor any cluster outbreaks and to evaluate health disparities.
- Data are used to generate fact sheets, data briefs, and presentations.
- Data are provided to research facilities for independent research studies.

System Evaluation

Data collection for KBSR is monitored closely with a quarterly analysis of timeliness (number of days from birth to import into the system) and uniqueness of reporting sources. In addition, with each quarterly submission of hospital discharge data, analyses are completed for omissions, errors, and completeness of records. A proportion of the cases within KBSR are audited for quality control to establish an error rate from the medical records abstraction component, and an annual comparison of the percentage of Kentucky residents reported with birth defects to national numbers is made.

Data Set Availability

KBSR data from 2005 to 2014 are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. KBSR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances. National data are available on the National Birth Defects Prevention Network web site. Data requests should be submitted to the coordinator listed above once Cabinet IRB approval is completed.

Data Release Policy

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

Data Publications

KBSR also participates in the annual report on birth defect surveillance systems published in Birth Defects Research, which includes a basic description of the surveillance system and selected birth defects data for five years broken out by race and maternal age. In 2016, KBSR published a 10-year report (2005-2014 data) and related data briefs.

Suggested Data Citation

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

Contributing Authors

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Kentucky Cancer Registry (KCR)

Kentucky Cancer Registry

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Data Contact:	Jaclyn K. McDowell, DrPH Kentucky Cancer Registry 2365 Harrodsburg Rd., Suite A230 Lexington, KY 40504-3381 (859) 218-2228 jnee@kcr.uky.edu
State Web Site:	http://www.kcr.uky.edu/

Source of Information for the Database

Kentucky Cancer Registry (KCR) began as a voluntary reporting system in 1986. In April of 1990, the State General Assembly passed legislation that formally established KCR as the population-based central cancer registry for the commonwealth. The legislation provided recurring funding for staff, travel, and computer equipment. Mandatory reporting to KCR officially began January 1, 1991.

In 1994, the legislation requiring reporting of cancer cases was modified to include reporting from all health care facilities that either diagnose or treat cancer patients. These additional facilities include freestanding treatment centers, non-hospital (private) pathology laboratories, and physician offices (See KRS 214.556). In this same year, KCR received funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR). This additional funding allowed KCR to institute a formal quality assurance program, implement complete death clearance follow back, and hire staff to ensure that all cases of cancer were systematically reported by non-hospital facilities. All of these activities were initiated in 1994. Since 1995, KCR has collected uniform, high quality data on approximately 27,000 new primary cases of cancer occurring in Kentucky residents each year. In 2000, KCR was selected as one of four expansion registries to become part of the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program.

KCR

The SEER registries are considered to be among the most accurate and complete population-based cancer registries in the world. Funding from the SEER program has allowed KCR to further expand its quality control of activities and gather complete follow-up information.

KCR collects data from hospitals, outpatient facilities, freestanding diagnosis and treatment facilities, pathology laboratories, multi-specialty clinics, and doctors' offices. In addition, reciprocal data exchange agreements allow KCR to obtain information on Kentucky residents with cancer who are seen or treated in contiguous states. Finally, KCR links registry data with the Kentucky death certificates to identify any cancer diagnoses made upon death that were not previously reported to the registry.

Description of the Data Collected

Cancer information collected includes primary site and cell type of cancer, as well as date and stage of disease at diagnosis. Follow up information includes vital status at date of last contact, as well as date and cause of death, when applicable. Patient demographic information is also collected including address, race, sex, Hispanic ethnicity, and date of birth.

Strengths of the Data

The cancer registry is population-based, rather than relying on a sampling strategy. Electronic data have been maintained in a consistent format since 1991. Collection protocols and formats follow national standards set by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program; the American College of Surgeons' Commission on Cancer; and the North American Association of Central Cancer Registries (NAACCR). Data from KCR have been submitted to the [North American Association of Central Cancer Registries \(NAACCR\)](#) for an objective evaluation of completeness, accuracy and timeliness each year since a formal certification program was established in 1997. In each year (1999 - 2016) KCR received the highest level of NAACCR certification available (Gold). KCR has also submitted its data for inclusion in the Cancer In North America (CINA) publication. A registry must have complete data for the most current five-year period before their data can be evaluated for inclusion in the CINA combined rates. KCR data have been included in the CINA combined rates each year since five years of KCR data have been available.

Data Limitations

There are two main limitations to the cancer registry data. The first is incompleteness of treatment data. Patients are often treated with multi-modality therapy in a wide variety of settings over a long period of time. Due to the confidential nature of the data being collected, it is often difficult to capture complete information on all treatments received. The second limitation is timeliness. Facilities are allowed six months from the date of initial contact with a patient before the cancer report is required to be sent to KCR. This is necessary in order to allow time for collection of complete or nearly complete records. Time is then spent to obtain out-of-state and death certificate records and complete a final edit of the data. There is currently a delay of two years in establishing a "complete" annual database. Finally, in order to produce the cancer rates for the numerous tables in the annual Kentucky Cancer Incidence Report, KCR must rely on other agencies for population estimates, which also contributes to the delay in data availability.

Specific Uses of Information

- Provide data used to calculate cancer incidence by age, race, gender, and place of residence.
- Provide cancer incidence statistics for a variety of purposes and programs of state government for cancer prevention and control efforts.
- Provide data to assess the cancer burden in Kentucky, by both government agencies and other healthcare researchers.
- Provide data to the National Cancer Institute, the Centers for Disease Control and Prevention, and the NAACCR for estimating the cancer burden in the United States.

System Evaluation

The data are subject to computerized edit checks when entered. Corrections and amendments are made to the database on an on-going basis. The KCR data are also subjected to annual external audits and evaluations and have been deemed to be of high quality.

Data Set Availability

Kentucky Cancer Registry 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 (i.e. case counts by race, sex, county, etc.).
- Data files containing individual, record-level data with no personal identifiers. The files will not contain name, street address, phone number, social security number, date of birth, any reporting facility, or physicians involved in the patient's care. The files may contain zip code and county of residence.
- 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. Once the record linkage is complete, the personal identifiers will be removed from the data set.
- Files containing individual, record-level data with personal identifiers, to be used for research purposes involving direct patient or family contact.

Investigators who wish to use registry data for research purposes must complete the appropriate application for review by the KCR review panel, including description of the proposed study and justification of the necessity of such research, assurances of upholding confidentiality, and for levels two through four data, documentation of approval by an appropriately constituted institutional review board or human subjects review committee.

Please contact the KCR Research Coordinator for further information on requesting any data sets.

Data Release Policy

The Kentucky Cancer Registry web site provides the public with user-friendly access to cancer data in Kentucky. Cancer incidence and mortality data for the state is available by cancer site, sex, race, geography (i.e. state, Appalachian region, urban/rural region, county), and year of diagnosis. Case counts are suppressed if fewer than 5 cases were reported in a specified category. Due to the sensitive nature of the data and laws designed to protect the individual, the fully identified cancer case records are subject to a strict confidentiality policy. They are NOT available to the public.

KCR

Data sets may be made available to qualified researchers who have submitted a written application to KCR and have been approved by an internal review panel. Approval from the institutional review board is also required.

Data Publications

Cancer incidence and mortality data for the state is updated annually. Data for the years 1995 to 2014 are currently available on the web site: <http://www.kcr.uky.edu/>.

Suggested Data Citation

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

<p style="text-align: center;">Contributing Author</p>

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Kentucky Childhood Lead Poisoning Prevention Program (KCLPPP)



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

Sources of Information for the Database

The Kentucky Childhood Lead Poisoning Prevention Program (KYCLPPP) is a state-mandated program that is cosponsored by the Centers for Disease Control and Prevention (CDC) and the Kentucky Department for Public Health. KYCLPPP is to provide a statewide program for the prevention, screening, diagnosis, and treatment of lead poisoning, including identification of the sources of such poisoning through such research, educational, epidemiological, and clinical activities as may be necessary. KYCLPPP operates under the authority of Kentucky Revised Statute (KRS) 211.900-905 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Maternal and Child Health. The surveillance system (Health Homes and Lead Poisoning Surveillance System – HHLPSS) was provided by the CDC and is funded with a mix of agency funds and a cooperative agreement from the CDC.

Description of the Data Collected

KYCLPPP collects information from any physician, nurse, hospital administrator, director of a clinical laboratory, or public health officer who receives information of the existence of any person found or suspected to have a two and three-tenths (2.3) micrograms per deciliter or higher of whole blood level of lead in his or her blood. A comprehensive record of such reports are electronically and/or manually entered into HHLPSS. These reports include, but are not limited to the patient name, full address, date of birth, phone number, guardian's name, relation and occupation (if applicable), date of initial and confirmatory blood lead draw, blood lead test results, blood lead test type (venous or capillary), date received by KYCLPPP, provider and insurance information, testing laboratory, local health department (LHD), assigned LHD case staff,

environmental assessment dates, and other demographic and case specific information. HHL PSS also houses results from on-site environmental lead inspections/risk assessments, which collects housing specific data (i.e. full address, year built, ownership type, and type of dwelling) on homes or structures that have been assessed by certified risk assessors. The Risk Assessment section of HHL PSS also stores all the environmental measurements taken during the lead inspection/risk assessment. Some of these measurements include samples from paint, floors, dust, windows, soil, water, etc. This housing data is used to report to CDC.

Strengths of the Data

Data is received in a timely manner, which allows for accurate reporting. With current electronic data submission nearing 100% there is little manual data entry from outside labs. However, out-of-state laboratories that voluntarily report blood lead levels on Kentucky residents need to be manually entered. The current system is population-based rather than relying on a sampling strategy.

Data Limitations

Incompleteness of data:

- a) Data submitted lacks information necessary for analysis. Names, addresses, and date of birth, for example, are absolutely necessary for entry into the system. Patient records with incorrect data fields are held for manual review before uploaded into the system. Due to the vacant epidemiologist position, there is a backlog of held records.
- b) There is a lack of blood lead screening tests and reporting despite federal and state mandates. As a result, the reported screening numbers are subject to non-coverage bias. As non-compliant laboratories and providers are identified, the program makes effort to collect missing lab reports.
- c) Blood lead data for years 2010-2015 is missing some required data fields such as address and source of specimen. Currently the program is working to collect missing data through phone contact. Corrected data must then be entered into the child's HHL PSS record.

Difficult to analyze data:

Most analysis of the data is performed at the county level. Unfortunately, county and zip code are missing for a large percentage of records making geographical analysis inaccurate or unrepresentative. In addition, the data includes true duplicates, which must be removed prior to analysis.

Specific Uses of Information

- Ensure timely local health department intervention for elevated blood lead levels (EBLLs).
- An EBLL case review history to help identify and prevent further access to potential and identified lead hazards.
- Ensure continual decrease in the blood lead level.
- Submit quarterly reports to the CDC.
- Complete annual reports and performance evaluations.
- Fulfill data requests.
- Estimate the population of lead poisoned children in the state of Kentucky.
- Estimate a populations' risk of lead poisoning based on their specific demographic and address information.
- Use by the CDC to assemble a national surveillance database.

System Evaluation

The data collected are based on CDC and National Institute for Occupational Safety and Health (NIOSH) guidelines. The data are subject to computerized edit checks when entered.

Data Set Availability

KYCLPPP data from 2005 to 2015 are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. KYCLPPP staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances. Data requests should be submitted to the coordinator listed above once Cabinet IRB approval is completed.

Data Release Policy

All data requests that are HIPAA compliant will be met. An IRB approval and data sharing agreement/memorandum of understanding may be requested by the Department before data requests are completed. Datasets in their entirety are not available to the public. Data are generally given in aggregate form by county level. However, if the total number of children having elevated blood lead levels is less than five (5) for a county, the exact count is not presented to help protect the identity of the client.

Data Publications

KYCLPPP currently reports both child blood lead and environmental data to the Centers for Disease Control and Prevention (CDC) on a quarterly basis. The CDC website provides statistical information for the state of Kentucky based on the reports received from the KYCLPPP:

<http://www2.cdc.gov/nceh/lead/census90/house11/house11.htm>.

Additional reports and data are available upon request and on KYCLPPP's website:

<https://chfs.ky.gov/agencies/dph/dmch/cfhpb/Pages/clppp.aspx>.

Suggested Data 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 Authors

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Kentucky Health Issues Poll (KHIP)



Coordinator: Rachelle Seger
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Foundation for a Healthy Kentucky
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Report Web Site: <https://www.healthy-ky.org/research/category/4/kentucky-health-issues-polls>

Data File Web Site: <http://www.oasisdataarchive.org>

Sources of Information for the Database

The Kentucky Health Issues Poll (KHIP), funded by the Foundation for a Healthy Kentucky and Interact for Health (formerly The Health Foundation of Greater Cincinnati) is conducted annually to assess what Kentucky adults think about a variety of health topics affecting the Commonwealth. The survey has been conducted each fall by the Institute for Policy Research at the University of Cincinnati.

Each year, a random sample of 1600+ Kentucky adults are interviewed by telephone (landlines and cell phones). Responses are weighted using data from the American Community Survey.

The potential sampling error for the survey is typically $\pm 2.5\%$. Caution should be used when interpreting subgroup results because the margin of error for any subgroup is larger than that of the overall survey.

Description of the Data Collected

KHIP provides health status and brief socioeconomic profiles of the state combined with public opinion on health-related topics. While the specific questions change from year to year, KHIP is intended to give state-level policymakers, advocates, and community organizations valuable information for keeping health on the public agenda. Recent topics have included: state legislative priorities, prescription pain reliever and heroin misuse, school-based policies, health insurance status and continuity of coverage, views on the Affordable Care Act, and access to physical, mental and oral health services. To suggest a question or topic for inclusion on a future KHIP, please contact the survey coordinator.

Strengths of the Data

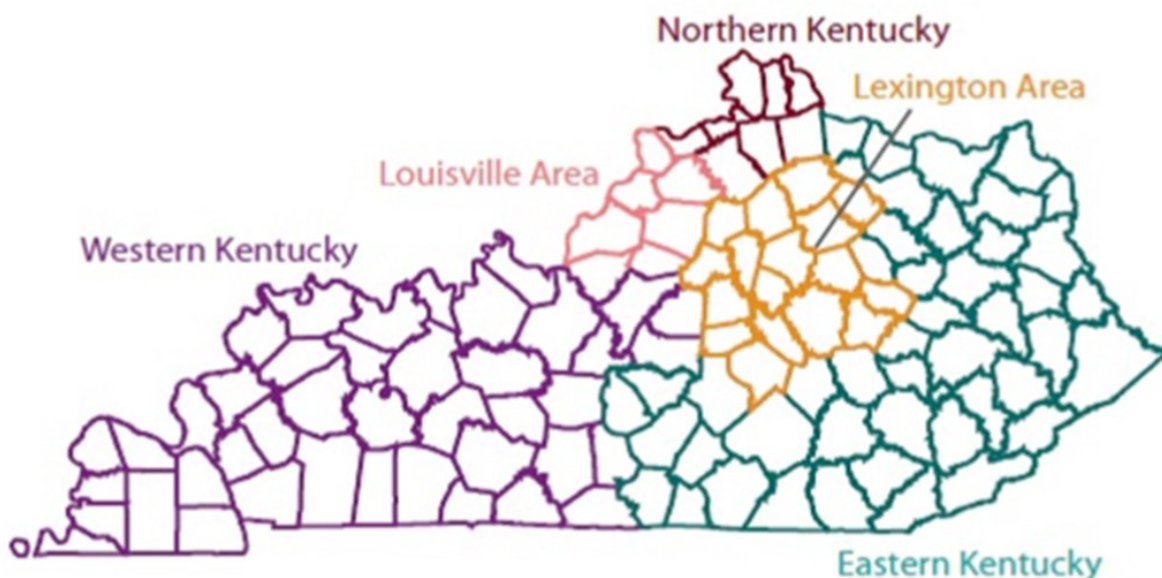
KHIP provides timely data on health policy issues that are not collected by other surveillance systems. Many health-focused public opinion polls are national and the data cannot be used to determine what an individual state's residents think about a topic, yet policymakers and advocates often want state-level public opinion data to help guide their decisions.

The large statewide sample used for KHIP provides very reliable estimates at the state-level. Data are also available for a number of demographic groups and geographic regions. Notably, KHIP identifies first- and second-generation Appalachians, and is one of the only surveys to collect data on Appalachian heritage. KHIP also includes five regional geographic samples based on Area Development District boundaries (see map below).

Data Limitations

There are sources of variation inherent in public opinion studies like KHIP, and these variations may introduce error or bias.

- **Non-Response:** The characteristics of people who agree to participate in a telephone survey may be different from those who decline to be interviewed and those who are never reached.
- **Question Wording and Context Effect:** The way that questions are phrased and the order in which they are asked may subtly influence the responses that people provide.



Specific Uses of Information

- Monitor public opinions regarding proposed (e.g. statewide smoke-free law) and enacted (e.g. Patient Protection and Affordable Care Act) legislation over time.
- Measure health risks and challenges that could potentially be addressed through

KHIP

- policy (e.g. firearm storage practices).
- Inform policymakers about the views of their constituents.
- Increase visibility and awareness of health policy issues in the media and among the general public.
- Research policy issues that disparately effect certain regions or demographic groups (e.g. burden of prescription drug misuse in Appalachia).
- Evaluate the impact of health education messages (e.g. prescription drug disposal practices).

Data Set Availability

KHIP data from 2008 to the present are available to the public on the Online Analysis & Statistical Information System (OASIS) Data Archive website. OASIS permits users to analyze data and generate maps directly from the website (www.oasisdataarchive.org). Users can also download the survey codebook and data files for SAS or SPSS.

Weighting variables are included in the data sets so that prevalence estimates can be generalized to the statewide or regional population.

If the data user is producing a report, the sponsoring Foundations would appreciate a copy of any printed and published materials using KHIP data. Please send copies to the address listed for the coordinator.

- **Average Yearly Sample Size:** 1,600
- **Smallest Geographic Level Released:** KHIP Region
- **Data Format:** SAS, SPSS, comma delimited
- **Cost of Data Set:** Free

Data Release Policy

The program does not release data for small geographies (i.e. county level) to protect respondent privacy. Caution should be used in interpreting demographic analysis with small sample sizes since estimates produced from fewer than 75 unweighted records have the potential for large statistical variation.

Data Publications

The Foundation for a Healthy Kentucky and Interact for Health use KHIP data to produce statewide data briefs on 10-15 key topics each year. Additionally, they release summary reports for each of five regions: Western Kentucky, Greater Louisville, Greater Lexington, Northern Kentucky, and Eastern Kentucky. Publications from 2008 to the present are available on the Foundation for a Healthy Kentucky's website (<https://www.healthy-ky.org/research/category/4/kentucky-health-issues-polls>) or on Interact for Health's website (<https://www.interactforhealth.org/whats-new/category/kentucky-health-issues-poll/>).

Suggested Data Citation

Foundation for a Healthy Kentucky and Interact for Health. *Kentucky Health Issues Poll Data*. Louisville, Kentucky: Authors, [**survey year**].

Contributing Authors

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Kentucky Immunization Registry (KYIR)

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KYIR Public Web Site:

<https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/kyir.aspx>

Source of Information for the Database

Kentucky Immunization Registry (KYIR) receives immunization and demographic data from CHFS Vital Records, local health departments, private health care providers and hospitals across the Commonwealth of Kentucky. The purpose of the KYIR is to securely share immunization information among health care professionals, assure adequate immunization levels, and avoid unnecessary immunizations. Registry data is used by healthcare professionals to: monitor the immunization status of children and adults; assure compliance with state laws on immunization requirements for individuals; identify geographic areas at high risk due to low immunization rates; and document/assess vaccination coverage during disease outbreaks. The KYIR also has a feature which, based on previous vaccination data, can recommend to providers any vaccinations needed by any child or adult in the system.

In addition to receiving and maintaining this vital data enhancing the welfare of the citizens of the Commonwealth, the KYIT includes a vaccine inventory management system incorporated into the application. This inventory system allows providers to maintain accurate, adequate, and viable vaccines. Utilization of this inventory and ordering process allows the provider to more accurately maintain appropriate doses on hand in order to provide immunization services to the public.

KYIR

It also ensures that the provider can easily and accurately identify viability of vaccines based on manufacturer expiration dates maintained in the registry inventory module.

Description of the Data Collected

KYIR collects historical and newly administered vaccination data from hospitals, federally qualified health centers, local health departments, rural health clinics, medical clinics, doctors' offices and pharmacies. Patient demographic information is also collected, which may include address, race, sex, ethnicity, and date of birth, parental data, and next of kin for contact regarding vaccination information.

Specific Uses of Information

KYIR serves as a repository for accurate, current, and complete immunization records. This web-based system enables users to accurately assess a patient's immunization status. Continuous enrollment of providers, who actively use the registry on an ongoing basis, will ultimately result in readily accessible and complete immunization health records for all Kentucky residents. Official Immunization Certificates that are valid for school entry can be obtained and printed from KYIR.

Strengths of the Data

The KYIR registry is comprised of, immunization and demographic data being maintained and updated over the life of each patient, from birth to death. Changes in status, such as vaccines administered, address, VFC program status and recommended vaccines to administer are based on the patient record, which begins at birth with their very first vaccination. Vaccination records from any county within the Commonwealth of Kentucky, or from outside the Commonwealth can be entered by health care providers to keep the record of every patient accurate and up to date.

Data Limitations and Availability

Data sharing will be reserved until January 2018. The registry is working with the Kentucky Health Information Exchange and the Department of Education to bring more historical records into KYIR. At this point, only 30% of children in Kentucky have 2 immunizations recorded in KYIR. In order to have meaningful information to share, the data in KYIR needs to be representative of the population.

Data Release Policy

The KYIR web site provides clinical staff with user-friendly access to immunization related data in Kentucky. 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. They are NOT available to the public. 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 web site:

<https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/kyir.aspx>

Contributing Author

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Kentucky Incentives for Prevention Student Survey (KIP)



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State Web Site: <https://reacheval.com/projects/kentucky-incentives-for-prevention-kip-survey/>

Sources of Information for the KIP

Every other year, the Kentucky Division of Behavioral Health and Substance Abuse, with the support of the Governor's Office of Drug Control Policy and the Federal Center for Substance Abuse Prevention, jointly sponsor the statewide Kentucky Incentives for Prevention (KIP) Student Survey to assess the extent of alcohol, drug, and tobacco (ATOD) use among 11 to 18--year-olds throughout Kentucky, and to evaluate the impact of prevention efforts aimed at reducing substance use. Participation in the KIP Survey is optional, and at the discretion of each school district. The survey originated in Kentucky with a Center for Substance Abuse and Prevention (CSAP)-funded project in 1999. The KIP survey is administered to 6th, 8th, 10th, and 12th graders. All student responses are completely anonymous. Since 2008, districts have had the option of administering the survey online or using a paper version of the survey. Once the data are gathered and analyzed, a report outlining information specific to the district is sent to each participating district. The entire administrative cost of the survey is borne by Kentucky's Division of Behavioral Health.

Description of Data Collected

The KIP survey provides comprehensive information about student self-reported ATOD consumption patterns and consequences related to ATOD. In 2016, the survey involved 149 (out of 173) Kentucky school districts and over 111,000 students. Survey items assess such domains as demographics, ATOD use, ATOD related problems, ATOD accessibility, values (personal and parental), school safety, bullying, and mental health. REACH Evaluation is the evaluation contractor responsible for administration, scoring, and dissemination of results, and has held this responsibility for seven survey administrations since 2003.

Strengths of the Data

Since 2004, easy-to-interpret presentation-ready reports primarily comprised of color graphs showing averages for a selection of key variables have been provided to each participating district. Comparisons with the Regional Prevention Centers designation (RPC), most of Kentucky (the other participating school districts), and (when available) a national score (e.g., from the Monitoring the Future national survey which uses the same items) are also shown on these graphs. REACH also creates trend graphs for districts that have participated in at least two KIP administrations. In addition, REACH has made available graphs 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. Each district is issued an electronic copy and hard copy of their summary report, along with a unique username and password, to access their most recent KIP report and data from all prior survey administrations, via REACH's district-specific KIP Survey Data website.

Web-based software developed by REACH is used to create all graphs and maps for the KIP report, and facilitates the option of specifying grade, race, or year for any question in the survey. Further, REACH responds to requests for additional reports specifying gender, race, groups of school districts, groups of schools, or individual schools (if there are a sufficient number of students who completed the survey to ensure the protection of confidentiality).

Significant efforts go into protecting the anonymity of responses and this greatly reduces any risks associated with accurate reporting. Stringent administration guidelines ensure that data are collected in the same manner across school districts, further increasing the reliability of the data. In the data cleaning process, REACH searches for implausible response and discrepancies and eliminates those surveys from the tallied results.

For more information about the KIP survey please visit:

<http://reachevaluation.com/projects/kentucky-incentives-for-prevention-kip-survey/>

Data Limitations

The primary limitation of the KIP survey is that the largest urban area in Kentucky does not participate in the survey, and therefore, is not included in the statewide analyses and report. In addition, each individual school district decides what part of its report to make public, possibly limiting the use of local-level data. However, state and regional level data are made available through reports created by REACH Evaluation and are posted on their website. The anonymity of the responses greatly reduces the risk associated with telling the truth. However, some limitations associated with self-report data are inevitable.

Specific Uses of Information

The KIP survey enables schools to obtain valuable information about ATOD and school safety issues to be used in prevention activities. The data help statewide planners obtain a picture of the prevalence and consequences of ATOD issues statewide in order to allocate resources and support communities. KIP survey data can be used by government agencies to monitor Healthy Kentuckians 2020 goals pertaining to substance abuse. The data are also useful in designing and evaluating substance abuse prevention initiatives and meeting Federal reporting requirements related to ATOD.

System Evaluation

Following each biennial administration, analysis begins with data cleaning to insure that any problems with the data set are discovered and resolved (e.g., transposed or missing data). Analyses are then conducted to assure that the data are psychometrically sound (i.e., reliable and valid). To find inconsistencies, pairs of answers are compared. To recognize exaggeration, REACH statisticians create summary variables that combine groups of individual variables. Using the same standard in each participating Kentucky school district, data is excluded from students whose answers are substantially inconsistent or exaggerated.

Once data cleaning has been completed, a set of cross-tabulations can be produced for each school district or group of school districts, and the data can be related with data from previous years to enable the production of multi-year charts and graphs.

Data Set Availability

KIP statewide and regional reports are available to the public free of charge and can be accessed on the REACH Evaluation KIP website at: <http://reachevaluation.com/projects/kentucky-incentives-for-prevention-kip-survey/>.

The KIP Survey 2016: Statewide Trends Related to Substance Abuse, School Safety, & Gambling (2004-2016): Sourcebook represents a total sample of 111,700 6th, 8th, 10th and 12th grade students. Requests for statewide data in cross-tabulation format may be submitted to Lisa Crabtree, KIP Survey Manager at REACH Evaluation (lisa@reacheval.com, 502-585-1911).

Data Release Policy

Since KIP survey data are the “property” of the schools, written permission from the school district is required in order to access district-specific results. Persons wishing to request district-specific data may contact the KIP Coordinator or superintendent directly, or Lisa Crabtree, KIP Survey Manager at REACH Evaluation (lisa@reacheval.com, 502-585-1911).

Suggested Data Citation

REACH Evaluation. *KIP Survey 2016: Statewide Trends Related to Substance Abuse, School Safety, & Gambling (2004-2014)*: Sourcebook. Louisville, KY: REACH Evaluation, [2016].

Contributing Authors

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Kentucky Occupational Safety and Health Surveillance (KOSHS)

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State Web Site:

<http://www.mc.uky.edu/kiprc/programs/koshs.html>

Sources of Information for the KOSHS Program

The Kentucky Occupational Safety and Health Surveillance (KOSHS) program is funded by the National Institute for Occupational Safety and Health (NIOSH) to conduct surveillance of 19 fatal and nonfatal occupational injuries and illnesses indicators, perform epidemiologic analysis of fatality data, develop priorities for intervention development based on high injury-risk worker population surveillance data, and to produce and disseminate prevention information to industries and occupations.

Since 2005, the KOSHS program has collected surveillance data on fatal and nonfatal occupational injuries and illnesses. A work-related injury is included in KOSHS datasets if it occurred in Kentucky and the decedent was performing work tasks. Multiple sources of information for occupational injury and illness surveillance include Bureau of Labor Statistics data, Kentucky Cancer Registry data, Adult Blood Lead Epidemiology Surveillance (ABLES) data, hospital discharge data, Census of Fatal Occupational Injuries (CFOI) data, National Academy of Social Insurance data, vital statistics data, Occupational Safety and Health Administration (OSHA) annual reports, and Office of Workers' Claims (OWC) data, among others. There is no Kentucky mandate that requires collection of occupational injury and illness data.

Description of Data Collected

Public access data sources include Bureau of Labor Statistics (BLS) Survey of Occupational Injuries and Illnesses, BLS Current Population Survey, Year 2000 US standard population data, US Census State Population data, National Academy of Social Insurance, CFOI, Bureau of Census County Business Patterns, OSHA annual reports, BLS statistics on covered employers and wages, and professional trade organization data.

Authorized resources (permission granted to the KOSHS program to use data) include data from the Kentucky inpatient hospitalization discharge set, death certificates, OWC, ABLES, Fatality Assessment and Control Evaluation (FACE), Collision Reporting and Analysis for Safer Highways (CRASH), Kentucky Cancer Registry data, and Kentucky Regional Poison Center data.

Electronic records are not identified by victim's name or employer's name. Data are updated and edited as new information is obtained. The KOSHS program works closely with other states, and NIOSH to facilitate data sharing through the ongoing development of common data input and output formats, and variables.

KOSHS data are analyzed with descriptive and advanced statistics using SAS®. Basic descriptive analysis on data variables is performed to assess data quality, validity, and to describe cases. Frequencies are determined for the datasets to account for any missing values. Routine cross-tabulations are performed to assess relationships between selected variables. Outliers are investigated for accuracy. Non-parametric statistics are run on all non-normally distributed variables, and chi-square and t-tests are performed where appropriate.

Strengths of the Data

The KOSHS program 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. The strengths of the program are the timely, comprehensive multi-source surveillance, and epidemiologic analysis of fatal and nonfatal work-related injuries to identify risk factors. Also, research-to-practice (R2P) initiatives are promoted through effective dissemination of occupational injury and illness data, results, and materials to occupational safety and health stakeholders.

Data Limitations

Even though a multitude of data sources are used for the KOSHS program, not all occupational injuries and illnesses are being captured through the surveillance system. Undercounting of occupational injuries and illnesses is occurring due to increases in the temporary work force, self-employment status, and lack of workers' compensation coverage. Nevertheless, the KOSHS program provides an accurate indication of the scope of occupational injuries and illnesses in Kentucky to analyze trends within the state and to compare data to other states.

Specific Uses of Information

- Hazard alerts on specific types of occupational injuries.
- Peer-reviewed publications on occupational injuries and illnesses.
- Data requests from external and internal agencies, organizations, and associations.
- Production of prevention materials to educate legislators.
- Multi-state data collaborations.

System Evaluation

Evaluation of the KOSHS program is based on updated Centers for Disease Control and Prevention (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 began in June 2005 so it is primarily a process evaluation to date. The indicators, prevention, and dissemination processes are included in the evaluation.

KOSHS

Data Set Availability

KOSHS data utilizes data from a number of 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 at (859) 257-4954.

Data Release Policy

KOSHS program data is derived from data sets maintained by other entities. Data release inquiries should be directed to the primary custodians of the data sets.

Data Publications

An annual KOSHS report, hazard alerts, and peer-reviewed publications are produced and available on the state KOSHS website.

Suggested Data Citation

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

References

Thomsen C, McClain J, Rosenman K, Davis L., Centers for Disease Control and Prevention (CDC)(2007). Indicators for occupational health surveillance. MMWR Recomm Rep. 56(RR-01):1-7.

Contributing Author

Terry Bunn, PhD, Kentucky Injury Prevention and Research Center

Kentucky State Ambulance Reporting System (KSTARS)



Coordinator/Data Contact: Kentucky Board of Emergency Medical Services
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Lexington, KY 40505
(859) 256-3572

State Website: <http://www.kyems.com/kstars/>

National Website: <http://www.nemsis.org>

Sources of Information for the Database

Information in the system is collected by Kentucky certified and/or licensed Emergency Medical Service (EMS) practitioners on behalf of licensed ambulance services. Data is based on the National EMS Information System (NEMSIS) Version 3 standard and collected in certified compliant software packages then submitted to the KSTARS database using web services or direct entry.

Description of the Data Collected

The KSTARS database contains patient care report (PCR) information associated with calls for service such as demographics, injury severity, vital signs, treatments provided, medications administered, location, and destination.

Strengths of the Data

All licensed ambulance services are required by 202 KAR 7:540 to submit data to KSTARS using the latest version of NEMSIS by the 15th of the month following the incident. More than half of services report within 48 hours and nearly all services are compliant on a recurring basis providing a comprehensive picture of EMS response activity. Data collected is part of a national standard with comprehensive data dictionaries at the NEMSIS website.

Data Limitations

- Reporting deadline could mean a six weeks between the incident and receipt making real-time use unrealistic.
- Reports limited to flat file formats (i.e. CSV, XML).
- Elements with multiple values (i.e. Vital signs) cause a repeating row in the report that makes one incident appear across multiple rows.
- Validation rules are in place to improve data quality but are difficult to enforce with imported records.

System Evaluation

Validation rules used to enforce Mandatory and Required data elements though services still submit without 100% validation scores.

Data Set Availability

The fully identified data set is not available to the public. Portions of the data set can be shared and identified data can be made available to research organizations providing the requestor enter into a Data Sharing Agreement with the Kentucky Board of Emergency Medical Services.

Data Release Policy

Any data released to the public will be de-identified. Requests are accepted through Open Records procedure or through the Support Portal (for Data Sharing Agreements), both listed on the kyems.com site.

Data Publications

The Kentucky Board of Emergency Medical Services publishes a report each year with a variety of interesting topics. It is posted to the kyems.com website under: *About > Meeting Minutes*.

Suggested Data Citation

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

Contributing Authors

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Kentucky Trauma Registry (KTR)

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State Web Site:

<http://www.mc.uky.edu/kiprc/programs/trauma-registry.html>

Sources of Information for the Database

In 2012, Kentucky administrative regulations (902 KAR 28:040) established a single statewide Kentucky Trauma Registry (KTR) with the Kentucky Injury Prevention and Research Center (KIPRC) designated as the statewide repository for trauma data. The Kentucky Trauma Registry is currently 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. Funding also makes ongoing evaluation possible. Currently, 29 Kentucky hospitals are designated and verified or in a process of designation as trauma centers in Kentucky.

Designated/Verified trauma facilities (20 of 29):

- 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 Center: Pikeville Medical Center (Pikeville);
- Level 3 Trauma Centers: Ephraim McDowell Regional Medical Center (Danville), Frankfort Regional Medical Center; Owensboro Medical Center, Taylor Regional Hospital (Campbellsville);
- Level 4 Trauma Centers: Ephraim McDowell Ft. Logan Hospital (Stanford), Harlan ARH, Harrison Memorial (Cynthiana), James B. Haggin Memorial Hospital (Harrodsburg), Livingston County Hospital (Salem), Marcum & Wallace Hospital (Irvine), Methodist Hospital Union County (Morganfield), Morgan County ARH (West Liberty), Rockcastle Regional Hospital (Mt. Vernon), St. Claire Regional Medical Center (Morehead), Tug Valley ARH (So. Williamson).

KTR

Facilities in process of designation/verification (9 of 29):

Hazard ARH Hospital, McDowell ARH Hospital, Middlesboro ARH Hospital, Russell County Hospital, St. Claire Medical Center, St. Joseph Berea, St. Joseph Hospital Mt. Sterling, Trigg County Hospital, Whitesburg ARH.

All of these hospitals submit data to the KTR. KIPRC has an important role in synthesizing and analyzing statewide trauma registry data and producing statewide trauma registry reports.

Description of the Data Collected

Trauma registry data includes hospital name, patient gender, date of birth, race, county of injury and residence, zip code, date and time of injury, arrival, and discharge, referring hospital, E-code, Injury Severity Score (ISS), Glasgow Coma Score (GCS), trauma score, Revised Probability of Survival (RPS), Blood Alcohol Level (ETOH), ICD-9 codes, length of stay, number of ICU days, and disposition.

Strengths of the Data

The Kentucky Trauma Registry provides a rich database that includes Kentuckians who incur serious traumatic injury and are cared for in the state's verified facilities. It supports the identification of areas in which the state deviates from national norms regarding traumatic injury incidence, characteristics, and care.

Data Limitations

There are three important limitations that users of KTR data should keep in mind:

1. It only includes data from facilities that are either American College of Surgeons (ACOS)-verified, state-verified Level IV centers, or those preparing for initial verification. It is clear that serious trauma is also cared for at many other general acute care facilities across the state that do not elect to pursue ACOS-verified status. The trauma registry, therefore, does not provide as complete an account of traumatic injury in Kentucky as it would if reporting were spread across a larger group of facilities.
2. Registry data cannot include patient identifiers under Kentucky law, so repeat visits by the same patient are not identifiable. Thus, the registry data analysis describes cases rather than unique patients.
3. Some Kentucky residents who incur traumatic injury near the state's borders are hospitalized in adjacent states, notably Ohio and Tennessee. Our trauma registry does not have access to information about these patients.

Specific Uses of Information

Trauma registry data are used for trauma system planning, informing legislative initiatives, and identification of areas in which additional activity is necessary.

System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by the CDC. Evaluation of quality is determined through quarterly and annual reports of these performance standards.

Data Set Availability

Kentucky Trauma Registry data sets are not generally available. Requests for data summary and reports should be addressed to Julia Costich at KIPRC.

Data Release Policy

Spreadsheet versions of KTR data are available upon request from the KIPRC. Summary KTR data can be made available to appropriate research agencies through submission of a formal request to KIPRC. Each request should identify the requesting organization, purpose of research, proposed methodology to be employed and publication plan. On a case by case basis, KIPRC reviews the request and obtains additional information as needed. KIPRC and the research team agree upon a collaboration plan which will include schedule, methods, analysis, reporting, and publication of the study. Upon review and agreement of the study plan, KIPRC may approve the request for data. Reports using KTR data cannot identify any individual patient or hospital.

Data Publications

Detailed reports, profiling the traumatic injuries treated in Kentucky trauma facilities, are available at:

<http://www.mc.uky.edu/kiprc/projects/trauma/index.html>

Suggested Data Citation

- Costich JF, Rock PJ. *Kentucky Trauma Registry Report 2015 Annual Report*. Kentucky Injury Prevention and Research Center, Lexington, KY, October 2016.
- Rock PJ, Costich JF. *2014 Kentucky Inpatient Traumatic Injury Data Report*, Kentucky Injury Prevention and Research Center, November 2015.

<p style="text-align: center;">Contributing Author</p>

<p style="text-align: center;">Julia Costich, JD, PhD, Kentucky Injury Prevention and Research Center</p>

Kentucky Violent Death Reporting System (KVDRS)



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State Web Site: <https://kvdrs.ky.gov/Pages/default.aspx>

Sources of Information for the Database

Information collected for this surveillance system is gathered from death certificates, coroner/medical examiner reports, police reports, crime laboratory reports, and toxicology reports and then combined into the KVDRS database. After all raw data is stripped of personal identifying information, it is sent to the national database to be combined with information from the other 40 funded states, the District of Columbia and Puerto Rico. Together, this information provides a more complete picture of violent death. The national database is the only state-based surveillance system that pools data on violent deaths from multiple sources into a database. The sources that are used include the local and state medical examiner, coroner, law enforcement, crime lab, and vital statistics records. Without these pieces, the problem of violent Death in Kentucky, or in the nation, cannot be accurately explained. This project is funded by Cooperative Agreement CE09-904 from the Centers for Disease Control and Prevention. While there may be mandates for the data sources (i.e. death certificates and police), there is no federal or state mandate that requires the collection of this data. However, if the data were not collected, funding would be lost.

Description of the Data Collected

In Kentucky, information related to homicides, suicides, and firearm-related deaths have, in the past, remained inaccessible and unreliable. The coroner system is not centralized, and while police and forensic laboratory data are centralized and available, they have not been collected and combined with additional investigative information for violent death research purposes. By integrating multiple data sources to form a violent death surveillance system, formerly disparate pieces of information can be compiled and analyzed.

In addition to adult data, Kentucky collects Child Fatality Review (CFR) data using the pediatric module within the National Violent Death Reporting System (NVDRS). The Division of Maternal and Child Health (MCH) within the Department for Public Health collects CFR data, and data is exchanged for use by both agencies.

Strengths of the Data

To improve coroner reporting *The Coroner Investigation Reporting System (CIRS)* was designed, developed, and distributed. County coroners use CIRS reporting forms and/or notebooks and/or the CIRS web system for improved record keeping. This system was the first step in centralizing coroner investigation reports in the commonwealth for the benefit of not only the KVDRS, but of many other research activities. The CIRS is expanding to the "Death Scene Investigation" (DSI) system with users being any death investigator.

Data Limitations

KVDRS reports include only deaths occurring within Kentucky; this allows KVDRS staff to collect additional investigative information. Therefore, the counts of suicides, homicides, and unintentional firearm-fatalities in KVDRS reporting will 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.

Specific Uses of Information

Results from KVDRS data analysis are used for peer-review publications, reports, briefs for advocacy groups preventing suicide, intimate partner violence, veteran suicide, child abuse, and responding to media requests. KVDRS data has also been used to develop proposals for National Institute of Health funding and National Institutes of Justice funding.

Publications

Khaleel H, Brown SV, Christian WJ, Fleming S. Alcohol Sale Status and Suicide in Kentucky, 2005-2012. *J Alcohol Drug Depend.* 2016, 4:3.

Comiford A, Sanderson WT, Chesnut L, Brown SV. Predictors of Intimate Partner Problem-Related Suicides among suicide decedents in Kentucky. *Journal of Injury and Violence Research.* 2016 April 19, 8 (2).

Cerel J, Brown SV, Singleton, M, Brown M, Brancado C, Thaxton A & Bush HM. Emergency department visits prior to suicide and homicide: Linking statewide surveillance systems. *Journal of Emergency Medicine.* Crisis. 2016 Jan; 37 (1):5-12. [Epub ahead of print, 2015 Dec 1].

Publications (Continued)

Holland KM, Brown SV, Hall J, Logan JE. Homicide-Followed-By-Suicides Involving Child Victims: A Qualitative Assessment of Perpetrators. *Journal of Interpersonal Violence*. 2015 Sep 17; [Epub ahead of print].

Cerel J, Moore M, Brown MM, Van De Venne J, Brown SV. Who Leaves Suicide Notes? A Six-Year Population-Based Study. *Suicide & Life Threatening Behavior*. 2015 Jun; 45(3):326-34. [Epub ahead of print, 2014 Oct 13].

KVDRS Reports

Brown SV, Seals J, McCarthy M, Bush H (2017). *Violent Deaths in Kentucky 2005-2014: A Statewide Statistical Summary of Homicides, Suicides and Unintentional Firearm Fatalities*. Lexington, KY, College of Public Health, Kentucky Injury Prevention and Research Center, University of Kentucky.

Presentations

Seals J, Brown SV, (March 2017) Kentucky's Homicide and Suicide Trends Examined by Stream Analogy for Lethal Violence, 2005-2014. University of Kentucky – College of Public Health's Annual Clinical and Translational Science Conference. Lexington, KY.

McCarthy M, Seals J, Brown SV, (March 2017) Millennials and Suicide: an Ecological Study of Kentucky Suicide deaths, ages 18-24. University of Kentucky – College of Public Health's Annual Clinical and Translational Science Conference. Lexington, KY.

Blondino C, Brown SV, Seals J, (March 2017) Do numbers matter? Comparing single homicide followed by suicide and multiple homicide followed by suicide using the National Violent Death Reporting System, 2003-2012. University of Kentucky – College of Public Health's Annual Clinical and Translational Science Conference. Lexington, KY.

Akosua A, Brown SV, Sanderson W, Abner E, Meints L. "IPP/IPV-associated suicides and homicides in pregnant, postpartum and non-pregnant suicide and homicide victims (15-54 years), NVDRS 2003-2012." Poster Presentation during the APHA 2016 Annual Meeting and Expo (Oct. 29-Nov.2, 2016) in Denver, CO.

Brown SV, (May 2014) Panelist, The Value of the NVDRS Data. National Violence Prevention Network's National Violent Death Reporting System Midwest Regional Meeting. Chicago, Ill.

Brown SV, (May 2014) Oral Presentation, Opportunities for NVDRS Data Publication. National Violence Prevention Network's National Violent Death Reporting System Midwest Regional Meeting. Chicago, Ill.

Khaleel HA, Brown SV, Brown M (May 2014) Poster Presentation, Association of Alcohol-Related Suicides with Alcohol Sale Status in Kentucky from 2005-2012. College of Public Health Research Day. 10th Annual Center for Clinical and Translational Science Spring Conference. Lexington, KY.

Brown, M, Brown, SV, Cerel, J (April 2014) Intimate Partner Problems and Violence in Kentucky and North Carolina, a Reason for Suicide? Poster Presented at the American Association of Suicidology, Los Angeles, CA.

Brown SV, Bonta P (April 2014) Deaths from Violence: A Look at 18 States (Data from the National Violent Death Reporting System 2009-2010). Congressional Hill Briefing, Washington DC.

Media

Brown SV. Invited guest as an expert in violence prevention for WUFT Public Radio segment, "Public Health Minute."

<http://wp.lehman.edu/public-health-minute-with-william-latimer/homicide-suicide-dr-sabrina-brown-phd-university-of-kentucky/>

System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC. Evaluation of quality is determined through quarterly and annual reports of these performance standards.

Data Set Availability

Statewide and county level aggregate summary data can be provided upon request. In addition to reports, unidentified Excel data files may be requested.

This data set includes hundreds of variables including circumstantial data (i.e. precipitating events leading to a violent death), demographic and weapon information. Data are available from 2005 to 2015. National data are also available following the approval of the Data Sharing Agreement (DSA) with the Centers for Disease Control and Prevention (CDC). The NVDRS DSA was created to govern the protection and use of sensitive or potentially identifiable NVDRS data, as required by the NVDRS Data Release Plan. Prior to release of NVDRS restricted access microdata (RAD) by the CDC, a data sharing agreement must be established for any users who are not currently employed by the Division of Violence Prevention or the Office of Statistics and Programming, National Center for Injury Prevention and Control (NCIPC).

Average Yearly Sample Size: 1000-1300

Smallest Geographic Level Released: County

If you would like to request data please provide the following information:

Name, organization, reason for data, and intended data usage. The request will need to include years, geographic level, and specific variables. There is no cost for data sets, but following data usage, a return email would be greatly appreciated specifying in what capacity the data was used (i.e. citation from a presentation, grant application or a report).

Send data requests to Dr. Sabrina Brown, sabrina.brown@uky.edu.

Data Release Policy

Data with cell counts less than 5 will need to be reported as "<5." No personal identifying information will be released.

Data Publications

The KVDRS program produces annual statewide statistical summary briefs of important topics that emerge when monitoring trends and patterns of violent deaths. Staff and College of Public Health students produce peer-reviewed publications, contribute to state and national reports each year, collaborate on proposals for new funding, and conduct state and national presentations.

Suggested Data Citation

Brown SV, Seals J, McCarthy M, Bush H. 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**].

*Data are provisional and subject to change

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Kentucky Women's Cancer Screening Program (KWCSPP)

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State Web Site:

<https://chfs.ky.gov/agencies/dph/dwh/Pages/cancer-screening.aspx>

National Web Site:

<http://www.cdc.gov/cancer/nbccedp/>

Sources of Information for the Database

Kentucky Women's Cancer Screening Program (KWCSPP) collects surveillance data from all local health departments. Semiannual reports are submitted to the Centers for Disease Control and Prevention (CDC). These reports include a set of standardized data elements called Minimum Data Elements (MDE) to describe basic demographic characteristics, screening history, and screening and diagnostic outcomes for these women. The KWCSPP has collected MDEs continuously since 1998. The KWCSPP is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Women's Health.

Description of the Data Collected

MDEs are a set of standardized data variables developed to ensure that consistent and complete information on screening location, patient demographic characteristics, screening results, diagnostic procedures, final diagnosis, and treatment information is collected on women screened or diagnosed with National Breast and Cervical Cancer Early Detection Program funds. The MDEs are divided into three sections: All Patients Section, Abnormal Pap test Section, and the Abnormal Mammogram/Clinical Breast Exam (CBE) Section.

KWCSP

The "All Patients Section" is completed for each screening test performed for women with program funds. It includes the screening location, patient demographic information, and screening results for Pap tests, mammograms, and clinical breast exams. The "Abnormal Pap Test Section" and the "Abnormal Mammogram/CBE Section" are completed only for abnormal Pap test results and abnormal mammogram/CBE screening results. These sections provide data on diagnostic procedures, final diagnoses, and treatment for breast and cervical cancer.

Strengths of the Data

The MDEs are accurate, complete and timely and are used to establish KWCSP policies and practices, assess the program's statewide screening outcomes, and respond to the information needs of CDC stakeholders and partners. At present, the data at present are 99% complete. Screening data is available after 3 1/2 months and diagnostic data is available after 9 1/2 months from the MDE report cut off dates, which are June 30th and Dec 31st of every year. The CDC collects MDEs from all 50 states, 4 U.S. territories, the District of Columbia, and 13 American Indian/Alaska Native tribes or organizations; therefore, data from Kentucky may be compared to other states.

Data Limitations

Data is collected only on women ages 21-64, below 250% poverty level and not eligible for Medicare, Medicaid, and have no private insurance.

Specific Uses of Information

- Breast and cervical cancer screening participation.
- Breast and cervical cancer screening results.
- Breast and cervical cancer screening diagnostic follow-up.
- Breast and cervical cancer detection and diagnosis.
- Stage of invasive breast and cervical cancer at time of diagnosis.
- To evaluate health disparities.

System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC.

Data Set Availability

KWCSP's MDEs data may be obtained upon request through the open records process. The Statewide data is available in both SPSS and text formats. National data are available on the national web site: <http://www.cdc.gov/cancer/nbccedp/>.

- **Average Yearly Sample Size:** 6,000 records
- **Smallest Geographic Level Released:** County
- **Data Format:** SPSS, Text, and Access format
- **Cost of Data Set:** Free

Data Publications

The KWCSP program annually produces the Report of Breast Cancer Screening. The program uses encounter data to produce this report. This raw encounter data contains basic demographic characteristics and breast cancer screening and diagnostic services performed on women screened through all the local health departments in Kentucky regardless of payer source and age.

The encounter data system relies on the accuracy of reporting by the local health department sites. Aggregate data may be obtained upon request through the open records request process.

Suggested Data Citation

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

Contributing Authors

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Neonatal Abstinence Syndrome (NAS) Surveillance System

**Coordinator & Data Contact:**

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tracey.jewell@ky.gov

State Web Site:

<https://chfs.ky.gov/agencies/dph/dmch/Pages/default.aspx>

National Web Site:

[https://www.marchofdimes.org/complications/neonatal-abstinence-syndrome-\(nas\).aspx](https://www.marchofdimes.org/complications/neonatal-abstinence-syndrome-(nas).aspx)

Sources of Information for the Database

Neonatal Abstinence Syndrome (NAS) is the collection of signs babies experience in withdrawing from drugs that they were chronically exposed to in utero. Common symptoms that may be present with NAS include: high-pitched cry, restlessness, hyperactive reflexes, myoclonic jerks, jitteriness, tremors, seizure, poor feeding, vomiting, loose stools, fever, sweating, mottling, nasal flaring, apnea, and tachypnea.

Kentucky Revised Statute 211.676 requires the reporting of NAS cases to the Division of Maternal and Child Health within the Kentucky Department for Public Health. Specifically, it states: "All cases of neonatal abstinence syndrome (NAS) diagnosed among Kentucky resident births shall be reported to the Kentucky Department for Public Health by the facility where NAS is diagnosed. The report shall be made at the time of NAS diagnosis pursuant to guidance issued by the department."

Hospitals began submitting data on NAS cases on July 15, 2014.

Description of the Data Collected

Data collected by the NAS surveillance system include both demographic and medical information on the infant and mother. Variables reported include but are not limited to: infant sex, age at onset of symptoms, maternal county of residence and address, infant and maternal dates of birth, maternal history of substance abuse, substances found on infant and maternal testing, and medications used to treat the infant with date and time of first administered dose.

Strengths of the Data

The NAS surveillance system provides a population data set of diagnosed NAS cases in Kentucky from physician diagnosis at time of onset. Data are collected on a standardized form and include the ICD-9 and/or ICD-10 codes utilized at diagnosis. Surveillance performance standards and data quality are monitored at least monthly and technical assistance to reporting facilities is conducted on an as-needed basis.

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.

Specific Uses of Information

- Provides population level information about Kentucky's NAS cases reported to the Department for Public Health/Division of Maternal and Child Health.
- Provides data to create and evaluate prevention efforts and service initiatives for NAS.
- Used to identify target populations that are disproportionately affected by NAS.

System Evaluation

NAS data are monitored on a monthly basis for quality and accuracy.

Data Set Availability

Due to security and confidentiality restrictions, the NAS raw data are not available for public use.

Data Release Policy

As mentioned previously, in order to maintain the integrity of the surveillance system and protect the confidentiality of the information collected, data are not available for release to the public. Data may be disseminated in aggregate fashion at the discretion of the Maternal and Child Health Division Director provided appropriate approval procedures have been completed and documented. Aggregate data requests can be filled at the public's request with restrictions at no cost. For all requests, please contact Tracey Jewell at tracey.jewell@ky.gov or (502) 564-4830 ext. 4393.

Data Publications

In addition to mandatory reporting of NAS cases, there is a separate mandate requiring publication of an annual report. KRS 211.678 states that the Kentucky Department for Public Health shall publish on, at least, an annual basis de-identified statistical data on the number of reports made under KRS 211.676 relating to a diagnosis of NAS. The report may segregate the data into reporting blocks no smaller than the regional or county level. This report will be made available on the state website.

Suggested Data Citation

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

Contributing Authors

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Joyce Robl, EdD, MS, CGC, Kentucky Department for Public Health

Perinatal Hepatitis B Screening (Perinatal Hep B)



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Secondary Contact:	Julie A. Miracle, RN, BSN, CPAN Nurse Consultant Kentucky Immunization Program Department for Public Health Division of Epidemiology and Health Planning 275 E. Main Street HS2E-B Frankfort, KY 40621

Sources of Information for the Database

System data are based upon identifying information and demographics collected by local health departments and private providers on any prenatal patient who has a positive hepatitis B surface antigen (HBsAg) screening test. These data also include the Estimated Date of Confinement (EDC), name of hospital, name of local health department and contact nurse, the private provider's name, maternal and infant insurance status and the outcome of the pregnancy. Kentucky State Law (KRS 214.160) mandates that all pregnant women must be screened for hepatitis B surface antigen testing. KAR 2:020 (Reportable disease surveillance) requires reporting of all HBsAg positive pregnant women to local health departments (LHD) or the state perinatal hepatitis B coordinator. The surveillance system is fully funded through the federal immunization grant.

Description of the Data Collected

Reports of positive HBsAg tests on all prenatal patients are forwarded from the state laboratory or from the local health department to the Department for Public Health, Division of Epidemiology and Health Planning. The Immunization Program then obtains the demographic and clinical information from the local health department and enters the patient in a restricted access registry. When the infant is born, the health

department reports dates of hepatitis B immune globulin (HBIG) administration, hepatitis B vaccine series receipt and date and the result of post serology testing including quantitative antibody to hepatitis B surface antigen and HBsAg. The Kentucky Immunization field staff follows up monthly for missing reports. Line listings with the above information are forwarded to the Division of Epidemiology and Health Planning, Immunization Program where prevalence of HBsAg, follow-up rates, and efficacy of the prevention regimen are calculated. Summary information is disseminated by the Immunization Program, Division of Epidemiology and Health Planning to local health departments, immunization field staff and the Centers for Disease Control and Prevention (CDC).

Strengths of the Data

The information 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 local health departments, primary care physicians and birthing hospitals and who can access the data.

Specific Uses of Information

- Monitor the prevalence of hepatitis B in the population of delivering mothers who use health department services and private doctors.
- Track changes in the overall epidemiologic characteristics of hepatitis B.
- Assure that infants at risk of perinatal transmission receive hepatitis B immune globulin and hepatitis B vaccine to prevent disease.
- Monitor for vaccine failures in infants of hepatitis B positive mothers who receive the preventative regimen.

System Evaluation

The system is evaluated annually by way of a report submitted to the CDC. The report enumerates the number of births to HBsAg positive mothers, vaccination completion rates, and post-vaccination testing rates.

Data Set Availability

Data are submitting on EPID-394, 395, and 399 forms by mail or fax to the state coordinator. The coordinator enters the data to a restricted Access registry. LHDs contact the providers for the information and forward to the state coordinator. Kentucky has a three year average of 84 infants born to HBsAg positive mothers. CDC estimated that in 2014, Kentucky could have between 102 to 160 infants born to HBsAg positive mothers. Costs incurred include those required for upkeep of the dataset as well as for various clerical responsibilities.

Data Release Policy

The current registry is a restricted only Access database housed on a server in Frankfort, KY. Kentucky follows the integrated security and confidently guidelines for HIV, STD, viral hepatitis and TB surveillance programs mandated by the CDC.

Perinatal Hep. B

Data Publications

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

Suggested Data Citation

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

Contributing Authors

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Pregnancy Risk Assessment Monitoring System (PRAMS)

**Coordinator & Data Contact:**

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National Web Site:

<http://www.cdc.gov/PRAMS>

Sources of Information for the Database

PRAMS, the Pregnancy Risk Assessment Monitoring System, is a surveillance project of the Centers for Disease Control and Prevention (CDC) and state health departments. Developed in 1987, PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. PRAMS surveillance currently covers about 83% of all U.S. births. PRAMS provides data not available from other sources. These data can be used to identify groups of women and infants at high risk for health problems, to monitor changes in health status, and to measure progress towards goals in improving the health of mothers and infants. PRAMS data are used by researchers to investigate emerging issues in the field of reproductive health and by state and local governments to plan and review programs and policies aimed at reducing health problems among mothers and babies.

Kentucky was recently awarded a cooperative agreement through a competitive grant application process by the CDC to conduct PRAMS surveillance. This is a five year cooperative agreement that began on May 1, 2016 and will continue through April 30, 2021. At the end of the five year funding cycle, states will again apply through a competitive grant application process for another five years of funding. The Kentucky PRAMS program is organizationally located in the Cabinet for Health and Family Services, Department for Public Health, Division of Maternal and Child Health.

Description of the Data Collected

PRAMS utilizes a mixed mode system consisting of mail and telephone surveys to collect data. The survey distribution cycle is conducted over a period of 3 to 6 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 3 to 6 months prior to sample selection. Fetal deaths, stillbirths, abortions, out-of-state births, and birth certificates with missing identification (i.e. mother's last name or mailing address) are excluded from the sample. Mothers are included regardless of age.

PRAMS

Participation in the survey is completely voluntary, and data are de-identified prior to analysis. Incentives and rewards are utilized to increase response rates.

PRAMS collects data on perinatal maternal behavior and experiences that may be associated with adverse birth outcomes. Data are collected on a variety of topics including: access to prenatal care, insurance status, quality of prenatal care, infant sleeping position, medical problems during pregnancy, delivery of the infant, mother's employment status, government assistance, pregnancy intent, contraceptive use, substance use, breastfeeding, smoking, and oral health. Demographic data are collected both from the PRAMS survey and from the birth certificate, and include race, age, education level, income, marital status, and insurance status.

All CDC funded PRAMS states collect data in the same manner following the guidelines of the PRAMS model surveillance protocol. There are three types of questions available for use by all PRAMS states and those include core questions, standardized questions, and state-added questions. Core questions are asked by all states, standardized questions are questions on particular topics developed by the CDC that the states may choose to use, and state-added questions are questions that the state develops that relate to health needs of the particular state. Data collection is on-going and conducted on a calendar year basis with the first sample batch of each new year being drawn in April. This is to comply with the sampling protocol requirement that eligible births must be between three and six months of age in order to be included on the sampling frame. Births that occur in January of a calendar year do not meet this requirement until April; therefore, sampling for a new year always begins in April.

Kentucky met all state requirements in the first year of the grant and was approved by CDC to begin data collection in April 2017 and is currently collecting its first year of PRAMS data.

Strengths of the Data

PRAMS was designed to supplement vital records data by providing state-specific data on maternal behaviors and experiences to be used for planning and assessing perinatal health programs. In addition, because PRAMS uses standardized data collection methods, it allows data to be compared among states.

PRAMS provides data on health indicators, such as prematurity, low birth weight, infant mortality, breastfeeding, and pregnancy intent that are not collected by other surveillance systems. In addition, the data are timely and typically available the year following collection. Data are weighted so results can be generalized to Kentucky's entire population of pregnant women.

Data Limitations

There are some limitations in the PRAMS data: recall bias, non-response bias, and small sample size. These limitations should not hinder the use of PRAMS data, but should be considered.

- **Recall Bias:** PRAMS respondents are contacted within 3-6 months after giving birth and questions are asked regarding behaviors throughout the perinatal period, which includes, at minimum, a 12 month span of time. Due to this long time frame it is possible that the accuracy of the data may be impacted by the mother's ability to recall all of 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.
- **Non-Response Bias:** PRAMS surveys are mailed based on address information collected from the birth certificate files. Transient populations and non-English speaking populations are more difficult to reach. It is possible that the results in the non-response population could differ from those of the respondents.
- **Small Sample Size:** The PRAMS projects are point in time surveillance systems and only sample the population for 3-6 months of the year. Approximately 150 women are selected each month to participate in the survey and only 50-60% of participants respond.

Specific Uses of Information

Findings from analyses of PRAMS population-based data can be generalized to an entire state's population of women whose pregnancies resulted in a live birth. Findings from PRAMS data have been used in many important ways:

- To increase understanding of maternal behaviors and experiences and their relationship to adverse pregnancy outcomes.
- To develop new maternal and child health programs and to 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 investigate emerging maternal and child health issues.
- To evaluate health disparities.

System Evaluation

The data collection for the Kentucky PRAMS program follows the CDC model surveillance protocol to ensure consistent and valid sampling techniques and survey monitoring.

Data Set Availability

Kentucky PRAMS data will be made available once the program has one full year of calendar data complete and has been weighted. The 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 statewide population. Requests for Kentucky data may be made to the PRAMS coordinator. National data are available on the CDC PRAMS website.

PRAMS

- **Average Yearly Sample Size** 1200
- **Data Format** SAS, comma delimited
- **Cost of Data Set** Free

Data Release Policy

Data requests should be addressed to the PRAMS data coordinator. Data release policies will be discussed at that time.

Data Publications

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

Suggested Data Citation

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

Contribution Author

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Reportable Disease Surveillance System (RDSS)



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State Web Site: <https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/default.aspx>

National Web Site: <http://wwwn.cdc.gov/nndss/>

Sources of Information for the Database

Disease reporting is a required activity by health care providers, hospitals, clinics, and laboratories, and is mandated and regulated by the Commonwealth of Kentucky through the Kentucky Disease Surveillance Administrative Regulation 902 KAR 2:020, Disease Surveillance. Data collection tools include the EPID 200 Reportable Disease form, Centers for Disease Control and Prevention (CDC) disease-specific supplemental forms, and clinical laboratory reports. Data are submitted by hospitals, clinics, local health departments, private practice physicians, commercial laboratories, and the state public health laboratory by mail, fax, or electronically through a CDC web-based system the National Electronic Disease Surveillance System (NEDSS) Disease Surveillance Module. Additionally, state and local health department staff conduct case investigations and report findings in NEDSS.

Description of the Data Collected

The Reportable Disease Surveillance System includes demographic information, clinical symptoms, risk factors, and outbreak associations on each occurrence of more than seventy reportable conditions. Demographic data collected include gender, age, race, ethnicity, and place of residence. Information from supplemental forms for certain diseases is also entered into NEDSS. These activities are supported by a combination of federal and state funds.

Strengths of the Data

The major strength of this data is that it provides an estimate of communicable disease incidence and trends across the state, which 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 K-NEDSS are often incomplete.
- Follow-up is difficult and may not result in obtaining the needed information.
- Data are often sent to the state or local health department weeks, and sometimes months, after the reportable event. This makes follow-up even more difficult.
- A complete data set is not readily available. Extracting data can be cumbersome and typically needs to be done by reportable disease staff.
- RDSS is a passive system and thus data availability is dependent on reporting by health care providers and laboratories.

Specific Uses if Information

- Monitor disease trends in the state.
- Provide data to create and evaluate prevention and treatment initiatives.
- Provide data to CDC for national reportable disease statistics.
- Provide 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.

System Evaluation

Data collection is routinely monitored utilizing quality control standards developed by CDC. Reportable Disease staff at the KDPH review individual cases before initial submission to CDC. Additionally, data are reviewed annually; any discrepancies between Kentucky and CDC are reconciled before data are finalized.

Data Set Availability

The fully identified data set is not available to the public. Portions of the data set may be shared, and identified data can be made available to research organizations providing that the requestor has signed a confidentiality/security agreement with the Department for Public Health. Occasionally approval by the Institutional Review Board (IRB) is necessary. Most data are released as an Excel file; other formats are available.

Data Release Policy

Data shall be released in accordance with the Kentucky Department for Public Health Data Release Policy. All requests should be submitted by email and should include a project justification, variables of interest, time period of interest, and an anticipated deadline. Any data released to the public will be de-identified.

Data Publications

The Reportable Disease Program produces a ten-year statewide reportable disease summary, which is available online at: <https://chfs.ky.gov/agencies/dph/dehp/idb/Pages/diseasesummary.aspx>. The most recent report includes data from 2006-2015.

Suggested Data Citation

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

Contributing Authors

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Brooke Happ, Kentucky Department for Public Health

Stroke Encounter Quality Improvement Project (SEQIP)



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Heart Disease and Stroke Prevention Program
Chronic Disease Prevention Branch
Division of Prevention and Quality Improvement
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State Web Site: <https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/heart-disease-stroke.aspx>

National Web Site: <https://www.cdc.gov/heartdisease/index.htm>

Sources of Information for the Database

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). SEQIP initiated a voluntary participation in a stroke registry for hospitals, the first in Kentucky. This data summary report is compiled pursuant to KRS 211.575, which requires the Kentucky Department for Public Health (KDPH) to establish and implement a plan to address continuous quality improvement for stroke care. KDPH is required to provide an annual report to the Governor and the Legislative Research Commission that includes data, related findings, and recommendations to improve the delivery of stroke care efforts in Kentucky.

Description of the Data Collected

SEQIP reports stroke data for most strokes that occur throughout Kentucky. Because the major hospitals in Kentucky participate in SEQIP, the estimation is that approximately 80% of all of the strokes occurring annually are tracked and managed through this surveillance system. Demographic data collected include gender, age, race, ethnicity, place of residence, and complete information regarding stroke type, mode of patient arrival, method of insurance payment, and clinically relevant information that is part of the American Heart Association's mission of 'Get With the Guidelines'. This information is sent from participating hospitals to Quintiles, a health information technology and clinical research organization that houses the data.

Strengths of the Data

The major strength of this data is allowing for a thorough understanding of stroke types and severity according to the National Institutes of Health Stroke Scale score, as well as clinically relevant outcome measures such as the modified rankin scale score. By understanding the severity of a patient's stroke, the data allows for many attractive points of analysis into their medical treatment course, for example the use and dosage of anti-thrombolytics and anti-coagulants, or clot-busting drugs that can be directly connected to that patient's outcome. By examining the medical management strategies from hospital arrival to discharge, one can also determine the pharmaceutical milieu used for each unique stroke.

Data Limitations

- Patient follow-up information beyond hospital discharge is not collected.
- Many records have incomplete information.

Specific Uses of Information

- Identify demographic variables associated with stroke to improve program/policy decision-making.
- Analyze the efficacy of clot-busting drugs as it relates to the modified rankin scale score.
- Ensure that Kentucky is achieving greater than 85% on the consensus 'Get With the Guidelines' performance measures.

System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC and the American Heart Association.

Data Set Availability

The 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 a yearly statewide summary. Annual summaries can be found at:

<https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/heart-disease-stroke.aspx>

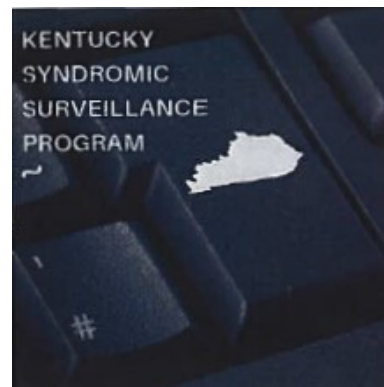
Suggested Data Citation

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].

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Syndromic Surveillance (SYS)



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National Web Site: <https://www.cdc.gov/nssp/index.html>

Sources of Information for the Database

Information in the SYS system is provided as a collaboration among public health agencies and other partners for timely exchange of syndromic data to improve the nation's situational awareness and responsiveness to hazardous events and disease outbreaks. The data for this collaboration is collected from local health care facilities; (Emergency Departments, Urgent Care, Inpatient and Ambulatory Care Settings) Electronic Health Record (EHR) systems in Kentucky in the form of Admit Discharge Transfer (ADT) messages through the Kentucky Health Information Exchange. The exchange of this data is required for eligible hospitals within Stage 2 Meaningful Use. This data project is a working partnership between the Kentucky Department for Public Health (KDPH), Kentucky Health Information Exchange, and the National Syndromic Surveillance Program (NSSP).

Description of the Data Collected

Syndromic Surveillance Data is collected using the Personal Health Information Number (PHIN) messaging guide for syndromic surveillance HL7 Version 2.5.1. High-level data elements that are collected include: facility name, patient type, event type, diagnosis codes, chief complaints, triage notes, gender, age, patient address, date, and time. Some of these data fields are required and others are optional. The KDPH also has access to this data utilizing a shared CDC environment of ESSENCE. The Kentucky Department for Public Health has access to the raw data and binned data within this application. All data sent from the Kentucky Health Information Exchange to the NSSP servers is de-identified.

Strengths of the Data

The major strength of this data comes from the ability to see events as close to real time as possible. Hospital exit data can take up to three to six months before it is finalized and released.

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, data feeds can drop off at anytime.
- Vendor issues within KHIE.
- CDC ESSENCE environment is controlled by KHIE.

Specific Uses of Information

- Opioid surveillance projects with Kentucky Injury Prevention and Research Center (KIPRC).
- Large event surveillance.
- Population health surveillance.
- Chronic disease surveillance.
- Environment related health issues.

System Evaluation

The system is evaluated daily utilizing data dashboards looking at facility connectivity and data completeness.

Data Availability

ESSENCE access is available on request and issued by the Kentucky Syndromic Surveillance administrator. The current administrator is John Prather.

Contributing Author

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United States Zika Pregnancy Registry (USZPR)



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National Web Site: <https://www.cdc.gov/pregnancy/zika/research/registry.html>

Source of Information for the Database

In 2016, the Centers for Disease Control and Prevention (CDC) established the United States Zika Pregnancy Registry (USZPR) to learn more about the effects of Zika virus during pregnancy and on the growth and development of infants born to infected mothers. In collaboration with state, tribal, local, and territorial health departments, the CDC is collecting information on pregnancy and infant outcomes for all mother-baby pairs who meet inclusion criteria. Pregnant women with laboratory evidence of Zika virus infection and periconceptionally, prenatally, or perinatally exposed infants born to these women as well as infants with laboratory evidence of congenital Zika virus infection and their mothers are eligible for inclusion. The inclusion of infants who appear healthy is important because the short-term and long-term effects of in utero exposure to Zika virus are unknown. Enrollment in the USZPR will close on March 31, 2018; no pregnancies completed after this date will be included.

Data are collected by state and local health agencies, including the Kentucky Department for Public Health, and submitted to CDC. Various methods, including medical record abstraction and telephone consultation, are used to collect surveillance data with CDC's standardized data collection forms at appropriate, pre-determined time intervals. Within the KDPH, the Division of Epidemiology and Health Planning and the Division of Maternal and Child Health are collaborating for the USZPR, including coordinating Zika virus testing, ensuring data collection and reporting to CDC, providing guidance and support to healthcare providers and birthing facilities, and ensuring referrals to specialty and early intervention services for infants.

Description of the Data Collected

The USZPR utilizes three primary data collection tools to obtain information about mother-baby pairs: the maternal health history form, the neonatal assessment form, and the infant follow-up form. The maternal health history form is completed at the time of the positive test result and at the end of each trimester; this form collects the following: demographic information, Zika virus history, exposure history, maternal health history, pregnancy information, and prenatal imaging and diagnostic results. The neonatal assessment form is completed around the time of delivery; this form collects the following: demographic information, physical examination, imaging and diagnostic results, and postnatal infection and cytogenetic testing results. The infant follow-up form is completed at 2, 6, and 12 months of age; the form collects the following: demographic information, weight, length, head circumference, and abnormal clinical findings.

Strengths of the Data

The USZPR allows for real-time, population-based monitoring of all mother-baby pairs who meet eligibility criteria. Collection protocols and formats follow national, standardized guidelines. Aggregate data are available online and are updated twice per month.

Data Limitations

Some data limitations should be considered when reviewing findings from the USZPR. Only pregnant women or infants who are tested for Zika virus infection and reported to the USZPR are included. The USZPR will therefore reflect reported Zika virus infection and outcomes and could underestimate infection and outcomes to the extent that these are not reported. The USZPR is not designed to determine whether poor pregnancy outcomes in women who had possible Zika virus infection during pregnancy were caused by Zika virus or other factors.

Specific Uses of Information

It can be used to enhance knowledge about Zika virus in pregnancy in Kentucky and in the United States.

Contribute data to the CDC and Prevention in order to:

- Provide aggregate national estimates of pregnancies with laboratory evidence of possible Zika virus infection.
- Improve understanding of the impact of Zika virus infection on pregnancy and infant outcomes,
- Inform recommendations for clinical care.
- Plan services for pregnant women and families affected by Zika virus.
- Improve prevention of Zika virus infection during pregnancy.

System Evaluation

Kentucky data are reviewed quarterly through a data completeness report conducted and distributed by CDC, providing metrics on the timeliness and completeness of data points for all three types of reporting forms. Additionally, informal review occurs each time subsequent forms of the same type are completed; data are compared with what has previously been reported about the case.

Data Set Availability

CDC provides aggregated data for the United States based on the USZPR.

Data Release Policy

Kentucky-specific USZPR data are submitted to CDC for aggregate publication. State-level counts may be released in accordance with the minimum criteria found in the Kentucky Department for Public Health Data Release Policy.

Data Publications

The cumulative number of pregnant women enrolled in the USZPR is reported on the CDC website twice per month:

<https://www.cdc.gov/zika/reporting/pregwomen-uscases.html>.

CDC also reports poor outcomes of pregnancy among women with laboratory evidence of Zika virus infection twice per month, including live born infants with birth defects and pregnancy losses with birth defects:

<https://www.cdc.gov/zika/reporting/pregnancy-outcomes.html>.

Additionally, publications using USZPR data are available online, including: Update on Zika Virus-Associated Birth Defects and Evaluation of All U.S. Infants with Congenital Zika Virus Exposure – U.S. Zika Pregnancy Registry, 2016:

https://www.cdc.gov/mmwr/volumes/66/wr/mm6613e1.htm?s_cid=mm6613e1_w

Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). United States Zika Pregnancy Registry. Frankfort, Kentucky: Cabinet for Family and Health Services, Kentucky Department for Public Health, [**data year**].

Contributing Author

Brooke Happ, Kentucky Department for Public Health

Vital Statistics Surveillance System (Vital Stats)



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	Amah Martin, MPH Epidemiologist Kentucky Department for Public Health Division of Epidemiology and Health Planning Office of Vital Statistics (502) 564-4212 ext. 3234 Amah.Martin@ky.gov
State Web Site:	https://chfs.ky.gov/agencies/dph/dehp/vsb/Pages/default.aspx
National Web Site:	http://www.cdc.gov/nchs/nvss.htm

Sources of Information for the Database

The KRS 213.016 statute mandated the establishment of a vital statistics program in the Cabinet for Health and Family Services, Department for Public Health, which is entitled to maintain and operate as the only official system of vital statistics in the Commonwealth.

The information in the vital statistics system originates from birth, death, stillbirth, marriage, and divorce certificates, collected and maintained by the Office of Vital Statistics (OVS). Induced termination of pregnancy (ITOP) data is also maintained.

Currently, approximately 99% of the birth records are entered electronically from birthing facilities via the Kentucky Child Hearing Immunization Lab Data (KY-CHILD), most Stillbirth records are entered into KY-CHILD, and approximately 99% of all death certificates are reported electronically through the Kentucky Electronic Death Registration System (KY-EDRS). The remainder of birth records, death records, stillbirths, marriages, and divorce certificates are reported on paper; and, keyed to the OVS electronic data systems.

Several sections of KRS 213 mandate the collection and management of certificate data. KRS 213.141 prescribes fees for searches and searches resulting in certified copies of certificates. KRS 213.141 section (3) further mandates that these fees are to be used to support the costs of administering the system of vital statistics.

Description of the Data

There are 57 fields of data included in the Kentucky Certificate of Live Birth, and 40 fields in the Kentucky Certificate of Stillbirth, for which data is collected. Overall, data collected includes demographic information from the newborn and parents, as well as medical and health information.

KY-CHILD collects identifying data for births (and stillbirths), for the newborn and parents. Demographic data such as address, age, race, and Hispanic origin of the parents. Medical data such as mother's previous pregnancy history; circumstances of the birth such as plurality, birth weight, obstetric procedures, and abnormal conditions of the newborn; and medical risk factors, such as tobacco and alcohol use during pregnancy (and cause of fetal death in the case of stillbirths).

For deaths, there are 52 fields of data included in the Kentucky Certificate of Death. The data collected involves identifying information on the decedent; demographic data such as address, age, sex, race, and occupation; circumstances of the death, such as date and place; the underlying cause of death, and up to three supplemental causes, and contributing factors to death.

For marriages and divorces, the system collects identifying information on the two

Data are collected on all births and deaths that occur in Kentucky or that occur to a Kentucky resident out-of-state, conversely, marriage and divorce data are collected by occurrence in Kentucky, regardless of the place of residence. two parties involved (formerly husband and wife), and the date and county of the event on all marriages and divorces that occur in Kentucky.

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Strengths of the Data

There are multiple strengths associated with the vital statistics data as follow:

- OVS is the only agency that collects vital events (birth, death, stillbirth, marriage, and divorce) data, holding over 15 million unique and irreplaceable records.
- The records compiled in the OVS, contain extremely valuable health information that is used as a source for planning processes and public health program evaluation, and to determine key health measures in the state.
- OVS establishes written agreements with data users as needed, to provide data in regular basis. To date, OVS has over 25 active Memorandum of Understanding Agreements (MOU's).
- Registration of vital events is required by law, thus assuring that virtually 100% of events that occur in the state are reported.
- The system is fully population-based rather than relying on a sampling strategy.
- Vital statistics data have been maintained in reasonably consistent formats since 1977. In addition, electronic collection protocols and formats are similar among states. Data collected overtime is for the most part, comparable within the state as well as across the country.
- Electronic data collection systems (KY-CHILD and KY-EDRS) have tremendously improved the quality of the vital statistics data that is stored in the OVS, since implementation in 2006 and 2010 (mandatory in 2015) respectively. Electronic data is available from 1990 and forward.
- Electronic births and deaths lists are available from 1911 and forward. Per KRS 213.131, OVS prepares lists that include all Kentucky births and deaths. The lists are subject to inspection by the public upon request. The information contained in those lists includes, for the births lists: person's name, mother's maiden name, date and county of birth; and for the death lists: name of deceased, date and county of death.

Data Limitations

- Each state registers vital events that occur within its jurisdiction. Kentucky OVS relies on other states to collect data for its residents for events that occur out-of-state. The quality of the data received from out-of-state is not always comparable with the quality of data from within the state. An example, amendments to out-of-state data are not always received. At the moment, there are no standard procedures for reporting and handling out-of-state records among the states.
- OVS is not currently producing Annual Vital Statistics Reports. As the individual data requests are made, they are provided. The individual data requests makes the process of releasing data more time-consuming in some cases. Reduced staffing also affected the possibility of closing the years of data. To close years of data, staff are required to clean and processes several years of data to ensure overall quality of the data. For this reason, even though the years of data are very complete due to the efficient data collection systems, additional cleaning is required to officially close the data years. Birth data is open from year 2008 forward, death data from 2009 forward, stillbirth data from 2006 forward, and marriages and divorces from 2005 forward. Currently, OVS is actively working on solving these issues.
- Data on marriages and divorces are often incomplete because the collection method relies on submissions from those county clerk offices issuing marriage licenses, and divorce certificate submissions from the circuit county clerks granting divorce decree. OVS is studying the possibility of alternative systems to filling marriage and divorce records directly from county and circuit clerk offices.
- Due to the increasing numbers of data requesters with diverse uses of the vital statistics data, there is a need to develop an online query system to support customized queries of the vital statistics databases. This would provide the required data to the multiple users more efficiently. However, to date funds are not available towards that end.

Specific Uses of Information

- Data to the National Center for Health Statistics (NCHS) for incorporation into the National Vital Statistics System.
- Data for grant applications, community health assessments, program strategic planning, private researches, statistics for the state, etc.
- Data to estimate population statistics by age, race, gender, and place of residence.
- Provide data to assess the health status of the population, e.g., birth weight, infant mortality, and leading causes of death to governments agencies, universities, as well as other healthcare researchers.
- Provide denominators for the calculation of rates and ratios of health events.

Users of Vital Statistics Data

There are multiple and diverse users of the vital statistics data; to name a few:

- Centers for Disease Control and Prevention (CDC).
- Kentucky regional and local health departments.
- Health departments from other states, such as Tennessee, Ohio, and Indiana.
- Office of vital statistics and registrar offices from other states, such as Ohio.

Vital Stats

- Internal requesters from the Cabinet for Health and Family Services, such as: Division of Maternal and Child Health, Division of Women’s Health, Office of Inspector General, Office of Health Equity, Department for Medicaid Services, and the same OVS, among many other requesters.
- Kentucky cabinets, such as the Kentucky Education & Workforce Development Kentucky Injury Prevention and Research Center (KIPRC) at the University of Kentucky.
- Kentucky State Data Center.
- Kentucky Cancer Registry.
- American Heart Association.
- Multiple universities from within and outside of Kentucky.
- Office of State Medical Examiner.
- REACH of Louisville.
- Hospitals, hospices, and other medical institutions.
- Funeral Homes.
- School systems in Kentucky.
- Students and other researchers and private requesters.
- Press and media in general.
- Public libraries and historical societies.
- Many others.

Process for Making a Data Request to the OVS and Data Availability

No identifiable birth (>50,000 records annually), death (>40,000 records annually), or stillbirth data sets are available to the public. Any data requests made to OVS, requires an email to be sent to the epidemiologist (**ky.gov** email), which explains the purpose for the request and the type of data that is needed. After all clarifications are made regarding the request, the epidemiologist will prepare the data request. If necessary, an email will be forwarded to the state registrar or the Office of Legal Services for approval, to start processing the request. Once the data has being prepared, the epidemiologist will provide the data request. If necessary, the registrar or the Office of Legal Services will approve the release and distribution of the data. Data processing and preparation time may imply some costs. Data request processing is on an individual basis, and distributed accordingly, based on the type of data (whether or not it includes Personal Health Identifiers-PHIs) and the size of the file(s). De-identified, aggregate data sets are available to the public. The smallest geographic unit of analysis varies among data sets and stratification. All data is generated in either an Excel workbook or text file for release. The most common ways to distribute data are via email, encrypted files via email, transfer files through the state secure site MOVEitDMZ (mostly for big files with confidential data included), and password-protected files via CD (usually for non-confidential data). Some requestors will be required either to go through the processes of the Cabinet’s Institutional Review Board (IRB) approval, or to sign a Memorandum of Understanding (MOU) between OVS and the requester’s institution. Assistance will be provided to requestors in case of IRB.

System Evaluation

The 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. In addition, the Vital Statistics Branch conducts a final check of the files prior to establishing the official annual database. Any anomalies are checked against the actual certificates.

Data Release Policy

The current data release policy states that all numerators less than 5 are to be suppressed if the denominator is less than 1,000 for all data sets. OVS reserves the right, at the registrar's discretion, to suppress for denominators >1,000. Aggregate years of data (3-5 years) can be released for highly stratified data, in order to accommodate for low cell counts for specific cause or variable(s). All data requests are reviewed and approved prior to release under the discretion of the State Registrar.

Data Publications

Kentucky Annual Vital Statistics Reports from 1997-2005 are available on the Kentucky public health web site <https://chfs.ky.gov/agencies/dph/dehp/vsb/Pages/reports.aspx>. Although this manuscript is no longer being published, tables can be requested for release as long as the data requested meets the data release policy.

Suggested Data Citation

Kentucky Department for Public Health (KDPH). *Birth (or Death or Marriage or Divorce) Certificate Files*. Frankfort, Kentucky: Cabinet for Health and Family Services, 2018.

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Youth Risk Behavior Surveillance System (YRBSS)



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

Source of Information for the Database

The Youth Risk Behavior Surveillance System (YRBSS) is a questionnaire administered to students and is made possible by a cooperative agreement between the Kentucky Department of Education (KDE) and the Centers for Disease Control and Prevention (CDC). Schools participating in the survey are selected randomly and participation is voluntary. Personal identifying information, such as name or address, is not collected. The YRBSS has been conducted in Kentucky since 1989. In 2009-2017, the Kentucky Department of Education collaborated with the Family Resource and Youth Services Centers (FRYSC) to administer the YRBSS. There is no federal or Kentucky mandate that requires data collection.

Description of the Data Collected

The YRBSS collects data on prevalence of health-risk behaviors among middle and high school students, which are used to assess whether or not behaviors increase, decrease, or stay the same over time and if co-occurrences exist. To examine students' behaviors, the survey contains items related to unintentional injury and violence, suicide, tobacco use, alcohol and other drug use, sexual behavior, dietary behavior, asthma, and physical activity. YRBSS data are 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 in the United States. YRBSS includes biennial national, state, and local school-based surveys of representative samples of students in grades 9-12. In addition to the high school Youth Risk Behavior Survey (YRBS) for grades 9-12, Kentucky administers a middle school YRBS for grades 6-8. This biennial data is also collected during the spring of odd-numbered years.

Strengths of the Data

The schools taking the YRBSS are selected with 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 2007-2015 YRBSS had an overall combined school and classroom response rate of over 70 percent, making this data statistically representative of students in typical public high schools throughout Kentucky. The middle school data was statistically representative in 2009–2015.

Data Limitations

YRBSS data are self-reported, and the extent of over-reporting or underreporting behaviors cannot be determined. Also, the data apply only to youth who attend school and, therefore, are not representative of all persons in this age group. Another limitation of the YRBSS is that parental permission procedures are not consistent throughout the state. However, a 2004 study by the CDC revealed that inconsistency in parental permission does not affect prevalence estimates as long as student response rates are high.

Specific Uses of Information

- Determine the prevalence of health risk behaviors.
- Assess whether health risk behaviors increase, decrease, or stay the same over time.
- Examine the co-occurrence of health risk behaviors.
- Provide comparable data among subpopulations of youth.
- Monitor progress toward achieving the Healthy People 2020 objectives and other program indicators.

System Evaluation

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 2005–2015 for high schools, and 2009–2015 data for middle schools are available to the public. The data are available in both SPSS and comma delimited formats. Contact the YRBSS coordinator if requesting the raw data sets. Visit the state web site for data reports and data request forms.

- **2015 Sample Size:** *High School Students:* 2,577
Middle School Students: 1,640
- **Smallest Geographic Level Released:** State
- **Cost of Data Set:** Free

Data Release Policy

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

Data Publications

Once surveys are complete, the CDC includes results of all states that conduct the YRBSS in the Morbidity and Mortality Weekly Report. The 2015 Kentucky YRBSS results are highlighted in the latest report and can be found on the YRBSS website: <http://www.cdc.gov/healthyouth/yrbss/index.htm>.

YRBSS

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 2001-2015 by site and health topic.

Suggested Data Citation

Kentucky Department of Education (KDE), Kentucky Department for Public Health (KDPH), and Centers for Disease Control and Prevention (CDC). *Kentucky Youth Risk Behavior Surveillance System*. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department of Education, [survey year].

<p style="text-align: center;">Contributing Author</p>

<p style="text-align: center;">Stephanie Bunge, M.Ed., Kentucky Department of Education</p>

Data Resources in Development

Data Resources in Development

The Kentucky Department for Public Health and its partners proactively look for ways to improve existing data collection and surveillance systems as well as develop new resources. Unfortunately, there is not enough information available for some resources to build a complete chapter on them at the time of the 2018 update.

This section was created in an effort to highlight data resources that are in development, but are likely to be available prior to next edition of the Kentucky Public Health Data Resource Guide, which will be written in 2020. This section will feature a brief description of these data resources and their coordinators and/or data contact's information. It is the hope of the Kentucky Department for Public Health to have these resource operational as soon as possible.

In this 2018 edition of the Kentucky Public Health Data Resource Guide, we are featuring one data resource still in development, the Syringe Exchange Program Surveillance Database (SEPSD). At the time of publication, the SEPSD staff is developing this recourse interface and are still gaining access to the data itself. It is the hope of the SEPSD staff that this resource will operational in the near future. We encourage anyone who is interested in working with this data to reach out to their coordinator for further information.

Syringe Exchange Program Surveillance Database (SEPSD)



Data Contact:

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Monica.Ridgeway@ky.gov

Information about Kentucky SEPs can be found at:

<https://chfs.ky.gov/agencies/dph/dehp/hab/Pages/kyseps.aspx>

Sources of Information:

The Kentucky Syringe Exchange Program Surveillance Database will serve as a statewide surveillance system for all syringe exchange programs that choose to contribute their data. It will contain information on services provided and demographic and clinical characteristics of clients. We intend to use these data to respond to requests for information and to identify best practices in the prevention of blood borne pathogens and other health-related outcomes.

Data Set Availability:

The KY Syringe Exchange Program Surveillance data will not be available for public use due to security and confidentiality restrictions. We may provide aggregate data in response to specific requests for information. Please direct all data-related inquiries to Monica Ridgeway at Monica.Ridgeway@ky.gov or (502) 564-6539 ext. 4288.

Appendices

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 Data

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.

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.

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 the Public Health Professionals and general public at large.

Community Commons

<http://www.communitycommons.org/>

Mapping Section: <http://www.communitycommons.org/maps-data/>

Community Commons is an interactive GIS mapping information system that provides data related to communities, economics, environment, food, health etc. on thousands of map-able geographic regions.

Appendix A

County Health Rankings

<http://www.countyhealthrankings.org/kentucky>

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 each state's counties.

Health Landscape

<http://healthlandscape.org/>

The health landscape is an interactive web-based atlas that enables health professionals and other policy makers to analyze their data and produce results that can be comprehended easily.

Interactive Atlas of Diabetes, Obesity and Physical Activity

<http://www.cdc.gov/diabetes/atlas/>

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 ready access to 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.

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.

Glossary

- **Active Surveillance** - a health jurisdiction regularly contacts reporting sources (e.g. once per week) to elicit reports, including negative reports (no cases).
- **Area Development District (ADD)** - Kentucky has 120 counties that are divided into 15 ADDs for the planning of a variety of programs. The ADDs and their counties are detailed below.
 1. **Barren River** – Logan, Simpson, Butler, Warren, Edmonson, Hart, Barren, Allen, Metcalfe, and Monroe.
 2. **Big Sandy** – Johnson, Magoffin, Martin, Floyd, and Pike.
 3. **Bluegrass** – Anderson, Franklin, Woodford, Mercer, Boyle, Lincoln, Garrard, Jessamine, Fayette, Scott, Harrison, Bourbon, Nicholas, Clark, Madison, Powell, and Estill.
 4. **Buffalo Trace** – Bracken, Mason, Robertson, Fleming, and Lewis.
 5. **Cumberland Valley** – Jackson, Rockcastle, Laurel, Clay, Knox, Whitley, Bell, and Harlan.
 6. **Fivco** – Greenup, Boyd, Carter, Elliott, and Lawrence.
 7. **Gateway** – Rowan, Bath, Montgomery, Menifee, and Morgan.
 8. **Green River** – Union, Henderson, Webster, McLean, Daviess, Ohio, and Hancock.
 9. **Kentucky River** – Wolfe, Owsley, Lee, Breathitt, Leslie, Perry, Knott, and Letcher.
 10. **KIPDA** – Bullitt, Henry, Jefferson, Oldham, Shelby, Spencer, and Trimble.
Additionally – Clark and Floyd, Indiana
 11. **Lake Cumberland** – Taylor, Adair, Green, Casey, Russell, Pulaski, Clinton, Cumberland, Wayne, and McCreary.
 12. **Lincoln Trail** – Breckenridge, Meade, Grayson, Hardin, Larue, Nelson, Washington, and Marion.
 13. **Northern Kentucky** – Boone, Kenton, Campbell, Carroll, Gallatin, Owen, Grant, and Pendleton.
 14. **Pennyrile** – Livingston, Crittenden, Lyon, Caldwell, Hopkins, Muhlenberg, Trigg, Christian, and Todd.
 15. **Purchase** – Ballard, Carlisle, Hickman, Fulton, McCracken, Graves, Marshall, and Calloway.
- **Health Insurance Portability and Accountability Act of 1996 (HIPAA)** - These guidelines were developed to reform the healthcare industry by enforcing standards on health information, reducing fraud and abuse, and guaranteeing security and privacy of health care information.
- **Passive Surveillance** - a health jurisdiction receives disease or injury reports from physicians or other individuals or institutions as mandated by state law.
- **Sentinel Surveillance** - This is a type of surveillance that determines cases from a certain sample of the population. Cases may be determined by active surveillance from specified sentinel providers, or these providers may provide information on cases to the reporting authority on a regular basis.

Appendix C

**Kentucky Behavioral Risk Factor Surveillance (KyBRFS)
Data Set Request Form**

Name: _____
Organization: _____
Address: _____
City: _____ State: _____ Zip Code: _____
E-mail: _____
Telephone #: _____ Fax #: _____
Year(s) of data requested: _____
Date project will begin: _____
Date project will be completed: _____

Preferred Data Management Software (ex. SAS, SPSS): _____

How will data be used? Please specify topic(s) of interest:

- The undersigned investigator agrees to the following with respect to BRFSS data sets:
1. I will not release the data set I receive to any other persons.
 2. I will not use these data for any purpose other than statistical reporting.
 3. I will not attempt to contact or re-identify any respondents to the survey.
 4. I will acknowledge the Centers for Disease Control and Prevention (CDC) as the original source of the data.
 5. I will send a copy of any published reports using BRFSS data to the address listed below.

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

Signed: _____

Date: _____

Note: Sample sizes for states and subpopulations vary. Estimates produced from fewer than 50 unweighted records are not considered by the CDC to meet standards of statistical reliability. It is highly recommended that 95% Confidence Intervals or standard errors be reported for all estimates produced by data users.

Please mail or fax this form to:

KyBRFS Coordinator

Kentucky Department for Public Health, Chronic Disease Prevention & Control Branch

275 East Main St, HS2WE

Frankfort, KY 40621

Phone # (502) 564-7996 Ext 4434

Fax # (502) 564-466

SAMPLE

Appendix D

Kentucky Behavioral Risk Factor Surveillance (KyBRFS) Data Request Form

Name: _____
Organization: _____
Address: _____
City: _____
State: _____ Zip Code: _____
E-mail: _____
Telephone #: _____ Fax #: _____

Year(s) of data requested:

Topic(s) of data requested:

How will data be used:

Date data request should be completed:

The undersigned investigator agrees to the following with respect to KyBRFS data:

1. I will send a copy of any published reports using KyBRFS data to the address listed below.
2. I will acknowledge the Centers for Disease Control and Prevention (CDC) and Kentucky Department for Public Health as the original source of the data.

Suggested Citation:

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

Signed: _____
Date: _____

Please mail or fax this form to:
KyBRFS Coordinator
Chronic Disease Prevention & Control Branch
Kentucky Department for Public Health
275 East Main St, HS2WE
Frankfort, KY 40621
Phone # (502) 564-7996 Ext 4434
Fax # (502) 564-4667

SAMPLE

Appendix E

**Data Request Form
HIV/AIDS Branch – Epidemiology**

Date of Request: _____ Date Requested By: _____

For Office Use Only

Name: _____

Organization: _____

Address: _____

Address: _____

Zip Code: _____

Email Address: _____

Home Phone (if applicable): _____

Work Phone (if applicable): _____

Fax (if applicable): _____

Type of Request: _____

Would you like to be on the mailing list? YES NO

Would you like to receive the semi-annual/annual reports? YES NO

Return completed form to bob.ford@ky.gov or julie.kauzlarich@ky.gov or call 866-510-0008 for assistance.